

**IMPROVING DETECTION OF DEPRESSION  
AND/OR ANXIETY AS COMORBIDITIES OF  
EPILEPSY IN PRIMARY HEALTH CARE SETTINGS  
IN ZAMBIA**

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**UNIVERSITY OF KWAZULU-NATAL**

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EPILEPSY IN PRIMARY HEALTH CARE SETTINGS  
IN ZAMBIA**

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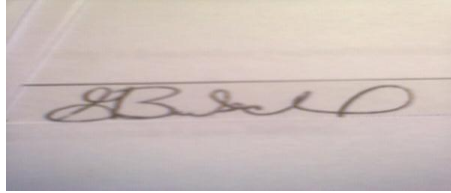
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**DATE:** 29<sup>TH</sup> JANUARY 2013

As the candidate's Supervisor I agree to the submission of this thesis.

**Signed:**   
**Professor Leana Ria Uys**

As the candidate's Supervisor I agree to the submission of this thesis.

A photograph of a handwritten signature in black ink on a light-colored surface. The signature is cursive and appears to read 'G. Lano Birbeck'.

**Signed:**  
**Professor Gretchen Lano Birbeck**

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## DECLARATION

I, **Edward Kondwelani Mbewe** declare that:

- (i) The research reported in this thesis, except where otherwise indicated, is my original work
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Not only did the two supervise me, but Professor Uys personally ensured that I was enrolled on the PhD programme at University of KwaZulu-Natal. Professor Birbeck ensured that I received my sponsorship and all logistical support that I needed throughout my study.

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## **ABSTRACT**

The focus of this study was on common psychiatric comorbidities of depression and anxiety in people with epilepsy (PWE). While international published data show that up to 60% of PWE suffer from depression and/or anxiety, most primary care (PHC) settings in developed countries display some oversight in this area. The study was conducted in Zambia, in three phases; which each culminated in submissions for publication in an internationally peer reviewed journal. Phase one involved chart review to establish the rate of detection of depression and/or anxiety in PWE at the outpatient clinic of Chainama Hills College Hospital. The detection rate was only 1%.

This formed the basis for phase two where we developed a ten item screening tool for depression and/or anxiety for use by PHC workers in busy clinical settings. The tool was validated, its sensitivity and specificity were determined and the inter-rater reliability was also calculated.

Phase three involved implementation of the tool validated screening tool. We measured the ability of PHC workers to use and interpret the screening tool in busy clinical settings. One month after training and implementing the use of the screening tool, a retrospective chart review was undertaken using the same tool that was employed in phase one chart review. There was a marked improvement when 120 files of PWE were reviewed as the percentage of screening for depression and anxiety increased from 1% to 49%.

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## CHAPTER ONE: INTRODUCTION

### 1.0 INTRODUCTION

According to Jones et al. (2005) several studies using structured psychiatric diagnostic interviews in samples of consecutive patients in epilepsy clinics demonstrate a prevalence of significant depression of up to 55%. Suicide is reported to be the cause of over 10% of all deaths in persons with epilepsy, compared with 1% in the general population (Jones et al 2005). There is lack of recognition of these facts in the approach used to diagnose and manage epilepsy in Zambia. The country has no established data on the burden of comorbid depression and/or anxiety among people with epilepsy (PWE). Clinicians providing epilepsy care may also be unaware of the high risk of psychiatric disorders among PWE. A cursory survey conducted in October 2009, showed that the rate of attendance for monthly reviews by PWE at Chainama Hills College Hospital outpatient clinic had tremendously increased. While 156 PWE were being attended to in 2004, this rose to 176 in 2005. Similarly, in 2006, 2007 and 2008; 234, 1491 and 2301 PWE were registered and attending reviews respectively. In 2009, the number had nearly doubled to 4150. An examination of records of 5% of registered PWE seeking care for the past three years indicated that none were screened nor treated for comorbidities of depression and anxiety.

### 1.1 PROBLEM STATEMENT

Among the 50 million people with epilepsy worldwide, 80% reside in low-income regions where human and technological resources for care are extremely limited (World Health Organisation [WHO], 2007). According to Birbeck et al. (2007), it is estimated that there are 170,000-256,000 people living with epilepsy (15-22/1000) in Zambia requiring urgent treatment, the prevalence was based upon Birbeck and Kalichi (2004) epilepsy prevalence study. This is a very high rate when compared to developed countries. For instance, Theodor et al. (2006, p.1700) state that 'In North America, overall epilepsy incidence is approximately 50/100,000 per year, highest for children below five years of age, and the elderly.

In epilepsy, depression is a common psychiatric comorbidity whose prevalence has been assessed to range from 20% to 50% by Kanner and Palac (2000) and others have put it as high as 55% (Jones et al. 2005) . Depression not only seriously affects people with epilepsy's (PWE) health-related quality of life (Friedman et al. 2009), but is also potentially life threatening as it contributes to the high suicide rates among PWE compared to the general population (Friedman et al. 2009).

Possible links have been noted between depression and epilepsy since about 400 BC when Hippocrates observed that melancholics ordinarily develop epilepsy and PWE becoming melancholics (Kanner, 2008). Irrespective of this, it has been noted that depression is the most prevalent, “relatively under diagnosed and undertreated comorbid condition in epilepsy” (Friedman et al. 2009, p.439).

In Zambia, epilepsy often goes untreated and patients are very often not brought for medical treatment. Where treatment is given, the possible presence of depression and anxiety may not ever be assessed, recognized or treated. In Zambia, most epilepsy treatment is delivered by primary health care workers who have had little training or experience in the diagnosis and management of anxiety and depression in PWE (Chomba et al. 2007). Previous studies by the Epilepsy Associated Stigma Team in Zambia (EASZ) that have evaluated the social construct of epilepsy and the social, economic and biomedical consequences of epilepsy through provision of research based evidence, showed that some PWE who participated in focus group discussions revealed that they were constantly feeling low, afraid of having an attack while alone, and being raped in case of women. Most of these complaints revealed an underlying element of depression and anxiety disorder. In relation to this academic organisation (EASZ), we have the Epilepsy Association of Zambia (EAZ) a Non Governmental Organisation (NGO) which advocates for the general improvement of service provision among PWE, fighting against epilepsy related stigma and improving access to antiepileptic drugs (AED). While these efforts seek to bring attention to the healthcare needs of PWE, the problem of recognition of depression and anxiety as comorbidities of epilepsy has not been addressed to date.

The need therefore exists to conduct research to determine the prevalence of depression and/or anxiety among PWE in Zambia and optimize the screening and treatment of these common psychiatric problems among PWE seen in primary care settings in Zambia.

## **1.2 RESEARCH SETTING**

Zambia is situated in sub-Saharan Africa (SSA) and forms part of the Southern Africa Development Community (SADC). The country has a geographical area of 753,000 square kilometers, with a population projection of 11.7 million. Being a former British colony, Zambia has adopted English as its official language although it has 72 ethnic groups and other major languages spoken include Nyanja, Tonga, Bemba and Lozi.

**Figure 1. Map of Zambia**



Source: [www.worldatlas.com/webimage/countries/africa/zm.htm](http://www.worldatlas.com/webimage/countries/africa/zm.htm)

According to the classification of Living Conditions Monitoring Survey (CSO, 2006), 64% of Zambians were poor, with the highest prevalence of poverty in the rural areas. From the Zambian context, poverty is defined as “lack of access to income, employment opportunities, and entitlements for citizens to such things as freely determined consumption of goods and services, shelter, and other basic needs of life” (UN, 2002).

Thirty eight percent of the population lives in the urban areas and 62% in rural areas. More than 90% of the population is less than 45 years old of which 45% are 0 to 14 years. This picture is classified as a young population, with only 2% of the population aged 65 years and above.

According to the United Nations Development Programme (UNDP, 2005) in Zambia, the literacy rates stand at 55.3% and have remained unchanged since 1990 (UNDP, 2005). The literacy rate in adults runs at 68% in males and 32% in females. Of the children in school 42% are males and 38% are females, with the national school leaving age estimated between 18 and 19 years. Age specific unemployment rates especially in urban areas, show a high level of unemployment among the young age groups 12-19 and 20-24 years at 70% and 47% respectively; compared to 12% and 9% in rural areas.

Zambia is economically a low income country. In 2004, 63.7% of the Zambian population lived on US\$1 a day. The Zambia Demographic and Health Survey [ZDHS](CSO, 2007) data indicate that during the seven year period prior to their survey, the maternal mortality ratio stood at 591 maternal deaths per 100,000 live births. Life expectancy for males was at 50 years in 1980 but declined to 46 years in 1990 before showing an increase to 48 years in 2000, with females living five years longer on average (CSO, 2007). However, according to the United Nations

Development Fund (UNFPA) the life expectancy decreased drastically to 38 years in 2005 due to HIV/AIDS. According to the ZDHS (CSO, 2007) 14.3 percent of people aged 15 to 49 are HIV positive and among women, the HIV rate is 16% compared to 12% among men. Although 1.1 million sexually active Zambians were HIV positive, only 44,000 were accessing the government's free treatment programme in 2005.

Only 57% of the population is estimated to have access to clean water and 16% have access to electricity. The doctor/people ratio stands at 1/13,859, and beyond this ratio there is a distribution problem in that, most physicians are located around urban areas. Although there are no internally displaced people, Zambia is host to more than 155,000 refugees from neighbouring countries. The population growth rate is estimated at 1.6% but other researchers put it at 3% (UNDP, 2005); with a human development index (HDI) of 0.407. Unless there is a radical change for the better, it is highly unlikely that Zambia will achieve most of the Millennium Development Goals by 2015 (AFRODAD, 2006). The United Nations has developed eight Millennium Development Goals which are:-ending poverty and hunger, universal education, gender equality, child health, maternal health, combating HIV and AIDS, environmental sustainability, and global partnership.

At least two thirds of people worldwide who are mentally ill receive no treatment, despite the fact that up to 30% of the world's population is expected to suffer from clear cut mental illness each year (Andrews and Titov, 2007). Worldwide, the situation is the worst in 70% of countries in Africa and 50% in Southeast Asia which are spending less than 1% of their health budget on mental health care (Patel et al. 2007). The World Health Organisation (WHO) states that the quarter of the world's population with the most common forms of mental illness (usually mixtures of depression and anxiety) should be treated in primary health care facilities rather than in specialized psychiatric institutions (Jacob et al. 2007). These facts pose a great challenge to governments of lower income countries, most of whom are concentrated in the sub-Saharan region like Zambia.

In the Zambian health sector, mental health care gets the most meagre funding among the health services being delivered. This is evidenced by resource allocation for mental health service delivery and a lower priority given to mental health issues, where the provision of service to PWE has also been placed. For instance, Kapungwe et al. (2011) demonstrate that at the moment government financing for health delivery is mainly oriented towards integrated health care through the budgets in the districts, but the proportion of the total budget spent on mental health services by the Ministry of Health remained below one percent at 0.38%. This is not unique to Zambia as most countries, especially developing ones spend negligible amounts of resources on mental health

activities in comparison with general health services. Most of the time, the resources are inappropriately allocated and as such, they fail to meet the mental health needs of the people. The allocation of resources for mental health in developing countries falls within the range of 0.5 to 1 percent of the country's Gross Domestic Product (GDP).

Further evidence shows that although the Zambia's central referral psychiatric hospital (Chainama) is supposed to deal only with referrals, in the absence of psychiatric services in other districts, Chainama has to provide basic mental health services for the whole country, without this being reflected in its budget. While it is expected that other hospitals at provincial and district level should provide mental health services, evidence shows that this has not been the case as some hospitals have virtually no allocation of any funds for mental health activities on their budgets. The argument here is that although the general and central hospitals have "integrated" mental health care, there is no direct funding to psychiatric department as is done for other departments such as internal medicine, surgery, obstetrics & gynecology and pediatrics (Kapungwe et al. 2011). In other words, mental health services de facto, remain centralized - but the budgets do not reflect this in practical terms. This overt funding neglect may be based on the stigma that is attached to mental illness and epilepsy. Health-related stigma has a great influence on policy decisions, access to care, health insurance, employment discrimination, marriage, access to education, loan facilities and allocation to research (Birbeck et al. 2007).

This brief description gives a picture of lack of adequate resources when it comes to mental health service delivery in Zambia, a situation which pertains to the majority of low and medium income group countries. This therefore raises a challenge in the issue of care given to PWE and the mentally ill. It has been shown that in Zambia, poverty and epilepsy work in tandem to worsen the situation of the sufferer. With high levels of poverty in the country, PWE are among the worst affected as they do not have resources to seek essential services (Birbeck et al. 2007). If they go to health facilities, they may be referred to Chainama Hills College Hospital in Lusaka, which is facing a critical shortage of mental health staff and operating with only three psychiatrists (two of whom have since retired) for the whole nation as noted by Mayeya et al. (2004) and Mbewe et al. (2006).

### **1.3 AIM**

The aim of this study was to improve the detection of depression and/or anxiety among PWE receiving epilepsy care in primary health care settings in Zambia.

## 1.4 OBJECTIVES

This would be achieved through the following specific objectives:

1. Conducting a chart review to quantify the frequency with which depression and/or anxiety are assessed, diagnosed and/or treated among PWE receiving care in PHC (Health centre, District hospitals) institutions in Zambia. The establishment of the rate at which depression and/or anxiety are being detected would then form the data base where the need for activity in objective two is based among PWE in PHC institutions in Zambia.
2. Developing and validating a screening tool for detecting depression and/or anxiety in PWE by primary health care workers. The development of a screening tool would be informed by established data in objective one, with focus on improving detection of depression and/or anxiety in PWE by PHC workers through application of the validated screening tool.
3. Implement the use of the screening tool in selected PHC institutions and; measure the effect of implementing the screening tool on the detection rate of depression and/or anxiety in PWE. The indicator for effect of implementing the screening tool would be an increase in the number of depression and/or anxiety in PWE as they attend PHC settings. This would result in a holistic approach to their routine reviews where they would not only be resupplied with AEDs but equally treated for the major and common psychiatric comorbidities of depression and anxiety.

## 1.5 OPERATIONAL DEFINITIONS/TERMINOLOGY

- (i) **Epilepsy:** The word “epilepsy” comes from the Greek and means to be taken, seized or attacked. Epilepsy is a condition characterized by *repeated seizures* due to a disorder of the brain.

In this study a person with epilepsy was recognised as PWE attending a weekly clinic for epilepsy care who were registered as patients between 2000 and 2010. Two hundred (200) files of PWE aged 18 years and above, on antiepileptic drugs (AED), with an established diagnosis of epilepsy and no diagnosis of mental illness.

- (ii) **Person with epilepsy (PWE):** Is an individual with recurrent seizures, unprovoked and not due to any drugs or underlying mental disorder.

In this study a person with epilepsy (PWE) was defined as anyone clinically diagnosed and on treatment for epilepsy (or) anyone with a history of recurrent seizures with the most recent occurring in the past 12 months if the seizure was not provoked by severe malaria or any other febrile conditions.

- (iii) **Seizure:** A seizure is a result of excessive nerve-cell discharges in the brain. It is seen as a sudden abnormal function of the body, often with loss of consciousness, an excess of muscular activity, or sometimes a loss of it, or an abnormal sensation of the brain cells.  
In this study a seizure included; tonic-clonic, absence, complex partial, partial, myoclonic, and atonic seizures.
- (iv) **Anxiety:** According to NICE (2004, p4) guidelines, it is a state of apprehension, cued panic attacks, spontaneous panic attacks, irritability, poor sleeping, avoidance, and poor concentration.  
In this study, anxiety as per the description and classification in the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition-Text Revised (APAS, 2000) was taken as that occurring in people with epilepsy.
- (vi) **Depression :** Low mood or loss of interest, usually accompanied by one or more of the following: low energy, changes in appetite, weight or sleep pattern, poor concentration, feelings of guilt or worthlessness and suicidal ideas (NICE, 2004).  
In this study, depression as per description and classification in the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition-Text Revised (APAS, 2000, p 369) was taken as that occurring in people with epilepsy.
- (vii) **Comorbidity:** Disease condition[s] occurring at the same time.  
In this study it was taken that depression and/or anxiety co-occur with epilepsy but the mechanism of causality remained totally unknown.
- (viii) **Basic level and level one health services:** These were taken to mean primary care services offered at health posts, Clinics, and District hospitals.
- (ix) **Screening tool:** was taken to mean step by step instructions arranged in a logical sequence and may include specific questions. The sequence allowed the user of the tool to reach the final impression without missing essential elements required to make an inference for the presence of depression or anxiety in PWE. However, a screening tool was not in itself a diagnostic tool.

## 1.6 RESEARCH QUESTIONS

1. How frequently were depression and/or anxiety among PWE currently being assessed, diagnosed or treated by non-physician primary health care workers of basic level and level one health institutions in Zambia?



2. What screening tool could be proposed based on the evidence in the literature to improve detection of depression and/or anxiety as comorbidities in epilepsy by primary health care workers of basic level and level one health institutions in Zambia?
3. (i) How valid would the screening tool be when tested against a gold standard of Clinical Officer Psychiatry (COP)?  
(ii) What would the inter-rater reliability among Clinical Officer General (COG) and Registered Mental Health Nurses (RMN) be when validating the screening tool for the detection of depression and /or anxiety among PWE?
4. What would the effect on detection rates of implementing a screening tool be, for detecting depression and/or anxiety as co-morbidities in epilepsy?

### 1.7 SIGNIFICANCE OF THE STUDY

The significance of this study lay in the fact that no similar study on psychiatric comorbidities in epilepsy had been carried out in Zambia or anywhere in sub Saharan Africa. It become imperative that this study be conducted amidst the mounting global campaign on the need to scale up and sustain the delivery of mental health services by integrating mental health into primary care (WHO and Wonca, 2008). The World Health Organisation notes that depression as the leading cause of disability ([www.who.int/medicentre/factsheets/fs369/en/index.html](http://www.who.int/medicentre/factsheets/fs369/en/index.html))

In addition, the need for local studies in augmenting international scientific evidence regarding problems surrounding epilepsy and its management had been well elaborated by researchers who emphasised that;

*“In elaborating their health-care strategies, regional and national communities should not simply refer to the available scientific information, but should also contribute to it by means of their own original investigations. This is mandatory if they are to meet specific local requirements taking into account the socioeconomic situations in which health-care policy is to be formulated. Moreover, the International League Against Epilepsy (ILAE) is active in promoting international collaborative research networks, facilitating partnerships between developed and developing countries, promoting fellowships and grant programmes and in sensitizing the relevant international institutions such as the World Bank, WHO and the United Nations Educational, Scientific and Cultural Organization (UNESCO) to epilepsy research” (ILAE et al. 2005).*

The study proposed would augment the existing body of knowledge by assessing and potentially addressing the under-screening and under-diagnosis of depression and/or anxiety as major comorbidities in epilepsy, by improving their detection and diagnosis through the development and

use of an appropriate screening tool, thus taking a holistic approach when managing PWE. This study would complement that of Birbeck et al. (2007) on how to address stigma related to epilepsy and the empowerment of PWE in Zambia. It would also augment the findings of the study that was then being undertaken by a consortium of South Africa, Uganda, Ghana and Zambia on mental health and poverty (Kapungwe et al. 2011), which in its first phase had clearly demonstrated that mental health issues were less prioritised, and consequently the epilepsy component with its psychiatric comorbidities, was not being adequately addressed. Subsequently, the findings would inform policy makers and programme officers in the ministry of health through policy briefs, on steps that can be undertaken to address epilepsy and psychiatric comorbidities. If the developed screening tool was of benefit, then the use of the screening tool would be rolled out to the rest of the country. The long term effects would include an indirect contribution to the reduction of stigma through independent promotion of activities that economically empower underprivileged persons, such as attending school and obtaining suitable employment. At present, people with epilepsy in Zambia have substantially poorer socioeconomic status than their peers with non-stigmatised chronic medical conditions (Birbeck et al. 2007). Suboptimum housing quality (including lack of piped water) differentially exposed these individuals to the risk of burns and drowning during a seizure. Vulnerability to physical violence was extreme, especially for women with epilepsy (Birbeck et al. 2007).

The findings from this study would also impact curriculum development for the detection and management of psychiatric comorbidities of this kind by primary health care workers. This would be especially important in Zambia which had a lack of skilled human resource of critical proportion i.e. one psychiatrist in active employment and two retired for the population of over ten million. The aspects of training would fit into pre-existing services which were already developed and running at Chainama College of Health Sciences. This would also take into account that some aspects of depression could benefit from non drug interventions like counselling. This counselling service for persons living with HIV, has already been well developed. In this regard, we envisioned a more holistic approach to dealing with depression and/or anxiety in PWE.

There were calls among various concerned groups including researchers (Patel, 2007) for the immediate scaling up of services for mental health disorders, especially in low-income countries like Zambia. Thus, with the full recognition that among the common causes of disease burden in the low-income and middle-low income countries, depression ranked number seven and because depression occurred typically with anxiety, they were classified as mental illnesses (Patel 2007). This observation accords with the findings and conclusion of Gaitatzis et al. (2004) as they

suggested that in adults suffering from epilepsy and being attended to in primary care settings, there was an increased risk of many common psychiatric and somatic disorders. Therefore, the presence of epilepsy should be expected to trigger suspicion of other common psychiatric disorders that might be present.

To this effect, Gaitatzis et al. (2004) strongly emphasised that primary care physicians needed to take a holistic view of the health of epilepsy patients by “treating not only the epilepsy but also any other present conditions, as well as ensuring that patients were given adequate advice on general aspects of their health”. Such skills needed emphasis among the Zambian primary health care workers who formed the majority of skilled health workers in rural, peri-urban and urban settings.

## **1.8 THEORETICAL FRAMEWORK**

This study was informed by the mental health and clinical psychiatry frameworks on the processes of arriving at the diagnosis of epilepsy and the search for the most common comorbidities of depression and anxiety. Ndeti et al. (2006) stated that “Anxiety is a state of tension and apprehension with hyperactivity of the autonomic nervous system as a natural response to perceived threat. In anxiety disorders the frequency and intensity of anxiety responses are out of proportion when compared to situations that trigger them.” To this effect, we have three basic elements of anxiety disorders: - the cognitive, physiological, and behavioural. The cognitive element caused one to have a subjective feeling of impending danger, apprehension and the inability to cope and failure to concentrate. At the same time there are physiological changes in form of an increase in the heart beat and blood pressure, while the muscles become tense, rapid breathing, dryness in the mouth, a feeling of nausea, frequent emptying of the bladder and diarrhoea. The behavioural aspect manifests itself in several forms such as avoidance of areas or tasks that may evoke anxiety feelings, and inability to satisfactorily perform a given task. According to the International Classification of Disease (ICD-10) by WHO (1992) the diagnostic guidelines of generalised anxiety disorder state that a person should have symptoms of anxiety that must have persisted for days or weeks, involving the following:- apprehension, (worries concerning the future, feeling on “edge”, difficulty in concentrating). From the motor aspect we have tension, headaches, trembling, lack of relaxation, and restlessness). This is accompanied by autonomic over activity such as increased heartbeat, sweating, epigastric discomfort, dizziness and dry mouth.

Similarly, the clinical condition of depression could be recognised by depressed mood, lack of pleasurable feelings, negative anticipation of the future, retarded motor activity (lack of energy), disturbance in sleep, lack of appetite, difficulty in thinking, and lowered sexual drive (Ndetei et al. 2006).

According to APAS (2000) the clinical overview of anxiety disorders included the following: Panic Attack, Agoraphobia; Panic Disorder Without Agoraphobia; Panic Disorder With Agoraphobia; Agoraphobia Without History of Panic Disorder; Specific Phobia; Social Phobia; Obsessive-Compulsive Disorder; Posttraumatic Stress Disorder; Acute Stress Disorder; Generalised Anxiety Disorder; Anxiety Disorder Due to a Medical Condition; Substance-Induced Anxiety Disorder; and Anxiety Disorder not otherwise Specified.

The APAS (2000) Sub-classified depression under clinical overview of mood-disorders which included the following:

Major Depressive Disorder, Dysthymic Disorder; Depressive Disorder Not Otherwise Specified; Bipolar I Disorder; Bipolar II Disorder; Cyclothymic Disorder; Bipolar Disorder Not Otherwise Specified; Mood Disorder Due to a General Medical Condition; Substance-Induced Mood Disorder; and Mood Disorder Not Otherwise Specified.

The ICD-10 also gave further guidance on the recognition of depression and anxiety in primary care settings. Furthermore, there were several screening tools for depression and anxiety based on self reporting, such as the Major depression Inventory (MIDI) which contained 10 items reflecting the presence or absence of depressive symptoms according to ICD-10. The inventory is filled in by the patient and then scored by a primary health care doctor. As already implied, it is most applicable in the European countries.

## **1.9 CONCLUSION**

This was a phased health systems study aiming at improving the health services and by so doing improving the lives of people living with epilepsy. It was anticipated that with improved lives, PWE would in turn contribute to the overall development of the country through participating in economically viable activities to a much larger degree. This was concordant with Zambia's prioritisation of the need to address challenges emanating from non communicable diseases.

## CHAPTER TWO

### LITERATURE REVIEW

#### 2.0 INTRODUCTION

In this chapter I review literature with an attempt to identify what has been and not been done concerning detecting and managing depression and anxiety as comorbidities in epilepsy with a focus on primary health care settings. To this effect, the chapter has been divided into four main sections. In the first section, I will demonstrate what is meant by the concept of Primary Health Care (PHC) in general. This will be compared to how Zambia's health system has applied the Primary Health Care Concept by focusing on pathways of care looking at how patients with epilepsy are managed through the existing primary health care institutions. The desired way of managing such patients will be demonstrated through comparison of what is actually taking place with what is expected. The processes of screening and diagnosis will also be examined to see how they are carried out by primary health care workers. This section will further examine existing Zambian policy regarding management of non-communicable diseases, focusing on mental health and epilepsy.

The second section will explore and examine guidelines used in PHC for screening depression and anxiety as well as epilepsy. The type of screening and diagnostic processes involved will be analysed in relation to issues of human resources, by looking at who exactly does what activity; what skills do they possess; the work environment and referral system. This section critically examines how the Zambian system takes into consideration issues of referral from health centres to general hospitals and vice versa.

The third section explores the diagnostic criteria used for eliciting signs and symptoms suggesting a diagnosis of depression and/or anxiety in the Zambian PHC setting. There is also an attempt to examine policy implications with regard to changes that would be proposed at training and working levels for PHC workers in Zambia.

I will conclude with a summary of the existing gap between what has been done, what has not been and what could be done as suggested by the literature reviewed.

## 2.1 PROCESS OF REVIEW OF PUBLISHED LITERATURE

Two leading international databases (Pub Med and Science Direct) were used to identify data from peer reviewed journals and other documents. Other related search engines were: COCHRANE and Google scholar.

Key search words included: depression, anxiety, comorbidities, epilepsy, primary health care, health policy, and guidelines for screening depression anxiety. The main combinations were: 1. depression, anxiety, comorbidities, epilepsy and primary health care. 2. Guidelines for screening depression and anxiety. 3. Health policy

The articles needed to have a focus on middle and low income countries, published between January 1990 and August 2008. The articles needed to be in English and/or translated into English if written in other languages; accessible as full articles. They should have considered screening tools used in primary health care approach when dealing with depression and anxiety as comorbidities in epilepsy.

No articles marching these criteria were found. However, some related links were suggested. The next search in suggested areas involved the following key words: -“Primary Health Care” and depression, screening tools. When this did not yield desired results, the limitation on years was removed and a general search yielded 1964 articles. Out of these, 29 dealt with depression scales.

## 2.2 Focusing

The next step was to:

- Select articles relevant to the focus of this study
- Select a number for detailed review, based on the fact that they present empirical evidence for analysis of what interventions can be used in setting up management protocols for depression and anxiety as comorbidities in epilepsy.
- I considered conference papers which contained information related to the subject of interest, for instance articles from Zambia’s International Conference (Lusaka from April, 2009); on the theme **Epilepsy and Stigma: How Do We Conquer It In Africa?**

Other information considered was from the dissemination and debriefing workshop on the study findings of the Epilepsy Associated Stigma Team in Zambia, to stake holders who included the Ministry of Health.

### 2.3 CONCEPT OF PRIMARY HEALTH CARE

According to Hall and Taylor (2003, p.17) ”**ACCESS TO BASIC HEALTH SERVICES** was affirmed as a fundamental human right by the Declaration of Alma-Ata in 1978. The reality is that, in 2002, more than 30 years later, many people in resource-poor settings still do not have equitable access to even basic services. In many places this gap is widening” (their emphasis). This situation is arguably continuing even in 2009, especially with the collapse of the world economies in the industrialized western nations, something that is having negative effects for developing nations with low economic status like Zambia. The goal of the Alma Ata declaration was to enable people to receive basic health care package as close to their residence as possible, but as indicated by Hall and Taylor (2003) it has not been realised, especially in low income countries.

Since 1978, the Alma Ata declaration has been interpreted and reinterpreted to suite various socioeconomic situations in developed and developing countries of the world. For instance, Mbambo et al. (2003) point out that primary health care is an integral part of the National Health System of South Africa. They further state that the definition of primary health care was focused on essential health care package based on scientifically sound, socially acceptable methods and **appropriate** technology; that was made universally acceptable to individuals and families; as they fully participated at affordable costs in maintaining every stage of development, under the spirit of self reliance and self determination (my emphasis). It is worth noting that the World Health Organisation (WHO, 1988:16) underscored five basic principles that governed the primary health care package and are worth repeating as they outlined these principles:

- “**Equitable distribution of resources**, which imply that the health care services must be equally accessible to all.

- **Community participation in decision making**, referring to the dimensions of community participation, which include:

- The organisation of services on a community basis;
- The contribution of the community to the operation and maintenance of the services
- Community participation in the planning and the management of services
- Community input into the overall strategies, policies and work plan of the programme

- **Focus on preventive/promotive health service**, referring to the focus on disease prevention and health promotion rather than curative services.

- **Appropriate technology**, which means that the material and methods used in health systems should be acceptable and relevant, including the human resources with appropriate skills, adapted to local needs.

- **A multi-sectoral approach**, which means that health care is regarded as one part or element of total care which includes education, nutrition, water supply and housing (all essential for achievement of wellbeing). According to the Alma Ata declaration (WHO 1978:24) eight essential elements of primary health care services are:

- Education concerning prevailing health problems and methods of preventive and controlling them
- Promotion of food supply and proper nutrition
- An adequate supply of safe water and basic sanitation
- Maternal child care including family planning
- Immunization against major infectious diseases
- Prevention and control of locally endemic diseases
- Appropriate treatment of common diseases and injuries
- Provision of an essential drug supply” (Mbambo et al. 2003, p.43)

Several challenges have contributed to the non realisation of full implementation of the primary health care concept by most African countries. Apart from the variations in geographic and social cultural background, the most notable factor is the variation in economic status they inherited from their former colonial masters at the time of political independence.

The most unfortunate part is that most developing nations especially those from the African region had just obtained their political independence at the time of the declaration of Alma Ata. Between early 1960s and the mid 1980s they were therefore still emulating their former colonial masters or the American models of delivering health care (Roemer 1986). It was soon realised by developing nations that while the idea of building large hospitals in major cities and towns was good, it did not take equity into consideration as evidence showed that the majority of people in the rural areas were not being catered for when it came to health service delivery.

Roemer (1986) points out that the Alma Ata declaration was premised on the concept that pre-existed in the United Soviet Socialist Republic (USSR) which emphasised that a health care system needed to be accessible to the entire population, while providing adequate basic health services, without necessarily achieving highly complicated technology for a small number of people. So simplicity and affordability for the majority was the key rather than sophistication for the minority. It is also evident that the underlying feature of the Alma Ata declaration was a multi-sectoral approach to the delivery of health services with focus on prevention rather than cure of various human diseases. It is worth repeating Roemer’s words when he argues that: “...the health care systems of most countries aggrandised the most specialized services, for which social needs



were relatively minor, and almost ignored the elementary preventive and treatment services for which social needs were enormous” (Roemer 1986, p. 59).

Several years down the line, we find that the concept of primary health care has met several challenges with the African region being most affected. According to the World Health Organisation (WHO) report **“The Health of the African people”** published in 2006, non-communicable diseases (NCDs) and injuries represented 27% of the total burden of disease in the WHO African region in 2001. The countries of the African Region are thus facing a double burden, with high mortality and morbidity due to communicable diseases and an increasing disease burden due to NCDs. For instance, Zambia has just finished its first draft document on non-communicable diseases that aims at offering information to the public on their recognition, common causes and available treatment, something one could never have imagined would cause such serious alarm in the recent past. This development comes as a challenge in the midst of the advent of Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS). It has been clearly observed that in Sub-Saharan Africa, while many opportunistic infections have posed various challenges, their attacks on and involvement of various systems in the human body, has brought about cancers, and neurological manifestations. These neurological disorders include conditions like mental illness and epilepsy. Conditions that were rare and mostly known to occur in old age, are now manifesting in a younger age group. Keeping these facts in mind we can now easily envision that NCDs are becoming of increasing public health concern. This therefore calls for the strengthening of appropriate skills at primary health care level, as well as the consideration of task shifting.

In a study on job analysis of selected health workers in a district health system in Kwazulu Natal, South Africa, Mbambo et al. (2003) emphasise that a primary health care team needs to be inclusive of key players; like health personnel with relevant skills, who can deal with frequently encountered disease conditions and appropriately refer to the next levels of care. To this effect, Mbambo et al (2003) identify primary health care team members as including community health nurses, midwives, doctors, primary health care nurses, enrolled nurses and nursing auxiliaries, oral therapist, psychiatric nurses, clerical and support staff and rehabilitation personnel.

In comparison, the Zambia primary health care team in an ideal situation comprises of clinical officer general (COG), clinical officer psychiatry (COP), registered mental health nurse (RMN), environmental health technologist (EHT), midwife, medical licentiate (ML) and general doctors. However, the reality is that these workers are seen to work throughout all levels of care from health centre to tertiary levels. It is not uncommon to find a clinical officer working at a rural

health centre referring a patient to a general hospital for further investigations, diagnosis and treatment, but have the patient land in the hands of fellow clinical officers before being seen by an intern doctor. Some cases are seen directly by consultants upon arrival, for instance in the obstetrics and gynaecology department at the University Teaching Hospital. The focus of this study is to follow the expected health seeking path of PWE in relation to the roles of COG and RN who initially screen PWE then refer them for further management to COP and RMN. In this case, by virtue of their skills, COP and RMN play a vital role in confirming and diagnosing depression and anxiety as comorbidities in epilepsy.

Another comprehensive version of a health care system is that according to Rebecca and Patronis (2007) which can be seen to contain three major aspects of health care delivery; the primary health care, the secondary and tertiary health care services. Thus we have the integrated health-care systems viewed as innovative, patient-centred hospital based delivery systems that constantly aim at improving quality and use effective utilisation of resources (Effken & Stetler 1997). The underlying mechanism is a network of health care delivery processes that combine to provide better continuity of care. Rebecca and Patronis (2007, p.51-52) explain the entire system as follows:

*“The shift to managed care has also changed the focus from secondary and tertiary care to primary health care. **Primary health care** prioritizes the importance of health promotion and illness prevention. This is the first line of defence for health care. Examples of health-care services provided in primary care include physician visits, immunization clinics, mammography, and teaching and education for clients. Primary health care covers services that prevent illness. **Secondary health-care** services focus on treating disease *Understanding Organizational Structures... through intervention. The patient has a health alteration and seeks treatment to improve the current state of health. Secondary health-care settings include the acute care setting, such as inpatient hospitals, surgical centres, and birthing centres. **Tertiary health-care** services focus on the restoration and rehabilitation services for patients with chronic health-care needs. The goal is to maintain the current state at the best possible level of health. Health-care settings include long-term care facilities, hospice, and rehabilitation centres”* (Rebecca and Patronis 2007, p.51-52)[their emphasis].*

In a related approach, Sokhela and Uys (1999) demonstrated that when human resource in PHC settings is given the appropriate targeted education, the results of improved service delivery in community psychiatry/mental health can be very realistically encouraging. Consequently, this study aims at improving the detection of depression and anxiety as comorbidities of epilepsy in

primary care settings in Zambia, by introducing a novel approach that will change the current way of diagnosing epilepsy and screening for depression and anxiety as common comorbidities by PHC workers.

#### **2.4 HEALTH CARE IN ZAMBIA – PRIMARY HEALTH CARE APPROACH WITH SPECIFIC REFERENCE TO EPILEPSY**

The health care system in Zambia has undergone several changes since its political independence in 1964. At independence, the United National Independence Party (UNIP) took over governance and by the early 1970s, declared itself the only party capable of governing without opposition, under the philosophy of humanism. Under this philosophy UNIP would ensure that freedom to the citizenry would be enjoyed through free education and free health services while food and other essential commodities were heavily subsidised. The policy of free health services was to be achieved through the adoption of the Primary Health Care (PHC) approach. In the Zambian context, PHC includes all services which are regarded as basic in nature that can be offered at health post, health centre, and district hospital levels. However, it must be pointed out from the start that the critical shortage of human resource has caused the deployment of primary care workers to secondary and tertiary levels.

In an attempt to promote efficiency in allocation of the limited available resources, the Government developed a Basic Health Care Package (CBoH 2000) Hospitals were then built in each of the districts and general hospitals in the then eight provinces, prior to Lusaka being declared a province to make them nine. The University Teaching Hospital and Chainama Hills College Hospital were regarded as the specialised referral tertiary hospitals for general and psychiatric services respectively. It was envisioned that this approach would be the Zambian version of PHC where districts would be leading in bringing health services to the communities through supervising health centres and health posts.

However, the situation has not been realised as observed from the government budget speech quoted in the government document entitled Governance, (Ministry of Legal Affairs 1998, p.44)

*“At the macro level, the declining ability of Zambia's economy to provide and, equally important, sustain basic health facilities has had a serious effect on the health status of an average Zambian. Following the 1978 Alma Ata Declaration, the Zambian government adopted the Primary Health Care approach: as a vehicle for attaining health for all by the year 2000. However, low level investment (both financial and human) in health has made it impossible to realise this goal. The status of primary health in Zambia could be gauged using social indicators such as infant mortality, and morbidity rates, birth weight, access to safe water and sanitation, immunisation coverage, maternal health and nutritional, status.*

*It is worth noting that most of these indicators have registered negative patterns” (Ministry of Legal Affairs 1998, p.44)*

#### **2.4.1 Human Resource and Level of Care**

When we talk about primary health care in Zambia, health care delivery is mainly through COG, RN, COP, RMN, EHT, laboratory assistants, dental technicians, pharmacy dispensers and general doctors. The backbone of primary health care activities is the COG, RN and EHT. As earlier mentioned, there is critical shortage of doctors let alone neurologists in Zambia. This has led the government to introduce several incentives to attract junior doctors to work in rural settings but to no avail, as these efforts do not yield their intended purpose since all the doctors end up at the district level where they assume administrative duties which see them more in meetings and travelling to and from the capital city, at the expense of patient care. Patients with mental illness and epilepsy are often the most affected.

#### **2.4.2 Training in Management of Epilepsy**

The COP work hand in hand with RMN, RN, COG, and EHT; all trained for three years at Chainama College of Health Sciences, the only one of its kind in Zambia. When it comes to dealing with epilepsy, the COP are taught neuropsychiatric aspects, diagnosis, classification and first line management as well as referral from health centres via district hospitals, through the provincial hospitals to the tertiary psychiatric institution at Chainama Hills College Hospital in the capital Lusaka. For COPs the theoretical component is expected to cover seven hours followed by practical placement. Similarly, the RMNs are taught the nursing component of epilepsy for almost the same duration followed by a practicum. The COG curriculum covers fifty percent fewer hours than their counterparts thus, putting less emphasis and assuming that the issue of epilepsy belongs to the psychiatric domain -curriculum for clinical officer psychiatry-direct entry,(CCHS, 2005). This trend has continued to date, where observations show that all patients with epilepsy attending Chainama Teaching Health Centre are sent directly to the cubicles that attend to patients with mental health problems.

Evidence has shown that despite their training having some components of recognising and treating conditions such as depression, anxiety and epilepsy, primary health workers in Zambia still require some targeted training in the area of recognising epilepsy and its comorbidities like depression and anxiety. In a study conducted by Chomba et al. (2007) it was found that health workers harboured some stigma towards epilepsy and some recommended interventions which proved unprofessional, and some of these health workers exhibited stigmatization in that they would not even allow their close relatives to marry patients with epilepsy.

In urban areas, the majority of people attending epilepsy clinics come from high density areas, designated as unplanned settlements. These share communal social amenities like, wells, taps and toilets. The residents' main economic activities are:- buying repacking and reselling essential commodities, employment in lowly paid jobs, and small scale industrial activities which include metal fabrication, welding and brick moulding. The population age range is between two to fifty five years with the majority falling between 12 to 28 years. The majority of PWE come with escorts to the clinics. These escorts are either adult females or young female children of school going age; only on rare occasions do we see young male children or men escorting their relatives who have epilepsy to health centres. Records from health centres show that there is an erratic supply of AEDs, with the frequently prescribed drugs being Phenobarbitone, Carbamazepine, Sodium Valproate, Sodium Phenytoin and rarely Lamotrigine. Despite coming from a low income status, the majority of PWE end up seeking these medications from private pharmacies with prescriptions from the government health institutions. A minority of PWE come from middle and high income bracket and thus can afford to consult with private clinics and hospitals.

The diagnosis of epilepsy is almost exclusively dependant on a clinical approach, even though some cases that are referred to the tertiary levels can be further investigated, with X-rays and EEG being carried out. The EEG investigation has been observed to be less helpful as it is based on insufficient technology and methodology. In rare cases, some PWE had been able to afford to go out of the country for advanced investigations. It must be pointed out that of late we have private clinics and hospitals capable of carrying out CT scans and it is not unrealistic to postulate that in the near future we could have MRI in the major government health institutions.

### **2.4.3 Levels of Care**

Levels of the health care system in Zambia can be described as mainly falling under four major categories, according to the Ministry of Health- National Health Strategic Plan ( MoH, 2006-2010). To this effect, beginning at the grassroots level, are:

#### **(i) Health Post and Health Centre Level (clinics) Basic**

Health posts offer first aid health care and are expected to cater for about 1,000 to 7,000 people in rural and peri-urban areas respectively, and are managed by volunteers and community health workers (CHW), who include traditional birth attendants. It is assumed that these health posts could be within five kilometre radius for access in areas which are sparsely populated. In the same category, the next level is health centres in urban and rural areas. These are expected to

service 30,000 to 50,000 and 10,000 people respectively, and are managed by COP, COG, RMN, and EHT.

**(ii) Level One Referral Hospital – (District Hospital)**

The next level is district hospitals. District hospitals service between 80,000 and 200,000 persons providing diagnostic and clinical services (MoH 2008). These are also referred to as level one hospitals. In ideal situations, these are supposed to be managed by doctors who are medical superintendents, but due to shortage of physicians some districts have clinical officers managing them.

**(iii) Level Two Referral Hospital – (General Hospital)**

We have General Hospitals at provincial level referred to as level two hospitals. At the moment there are eight provincial General Hospitals around the country leaving Lusaka a province that was created much later without any general hospital. At the time of writing this research protocol, plans have reached an advanced stage to build a general hospital for Lusaka province that will be situated within the Chainama Hills hospital grounds. The level two or secondary hospitals are managed by senior doctors and registrars, though it is possible to find junior doctors staffing them due to the reasons advanced above surrounding critical shortage of skilled human resources.

**(iv) Level Three Referral Hospital-(Tertiary Hospital)**

Level three or specialised hospitals (also known as tertiary hospitals) include the University Teaching Hospital and Chainama Hills College Hospital. They are expected to offer specialized care and cater for more than 800,000 persons. All cases deemed to be complicated at level two are referred to level three for specialized investigation and treatment. Senior medical superintendents manage these hospitals. We also find senior consultants, consultants, registrars in all specialised fields of health care, theatre nurses, midwives and clinical officers who staff the outpatient departments. (see table 1)

In summary, of the 1,563 health institutions in Zambia, the majority are rural health centres (66%), followed by urban health centres(17%), health posts(11%), level one hospitals (5%), level two hospitals (1%) and level three hospitals less than one percent (MoH 2006) Table 1 summarizes the information on the different levels of care and institutions providing it.

**Table 1. Level of Care, Services, and Personnel**

Level	Services	Coverage	Personnel
Rural Health Post	Basic, First Aid, preventive medicine	1,000 to 7,000	Community Health Worker
Rural and Urban Health Centres	Clinical, screening, diagnosis of common diseases, basic investigations, disease prevention through immunisation coverage and community programmes, referral to level one	10,000 for rural 30,000 to 50,000 for urban	Clinical Officers Psychiatry, General, Environmental Health Technologists, Registered Nurses, Dental Technicians, Radiologists, pharmacy dispensers, laboratory assistants
District Hospital	Supervision of Health Centres, Investigations, Diagnosis, and Clinical services, referral to level two.	80,000 to 200,000	District Medical Officers, Doctors, Clinical officers, Registered Nurses, Radiologists, Pharmacy Technicians, Laboratory Technologists,
General Hospital	Diagnostics and treatment, referral to level three	300,000 to 700,000	Medical Superintendent, registrars, consultants, Radiographers, specialized care nurses Clinical Officers*
Tertiary Hospital	Specialized treatment, widest coverage, receives cases from across the country through general hospitals	800,000 and above	Senior Medical Superintendent, registrars, consultants, Radiographers, specialized care nurses Clinical Officers*

\*At general and tertiary levels COP and RMN are still taking functional roles of provision of specialised care as there are qualified psychiatrists

It should be mentioned that besides these government institutions, several private hospitals offer specialized treatment, mostly concentrated in Lusaka. Other health related activities are also offered by Non-governmental Organisations and Faith Based Organizations, which concentrate mostly on preventive and palliative care. Other major stake holders in health service delivery within the PHC concept include traditional healers whose contributions have been increasingly recognised by the government through the Ministry of Health. Currently, a document on

guidelines for research in traditional medicines has been completed and research activities are expected to start shortly.

#### **2.4.4 Basic Health Care Package for PHC**

There is a package for the delivery of both public and private health care services. This package is known as “Zambia Basic Health Care Package”(MoH, 2003). Interventions in the basic health care package were selected using an epidemiological study to generate evidence of those disease conditions that caused the highest burden of disease and death ( Kapungwe et al. 2011). Ten areas for health service delivery were identified for inclusion in the basic health care package. These are Child and Health Nutrition, Integrated Reproductive Health, HIV/AIDS-tuberculosis and sexually transmitted infections, Malaria, Epidemics, Hygiene-sanitation and safe water, Human resources, Essential drugs and medical supplies (EDMS), Infrastructure and equipment and Systems strengthening. Mental health is not catered for in this package and epilepsy is to some extent attended to, through the basic health care package since antiepileptic drugs like Phenobarbitone and Carbamazepine are included in the Essential drug list. Due to the erratic supply and non availability of AEDs, it is therefore necessary to buy AED through the procurement system of hospitals using their grants or outside support from Nongovernmental Organisations (see table 2). To a large extent the cost is transferred to PWE and their families.



**Table 2. National Health Priorities**

Priority	Strategic Intervention
1. Child health and nutrition	To reduce the mortality rate among children under five
2. Integrated reproductive health	To reduce the Maternal Mortality Ratio
3. HIV/AIDS, TB, and STIs	To halt and begin to reduce the spread of HIV, TB, and STIs
4. Malaria	To reduce incidence and mortality due to malaria
5. Epidemics	To improve public health surveillance and control of epidemics
6. Hygiene, sanitation, and safer water	To promote and implement appropriate interventions aimed at improving hygiene and access to acceptable sanitation and safer water
7. Human resources	To train, recruit, and retain appropriate and adequate staff at all levels
8. Essential drugs and medical supplies	To ensure availability of essential drugs and medical supplies at all levels
9. Infrastructure and equipment	To ensure availability of appropriate infrastructure and equipment at all levels
10. Systems strengthening	To strengthen existing operational systems, financing mechanisms, and governance arrangements for effective delivery of health services

**Source:** Zambian Country Report. Mental Health and Poverty Project- Mental Health Policy Development And Implementation In Zambia: A Situation Analysis (2008 p.17)

#### **2.4.5 Referral System and Diagnosis of Epilepsy**

In an ideal situation, a patient with epilepsy should first be seen at the health post where Community Health Workers (CHW) would screen and refer to the next level if necessary, i.e. the health centre. At the health centre, further clinical assessment diagnosis, and treatment would be carried out by COGs. Where necessary, the patient would be referred to the district hospital or discharged to follow up at the health post. Further assessment and diagnostic procedures may be conducted by COPs and doctors who can treat and discharge through the health centres or refer to the next level. Consultants and registrars are expected to handle cases at general hospitals by conducting further investigations by carrying out EEG, X-rays, diagnosis and treatment before discharging patients who can follow up treatment at their nearest health centres or posts. The further decision would be to refer cases to level three for specialized treatment. At this level

facilities will be available for further investigation using Magnetic Resonance Imaging (MRI) or Computerised Tomography Scanning (CT Scan) etc. And where necessary, surgical intervention. A PWE might need to be seen by neurologists, neurosurgeons, psychiatrists or a combination of all three in consultation with each other.

Unfortunately, the current situation does not clearly show how a patient suffering from epilepsy for the first time could be referred to the appropriate level of health care. This is so partly because such illnesses are rarely, easily disclosed due to the stigma that surrounds them. Where psychiatric comorbidity manifests, the patient with epilepsy is more likely to find her/himself in a psychiatric institution, where epilepsy may or may not be recognized. In most cases relatives of patients initially consult traditional healers before finally bringing them to health centres. Lack of information and lack of health personnel normally influence where PWE can go for health services. Thus, it is not uncommon to find PWE travelling long distances on self referral to the University Teaching Hospital (UTH) or Chainama Hills College Hospital (CHCH) for initial attention. The activities of NGOs like the Epilepsy Association of Zambia, who are trying to sensitize people about epilepsy where to go when need arises, plays a role in this self-referral. However, in the case of children, some patients with epilepsy have found themselves at health centres where limited screening is done before they are commenced on AEDS. These are referred to UTH where specialized care is instituted after investigations and confirmation of the diagnosis.

Furthermore, the reality on the ground is that with severe shortage of skilled human resources COG, RN, COP and RMN manage patient treatment even at general as well as tertiary levels. For instance a study by Atkinson et al. (1999) on the referral process and urban health care in Sub-Saharan Africa, conducted in Lusaka Zambia, revealed several discrepancies. The study demonstrated that despite the advances in the Zambian health sector reform, the patterns of health seeking behaviour by people showed that the so-called specialized hospitals were actually functioning as either district or urban clinics contrary to their intended purpose. In a related study by Mbewe et al. (2006) on clinical and demographic features of first treatment of psychotic episodes at Chainama Hills College Hospital, the description of demographic data revealed that most patients had by-passed all levels of health care before arrival in Chainama for their first admission. This shows a situation where mental health and clinical psychiatric services are over-centralized, so that the third level referral hospital takes up all the roles of the primary health care system. These realities have created uncoordinated efforts towards the management of patients with epilepsy.

Recently, revelations from Lusaka Provincial Health Office (PHO) showed that in all districts, mental health activities had come to a halt due to several factors. For example, a head count of mental health personnel in March 2009 funded by the PHO revealed that several mental health staff had stopped performing their actual work but were redeployed into general duties in the wards. At one district in Luangwa, mental health activities had not been conducted nor budgeted for, over eight years since the death of the responsible COP.

Patel (2008) says that developing nations copy the health services delivery models of those in the West by aiming at building specialist hospitals. He observes that this might work for a while as long as specialists are available and matched with adequate infrastructure. But when both are in short supply, innovative thinking must dictate that non-specialist primary health care workers should be used, who should be included in the core of providing mental health services.

When it comes to issues of epilepsy, Patel et al's (2008) argument greatly contrasts with Gourie-Devi et al. (2003) who had argued for a specialist approach when it came to providing care for people who suffered from epilepsy as they stated that neurologists should be in the forefront followed by other health professionals, not forgetting political commitment. Their argument was that in an ideal situation, epilepsy was clearly a neurological disorder. However, they did accept that the International League Against Epilepsy (ILAE) together with International Bureau for Epilepsy (IBE) and World Health Organisation had fully recognised the fact that epilepsy was a public health problem. Towards the end of their paper Gourie-Devi et al. (2003) appear to have been partly in harmony with Patel (2008) as they acknowledged the fact that in India there was a shortage of neurologists and thus, recommended that doctors and other health personnel in PHC settings needed to be trained in detection of epilepsy. They recommended short term training stints of two to three days for PHC and other general doctors with appropriate skills in detecting and managing epilepsy. It is not clear whether their recommendation took into consideration the need to screen for depression and/or anxiety in PWE.

In a similar manner, the Zambian scenario still needs to be seen from the angle of a critical shortage of neurologists let alone general medical doctors. The country has just reintroduced psychiatric training of its front line PHC workers- the COP and RMN. These undergo training for three years and graduate with diploma certificates. They are posted to all provinces although there is still a need to develop the necessary infrastructure at the health post, health centre and district

hospital levels. Thus, in this study, the referral process of patients from COG to COP will be of prime importance, in that at both levels, there is need to investigate how depression and anxiety are recognised as comorbidities in epilepsy.

The above approach has been constantly advocated by the World Health Organisation (WHO) when they stressed the need to intensify the use of paramedical personnel and of the essential drugs list (Shorvon and Farmer 1988). But this has not been practically possible for Zambia, a low income country where up to 90% of PWE may not be accessing treatment.

Meanwhile, depression and anxiety on their own are well recognised and treated by COP and RMN. However, it is difficult to state the prevalence of depression and/or anxiety attended to in PHC in Zambia, let alone the determination of depression and/or anxiety in PWE. The only information available comes from a cursory survey at Chainama Hills College Hospital. Files of 10% of 600 PWE attending services at the outpatient department were assessed. It was established that in none of the reviewed PWE did the PHC workers consider looking for depression and/or anxiety symptoms. Where symptoms like palpitation and lack of concentration were listed as complaints from PWE, there was neither further probing nor entertainment of a diagnosis of depression or anxiety. This points to the need for the proposed research which seeks to improve skills by use of an appropriate screening tool in PHC settings in Zambia.

## **2.5 INSTRUMENTS USED FOR SCREENING DEPRESSION AND/OR ANXIETY IN PHC**

As implied in the subtitle to this section, there seems to be no comprehensive tool in primary health care settings that is specifically designed to suggest the presence of depression and anxiety in PWE. An ideal screening tool that would be most directly applicable to Zambia is the one that measures anxiety and/or depression signs and symptoms, taking into consideration the socio-cultural aspects of these conditions. It should also be used among primary health workers, like COG, ML, RMN and COP. The screening should include somatic symptoms of headache, palpitations, abdominal upsets all of which should not be attributed to infections. Medically unexplained symptoms have been commonly encountered in patients attending primary care. When no medical explanation has been available to explain their symptoms, these patients have been labelled as “worried well” by primary care physicians (Zaubler et al.1998). The screening tool should be easy to administer and should be completed in less than eight minutes. This was obtained from formal discussions we had with PHC staff targeted to use the screening tool.

A major observation is that for any tool to have meaningful effect, language barriers must be seriously considered. Avitzur (2009) argues that “language barriers can be an added challenge to

medical care” (Avitzur 2009 p. 27). We consulted two language specialists (one for Nyanja the other for Bemba; dialects that are commonly spoken in the capital city Lusaka), at the Zambian Ministry of Education –Curriculum Development Centre for guidance in translations of psychiatric terms and others which included: Depression, anxiety, anhedonia, feeling low, loss of libido, loss of interest and sleeplessness. The results of the respective translations have been presented in tabular form in table 3.

**Table: 3 . Translations of English medical terms into two common local languages of Zambia**

English	Bemba	Nyanja	Comment
Depression	Icikonko	Chikonko	While in both Nyanja and Bemba there is similarity, this interpretation may also mean tearfulness, deeper feeling of distress and a lump in the throat or heaviness
Anxiety	Isakamiko	Kuda nkawa	There is similarity between Bemba and Nyanja, but the meaning mainly denotes worry and uncertainty
Anhedonia	Imisula	kusasangalala	There is total dissimilarity between the Nyanja and Bemba as well as English meanings of the term. In Bemba the meaning is “not minding”, the Nyanja word means “unhappiness” while the English term indicates loss of pleasurable feelings
Feeling low	Ukutompoka/ukunaka	Kumva kuponderezeka/kulemedwa	The Bemba and Nyanja interpretations are in agreement but do not exactly come closer to the English term as their interpretation mainly means feeling tired or as carrying a heavy load.
Loss of libido	Ukukana kwata insuna mu cuupo	Kusowa Nyele	The Bemba interpretation limits its interpretation to “lack of desire in meeting in marriage” the Nyanja interpretation is direct and simply means lack of sexual desire.
Loss of interest	Imisula mu fintu	Kusula vinthu	Once more the meaning in Bemba and Nyanja does correspond to “not minding things” while the English term is clear in terms of loss of interest
Sleeplessness	Ukubulilwa utulo	Kusowa tulo	The meaning of lack of sleep is accurate for both Bemba and Nyanja

This difficulty of lack of words that have the same meaning without having to change the concept nor dilute the meaning of specific medical terms and English words for feelings, may have large negative impacts on the process of screening for depression and/anxiety among PWE.

What is evident at the moment is that the available tools for assessing depression, or depression and anxiety with a few used to assess depression and anxiety in PWE in PHC settings are inadequate. For instance, the Composite International Diagnostic Interview (CIDI), is a fully structured interview schedule which is available in lifetime and 12 months versions. It is available in electronic and paper forms, making it possible to be administered in pencil and on computer. The CIDI contains over 40 items and can be administered by researchers, physicians, non medical personnel; and self, especially in psychiatric patients who remain cooperative. The CIDI was thus “primarily designed to serve cross-cultural epidemiologic and comparative studies of psychopathology” (Robins et al. 1988 p.1069).

Andrews and Peters (1998 p.80) noted that the CIDI, which was fully structured, only assisted in eliciting signs and symptoms that would then be compared by being fitted onto the Diagnostic and Statistical Manual Version Four (DSM-IV) and the International Classification of Diseases Version Ten (ICD-10) diagnostic criteria and indicated whether or not the criteria had been fulfilled “nothing more, nothing less”. The inter-rater reliability was reportedly excellent, with good test-retest reliability. Considering the aspects of methodologies, the validity was equally judged as good. The CIDI was meant to be self administered in people who were cooperative despite their psychotic conditions. The CIDI is available in several languages and by the time Andrew and Peters had published their study results in 1998, the CIDI was being supported by ten centres around the world. The limitation of the CIDI is in its application in primary care settings especially for clinical purposes, as it seems to be more helpful in epidemiological research settings.

Another screening tool used in PHC settings is the Beck Depression Inventory for Primary Care (BDI-PC). This is a seven item self report instrument made up of cognitive and affective symptoms, used along with the Depression subscale from the Hospital Anxiety and Depression Scale (HADS). The HADS is scored by summing all of the highest ratings for each of its seven items, and each item is rated on a 4-point scale ranging from 0 to 3. Importantly, the ratings for the three positively worded items must be subtracted from 4 before summing. The total scores can range from 0 to 21. According to Zigmond and Snaith (1983 p. 363), total scores < 8 indicate 'non-cases'; total scores of 8 to 10 reflect 'doubtful' cases; and total scores of 11 and above represent 'definite' cases.

Alongside with the HDS, the Mood Module from Primary Care Evaluation of Mental Disorders (Klein 2008) was also used to diagnose Major Depressive Disorder (MDD) as a gold standard in differentiating medical patients who were diagnosed with DSM-IV Major Depressive Disorders (MDD) against those who were not. The BDI-PC was constructed by taking into consideration the need to add non somatic symptoms like anhedonia (loss of pleasurable feelings, sadness), suicidal ideas, pessimism, past failure, and self hatred. In their final analysis Beck et al. (1997) pointed out the limitation of their study by noting that the type of sample used in their study meant that their findings had no external validity and thus could not be over generalised. They also argued that the BDI-PC represented a self report instrument “based on non-somatic symptoms. Therefore, the BDI-PC may be especially helpful for a clinician who wants to ascertain in advance whether an extensive psychological evaluation or psychiatric consultation for clinical depression is warranted”.

Oopik et al. (2006) point out that the most commonly used screening measures for adults in primary health care include the Beck Depression Inventory, Zung Self-Depression Scale, General Health Questionnaire (GHQ) and the Patient Health Questionnaire (PHQ-9). To this list can be added their newly developed and improved Estonia Scale for Depression and anxiety (EST-Q2) all meant to improve the detection of depression in general medical settings.

The Zung Self-Rating Depression Scale (SDS) was developed by Zung and Duram in 1964 due to some inadequacies in the existing scales of those days in specifically assessing depression as a psychiatric disorder.

The accompanying specific reasons qualifying the inadequacies outlined by Zung and Duram (1964 p.63) included, “...factors such as the length of a scale or inventory being too long and time consuming, especially for a patient who is already depressed and having psychomotor difficulties. Another factor was that some of the scales were not self administered but based and relied on interpretation by the interviewer”. The focus of SDS was to assess for depression in persons with a primary diagnosis of depressive disorder and fulfilling the following; “it should be all inclusive with respect to symptoms of the illness, it should be short and simple, it should quantitate, rather than qualitate, and should be self administered and indicate the patient’s own response at the time the scale is taken”. A list of 20 items half of which were positively symptomatically worded the other half negatively symptomatically worded was developed. Participants to the study were required to respond to these items by scoring using a list of suggested responses as the situation applied to them at the time of interview.

In their final analysis, Zung (1964), argued that the SDS was a reliable screening instrument for quantitating depression as a disorder. What we learn from this study is that despite having achieved its supposedly intended goal, we still observe that the scale was on the lengthy side given the number of items to be completed, and that it would not be suitable in our settings where the levels of literacy may be low and prohibit self administration of such a tool. Above all, the scale was not used in PWE.

The Patient Health Questionnaire (PHQ-9) was developed by Kroenke and Spitzer (2002) for use in primary care settings. The PHQ-9, is constituted of nine depressive items with ability to measure degree of severity if depressive symptoms have been elicited and depression diagnosis entered. Noting that their study limitation was the cross-sectional design, Kroenke and Spitzer (2002) concluded that the PHQ was reliable and valid in measuring the severity of depression, besides the capacity to make criteria-based diagnosis of depressive disorders. To this effect, they recommended the PHQ-9 to be useful in clinical and study settings.

In addition, Kroenke and Spitzer (2002), noted that there were several case finding instruments for detecting depression in primary care. Their observation was that some of these instruments had only two items while others went up to 28. For instance, Arroll et al. (2003), conducted a study among 15 general practices in New Zealand to determine the sensitivity, specificity and likelihood ratios of two questions in comparison with the computerised composite international diagnostic interview. They concluded that the two verbally asked questions, (“during the past month have you often been bothered by little interest or pleasure in doing things?” The other one “during the past one month have you been bothered by feeling down, depressed or hopeless?”) had good sensitivity (97%) and reasonable specificity (67%). The relevance of this approach to our proposed study is the use of verbal communication between the patient and health care personnel. However, it falls short of satisfying the content that would be directly applicable in a setting like Zambia, where there is no direct translation of the word for depression carrying the same meaning as in English.

Perhaps the most appropriate screening instrument that has been recently promoted by Friedman et al. (2009) is the Neurological Disorders Depression Inventory for Epilepsy (NDDI-E), a 6-item questionnaire validated to screen for depression in people with epilepsy in a busy clinical setting. The characteristics of NDDI-E can be noted in figure 4.



**Table: 4 The Neurological Disorders Depression Inventory for Epilepsy (NDDI-E).**

	Always or often	Sometimes	Rarely	Never
<b>Everything is a struggle</b>	4	3	2	1
<b>Nothing I do is right</b>	4	3	2	1
<b>Feel guilty</b>	4	3	2	1
<b>I'd be better off dead</b>	4	3	2	1
<b>Frustrated</b>	4	3	2	1
<b>Difficulty finding pleasure</b>	4	3	2	1

**Source:** Friedman et al. (2009, p. 430) Seizure 18

Unfortunately, while it meets the criteria of being short and easy to administer, the NDDI-E was meant for self administration in busy clinical settings lending itself to the limitations already outlined in a scenario like ours where literacy levels among PWE are even much lower than the general public. It would take some training to standardize its administration among COP and RMN to use it in a uniform manner.

Similarly, Kobau et al. (2006 p.1916), have tried to develop an assessment tool with an inclusion of two items that do not necessarily screen for symptoms of depression nor anxiety, instead it only asks for depression and anxiety. It has not been tested in an African setting especially south of the Sahara where there are no exact words to mean depression or anxiety as required by questions 6a and 6b (My emphasis) in table 5 for this instrument.

**Table 5. Screening Questions for Epilepsy, Depression and Anxiety**

*2004 Health Styles Epilepsy, Depression, and Anxiety Questions*

1. Have you ever been told by a doctor that you have a seizure disorder or epilepsy?

a. Yes

b. No (skip to next section)

2. Are you currently taking any medicine to control your seizure disorder or epilepsy?

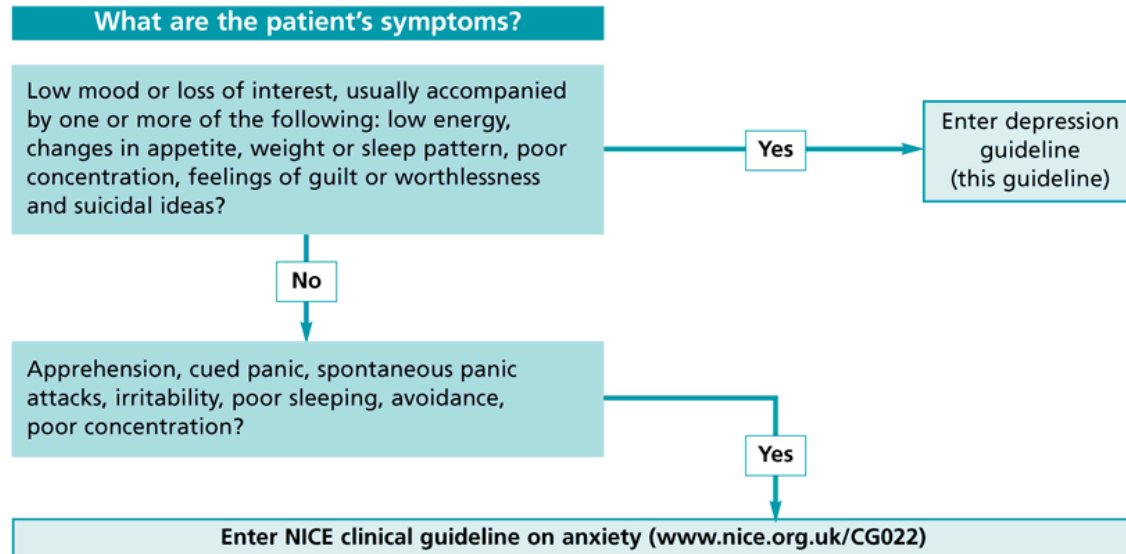
- a. Yes
  - b. No
  - c. Not sure
3. In the past year, have you seen a neurologist or epilepsy specialist for your epilepsy or seizure disorder?
- a. Yes
  - b. No
  - c. Not sure
4. During the past month, to what extent has epilepsy or its treatment interfered with your normal activities like working, school, or socializing with family or friends?
- a. Not at all
  - b. Slightly
  - c. Moderately
  - d. Quite a bit
  - e. Extremely
  - f. Not sure
5. How many seizures of any type have you had in the last 3 months?
- a. None
  - b. One
  - c. More than one
  - d. Not sure
  - e. No longer have epilepsy or seizure disorder
- 6. During the past year have you had (or do you currently have) any of these health conditions?**
- a. Depression**
  - b. An anxiety disorder (phobia or panic**

**Source:** Kobau et al. (2006 p.1916), *Epilepsy Epilepsia*, **47**, No. 11

Another tool is the National Institute for Clinical Excellence (NICE) Clinical Guideline 23(CG90) on Depression: which offers guidelines to the management of depression in primary and secondary care settings for the United Kingdom that was issued in December 2004 and has been undergoing revision since then to date. A small portion of one guideline is given in figure 2 as an example.

**Figure 2. The NICE Clinical Guide on Depression**

## Which NICE guideline?



**Source:** NHS National Institute for Clinical Excellence: Clinical guideline 23 ( NICE, 2004 p.4)

The guidelines mainly cover the following major steps in guiding the user towards screening, diagnosis and management of depression. There is a similar approach for anxiety. The major steps have been repeated with minor adjustments.

Step 1: recognition of depression in primary care and general hospital settings

Step 2: recognised depression in primary care – mild depression

Step 3: recognised depression in primary care – moderate or severe

Step 4: specialist mental health services – treatment-resistant, recurrent, atypical and psychotic depression, and those at significant risk

Step 5: depression needing inpatient care  
(NICE, 2004)

As already highlighted, the guidelines are meant to be used in settings that have no similarities with primary health situations of developing countries. If we were to adopt such a tool we would need to translate it and validate it then adapt it to our settings. Regionally, we cannot overlook the Shona Symptom Questionnaire developed in Zimbabwe for use among the local community. Some advantage with this screening instrument is that it is easy to use and contains 14 items

concerning depression and anxiety symptoms and avoids asking direct questions about whether one is depressed or anxious. Questions relate only to the patient's experience during the previous week. The respondents are required to answer yes or no throughout the interview. Another advantage is that the screening instrument can also be self administered where circumstances may allow.

The United States Preventive Task Force (USPSTF 2002) note that there are several and formally accepted screening tools for depression and anxiety. Despite many of them containing too many items for screening purposes, asking two simple questions about mood and anhedonia could be as effective as using longer screening tools. Another point to note is that most depression screening tools have been arguably proven to have good sensitivity (80%-90%), with only fair specificity (70%-85%). Consequently, the USPSTF (2002 p. 760) argues that "there is little evidence to recommend one screening method over another, so clinicians can choose the method that best fits their personal preference, the patient population served, and the practice setting". The major challenge in this study is a situation where there is a plethora almost, of screening tools for depression and/or anxiety with nothing specifically applicable to the country to choose from. Thus we have to adopt and adapt a tool that would be able to fit most closely to our situation.

It is also important to note that while depression and anxiety may co-occur in PWE, other possibilities are that each can occur on its own in PWE. To this effect Lopez-Gomez et al. (2008) note that anxiety may occur at pre-ictal and inter-ictal stages. Inter-ictal anxiety is taken to mean anxiety symptoms occurring without overall relationship with seizures (Hermann and Chhabria 1980). In their study of the clinical presentation of anxiety among 196 PWE, with focus on inter-ictal anxiety, Lopez-Gomez et al. (2008) used the BDI, Montgomery-Asberg Depression Rating Scale (MADRS), and the Hamilton Anxiety Scale (HAMA). Their findings revealed that 38.8% of PWE in their sample had anxiety symptoms, defined by a score of 18 points on the HAMA. They also noted that the symptoms indicating anxiety with high scores on the HAMA were:- anxious mood, tension, insomnia, intellectual dysfunction, depressed mood, cardiovascular and genitourinary in nature. Different researchers demonstrate that the prevalence of inter-ictal anxiety in PWE varies according to the sample size and methodology employed. For instance Gureje (1991) and Jacoby et al. (1996) recorded between 10% to 25% of PWE in the community with anxiety. Gureje (1991) indicated that anxiety worsened in PWE with focal epilepsy. Anxiety is also more pronounced among PWE when compared to normal controls and patients presenting with other chronic diseases (Gaistazis et al. 2004).

Some PWE may experience anxiety, fear, anger, irritability and nervousness in partial seizure or an aura to their complex partial seizure (Gaistazis et al. 2004). Lopez-Gomez et al. (2008) argue that there still remain no clearcut indicators about which symptoms could be related to seizures on one hand and those due to anxiety on the other. Given what has been done regarding research in depression and anxiety as comorbidities of epilepsy, one would have expected that by now a tool would have been developed that enables PHC staff to adequately screen for depression and/or anxiety in PWE, especially for use in low income countries like Zambia.

The above argument is premised on the fact that the relationship between depression and epilepsy which could be bidirectional (Kanner 2003), was observed as far back as 400 BC by Hippocrates as he stated that: “melancholics ordinarily became epileptics, and epileptics melancholics: what determines the preference is the direction the malady takes; if it bears upon the body, epilepsy, if upon the intelligence, melancholy” (Kanner 2003 p.S13). From that time onward, research has continued to demonstrate this relationship as Gilliam (2005) argued that depression and anxiety as some of the comorbidities in epilepsy had stronger effects on the sufferers’ health compared to the number of seizures they had. Gilliam (2005) then underscored the need for effective screening for such comorbidities in outpatient clinics so as to improve on the overall health outcomes.

Similarly, Kanner (2006) noted that depression was not only the most common but equally remained less recognised. The most worrisome aspect is that in a large number of patients, it remains untreated. Kanner (2006 p.141) summed up his observation as follows: “depression is the most frequent psychiatric comorbidity in epilepsy. Yet, it remains under-recognised and untreated in a significant number of patients. It may mimic primary depressive disorders, but in a significant percentage of patients, depression presents with atypical pleomorphic characteristics. The use of screening self-rating scales may help to identify depressive episodes in PWE, but a diagnosis cannot be established by the sole use of these instruments without an additional, in-depth evaluation. Timely recognition and treatment of depression is of the essence in epilepsy patients, as its persistence is an independent predictor of poor quality of life, increased suicidal risk, greater use of health services, and higher medical costs not related to psychiatric treatment. Neurologists will often find themselves in the position of being the only health care provider available to initiate treatment. Accordingly, they should be well trained to provide psychopharmacologic treatment for major depressive episodes, dysthymic disorders, and minor depression. However, patients with suicidal ideation, psychotic symptoms, or bipolar disorders should be referred immediately to the care of a psychiatrist (Kanner 2006 p.141).

Several issues emerge from Kanner's observations four of which are of great interest to this study namely; the issue of skilled human resource, screening tools, initiation of treatment and referral system. In PHC settings in low income countries like Zambia, where the realisation of an adequate number of Neurologists sounds like an impossibility for the next decades, there is heavy reliance on COP trained to specialize in mental health and clinical psychiatry, who are capable of diagnosing and treating depression and anxiety adequately. This means that if we target COG to improve in the screening and referral of PWE with depression and anxiety, we would be attending to their needs more meaningfully. The issue of specialization at primary level, though initially rejected in Zambia by WHO experts in early 90s, has been well embraced of late when WHO (2008 p.202) clearly states that:

*“some primary care workers will choose to undertake specialist mental health training. These workers, after training, are extraordinary resources for their primary care services. They are well-positioned to provide comprehensive assessment and management of complex cases, thereby reducing the need for special referrals. These health workers can also provide advice and support to their generalist colleagues. Depending on the training focus, primary care workers would be expected to:*

- *Undertake mental health assessment and arrive at an accurate diagnosis, taking into account potential comorbidities*
- *Understand and manage clinical risk*
- *Work effectively with population subgroups: children, adolescents or the elderly;*
- *Manage alcohol and other drug problems;*
- *Understand the use of psychotropic medication and other treatments;*
- *Provide specific psychological interventions such as cognitive-behavioral techniques;*
- *Understand the principle of evidence-based medicine;*
- *Understand how to keep up to date with developments in knowledge and treatments;*
- *Teach and facilitate small groups;*
- *Mentor and supervise other health workers;*

- *Understand policy development, guideline development, service design and implementations;*
- *Understand continuous quality improvement and change management.”*

(WHO 2008 p.202)

## **2.6 Generation of Knowledge Base**

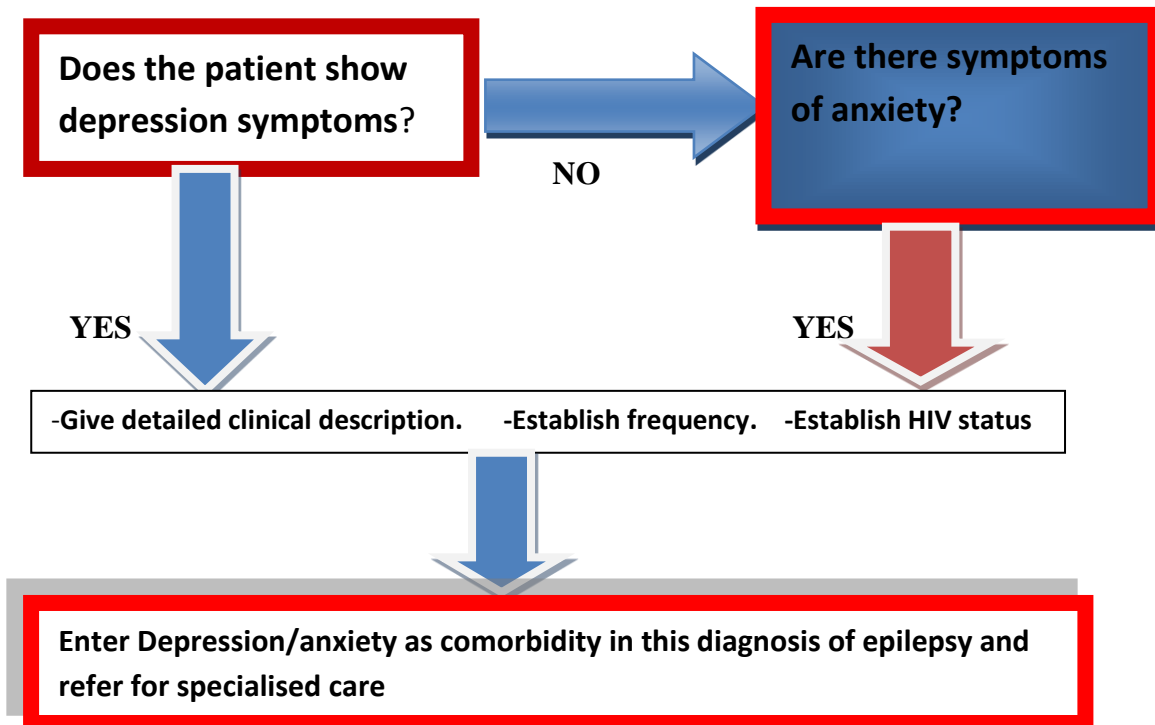
The evidence of additional burdens associated with comorbid psychiatric disorder in patients with chronic epilepsy had not received adequate attention up to 2000 and seems to remain so to date. Several researchers in the field of neurology and psychiatry have therefore called for prospective causal modelling of depression in epilepsy. Hermann et al. (2000) strengthen this point further by emphasising that the knowledge base in the area of depression as comorbidity in epilepsy has been generated through correlation and cross-sectional studies. This has left a need for studies based on causal relationships to be conducted in order to identify factors that are independent predictors of depression in epilepsy.

There is then the need to create a team that would involve a holistic approach to dealing with psychiatric comorbidities in PWE. These would involve COG, COP, RN, RMN, clinical psychologists, nurses, social workers and psychiatrists. Hermann et al (2000) advocated for optimal and cost effective models of care and techniques for use of specialists in mental health with studies in epilepsy that focus on pre-existing effective models of treating depression in primary settings.

## **2.7 Developing a Screening Tool for PHC Setting in Zambia**

With what literature has shown it is proposed that a screening tool which takes into consideration the local social cultural dimensions of detection and management of epilepsy, while simultaneously screening for depression and anxiety as comorbidities; be developed for use by primary care workers, in low income countries like Zambia. Figure 5 is a diagrammatic proposition of how the eventual stages to be followed by the PHC worker would look like:

**Figure 3. Outline of Proposed Stages for Detecting Depression and /or Anxiety in PWE**



The process of interviewing, investigation, diagnosis of patients' complaints in form of a disease entity, usually involves a complicated series of conjoint activities. Most of these activities create a routinized sequence of decisions. Since most procedures involved in some of the sequences involved in decision making can be time consuming but of a very predictable nature, the simplified way is to come up with tools on standard operating procedures based on advance analysis of a general form of each given problem.

In a low income country like Zambia, the development of guidelines for use in PHC is not only embraced as convenient, but the most realistic way of using standardized methods to screen, diagnose and treat diseases of public interest. It is in this interest that we observe that much as we have several protocols for treating sexually transmitted infections (STIs) including HIV and AIDS, treatment of Tuberculosis (TB) and diarrheal diseases, we do not have any guidelines developed locally in the field of mental health and clinical psychiatry for use by PHC workers. The guidelines being proposed here will be the first in the field of mental health to be developed and used in Zambia.

However, there is no agreement on the best way to develop and use clinical guidelines. For instance, if the guidelines become very restrictive and regarded as set standards, they may open room for litigation from those who feel vulnerable and over looked by some content or recommendations in the protocols. The other issue has to do with constant monitoring and



updating of the guidelines as new advances emerge in the field of medicine. Similarly, some guidelines may bring constant controversies from various professionals who may refuse to reach consensus on the basis that some guidelines tend to be based on average and arbitrary oversimplified recommendations. This is seen to eventually compromise the intended standard of care, and in most cases offer rigid advice that could limit the freewill of the primary health worker when other alternatives are readily available.

The development and use of guidelines has been employed in various levels of health care mostly in primary health. However, this is not to say that things have been all that easy for the developers, especially users of the guidelines, as they stand to be sued in the case of the United Kingdom. A case in question is on the revised draft NICE (2004) guidelines for depression, which some researchers argue to be in significant error regarding its recommendations against offering counselling to depressed patients.

## **2.8 CONCLUSION**

So far the literature has shown recognition that depression and anxiety are common comorbidities in epilepsy. It is also beyond argument that a relationship between seizure frequency and depression exists and that the prevalence of depression in epilepsy increases in patients with recurrent seizures (Friedman et al. 2009). The knowledge base in the area of depression as comorbidity in epilepsy has been generated through correlation and cross-sectional studies. This has created a need for studies based on causal relationships to be conducted in order to come out with factors that are independent predictors of depression in epilepsy (Hermann et al. 2000). Literature also displays some fragmented approach to issues of screening and detection of depression and anxiety as comorbidities in epilepsy. There is variation on the duration taken when screening for the presence of depression and anxiety as some tools focus on the current day of screening, past one week, and yet others go as far back as past one month.

There is a strong argument for the fact that the golden standard for diagnosing epilepsy is essentially clinical and relies on the accurate analysis of contemporary eyewitness's accounts of events (Osuntokun et al. 1987). Another idea that has appeared to dominate in the literature is the conviction that epilepsy is a disease entity that belongs to neurologists and when depression or anxiety is present, these should be treated in consultation with the psychiatrists.

The aspect of lack of adequately qualified personnel is mentioned several times, with some authors like Patel (2008) advocating task shifting. There is a total change of opinion from WHO when it comes to support for primary health workers to develop expertise at primary care level. For

instance, training of COP and RMN which used to take three years, was once stopped from 1990 to 2005, on the advice by experts from World Health Organisation (WHO) that Zambia could not train experts at basic level.

On social cultural aspects, the literature shows that this area had been less studied as Shorvon and Farmer (1988) had observed. They pointed out that the compounding factor related to epilepsy is the aspect of traditional beliefs and the role played by traditional healers. For instance traditional healers have been made to recognise their limitation in diagnosing and treatment, thus being capable of taking up their redefined role of screening and referral of PWE (Shorvon and Farmer 1988). Traditional healers have consistently been observed to play a vital role in PHC settings in Africa by providing a service to local communities through giving treatment that directly addressed cultural ideas of illness and causation of epilepsy (Kendal-Taylor et al. 2008, Millogo et al. 2004, McMillen 2004, Opong 1989).

On the other hand, literature is lacking from the Zambian perspective. For instance using PubMed showed that there were no articles on screening tools for depression and anxiety in Zambia and other sub Sahara African (SSA) countries. On Epilepsy and Zambia only 26 articles were found, seven of which were published by the research team on Stigma Against Epilepsy in Zambia (SAEZ).

So far the literature has shown that there exists no integrated tool nor protocols for screening tools for detection of depressive and anxiety symptoms in epilepsy in primary health care settings in low income countries like Zambia. Just as we anticipated, we could not find an appropriate screening tool existing in the local language. Most of the screening tools reviewed are focused on only one condition, mainly depression, and adding anxiety to an existing screening tool may make it quite long. There seems to be solid evidence that one or two questions have as much value as longer screening instruments, but the problem is that many questions in screening instruments inquire about feelings; translation into a local language can be difficult.

In the final analysis, this study hoped to develop two questions addressing depression, and two questions addressing anxiety, that could be used as a screening tool in the local language. The four questions would be broadly based on the Estonia, Shona and NDDI, but with the input of a linguist in the two most common languages in Zambia, we would come up with the four questions. The entire process would initially start with six questions to be adjusted accordingly until a shorter version with at least four questions is achieved.

## **CHAPTER THREE: THREE ARTICLES**

### **3.1 INTRODUCTION**

The University of Kwa Zulu Natal Faculty of Health Sciences where the department of nursing studies is located, also offers PhD to people who have no nursing background but wish to study with them. The potential candidate is given an option between pursuing PhD by research or by publication. The PhD work summarised in this paper was by publication. This work was conducted in Zambia where the candidate lives and works.

### **3.2 ARTICLE ONE**

Detection and management of depression and/or anxiety for people with epilepsy in primary health care settings in Zambia. *Seizure* 22(2013) 401-402.

### **3.3 ARTCLE TWO**

A primary healthcare screening tool to identify depression and anxiety disorders among people with epilepsy in Zambia. *Epilepsy and Behavior* 27(2013) 296-300

### **3.4 ARTICLE THREE**

The impact of a short depression and anxiety screening tool in epilepsy care in primary healthcare settings in Zambia. *American Society of Tropical Medicine and Hygiene* Sept 2013  
4 pages.

## CHAPTER FOUR: CONCLUSION

### 4.1 INTRODUCTION

The aim of this study was to improve the detection of depression and/or anxiety among PWE receiving epilepsy care in primary health care settings in Zambia. Over the period of June 2010 to November 2012 a series of studies was done to achieve this goal, and the results of these were submitted for publication in three articles provided above.

In this section the research questions, which had been dealt with extensively in the three articles, will be briefly answered, but will not be discussed again.

### 4.2 RESULTS

- (i) How frequently are depression and/or anxiety among PWE currently being assessed, diagnosed or treated by non-physician primary health care workers of basic level and level one health institutions in Zambia?

According to our findings in article one, the frequency of assessment for depression and/or anxiety in PWE was at 1%. This was far lower than the ones recorded internationally between 15% and 60%.

- (ii) What screening tool can be proposed based on the evidence in the literature to improve detection of depression and/or anxiety as comorbidities in epilepsy by primary health care workers of basic level and level one health institutions in Zambia?

An indigenous screening tool was developed and validated for use by primary care workers. Some characteristics of the screening tool are as follows:- At ROC of 18, screen was validated by a Psychiatric Clinical Officer using DMS-IV criteria. Cronbach's Alpha was 0.77 overall, and 0.67 and 0.57 for the depression and anxiety components respectively. Other test characteristics included sensitivity 56.63%, specificity 68.05%, positive predictive value 67.3%, and negative predictive value 57.5%. Inter-rater reliability (kappa) was 0.85. This screening tool may prove useful for improving psychiatric care for PWE in busy primary care settings in sub-Saharan Africa

- (iii) Is this screening tool for anxiety and depression valid and reliable?

According to our findings in phase two, the screening tool we developed proved to have some good statistical qualities, such as an internal consistency of 0.77 and an inter-rater reliability of

0.85. However, the sensitivity and specificity were relatively low and certainly lower than many of the screening instruments.

Despite these limitations, the tool represents a feasible option for screening, taking on average five minutes of the time of the health worker to administer. If sensitivity and specificity were the only consideration, one would choose to use the longer and better tool. However, the choice in the PHC service in a developing country might be between using a suboptimal but feasible (i.e. shorter instrument) vs. using nothing, since the demands of a longer instrument makes utilization by busy staff unlikely. Even with its limitations, this instrument has the potential of identifying at least 67.3% of those people with comorbid depression or anxiety disorders, most of whom are currently being missed since only 1% is being screened at all as part of standard care (Mbewe et al, under review).

- (iv) How valid is the screening tool when tested against a gold standard of a DSM-IV based interview by an experienced COP?

The validity of the tool against a gold standard of DSM-IV based interview by an experienced COP was quite favourable at 67%.

### **4.3 CONCLUSION AND RECOMMENDATIONS**

We conclude that, despite being weaker than other internationally validated instruments, the screening tool can be recommended for use and further strengthened on its sensitivity and specificity; before finally allowing it to be rolled out nationwide for use by PHC workers. The developed screening tool can be introduced in the new curricula for nurses and clinical officers at BSc level when the training is introduced in 2013.

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