

**THE EXPERIENCES OF PEOPLE LIVING WITH EPILEPSY IN NZHELELE,  
LIMPOPO PROVINCE**

By

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## DECLARATION

I declare that the study of the experience of people living with epilepsy in Nzhelele, Limpopo is my own work and has not previously been submitted by me for a degree at this or any other university and that all the sources used in the study have been acknowledged in the reference.

.....

**Signature**

.....

**Date**

## **DEDICATION**

**I dedicate this dissertation to my grandparents, Mr and Mrs Siriba and my husband Errol Mhlari who supported me unconditionally.**

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# CHAPTER 1

## INTRODUCTION

### 1.1 Introduction

Epilepsy is reported to be a serious public health problem (Mushi, Hunter, Mtuya Mshana, Aris & Walker, 2011; Nubupko, Clement, Houinato, Radji, Grunitzky, Avode & Preux, 2004) that affects many people worldwide (Meyer, Dua & Ma, 2010; De Boer, Mula & Sander, 2008). It is estimated that 80% of people suffering from epilepsy around the world reside in the developing countries (Diop, De Boer Mandlhate, Prilipko & Meinardi, 2003). Epilepsy (known as *tshifakhole* in Tshivenda) is one of the oldest condition known to mankind (World Health Organization, 2001) and still the most common neurological condition affecting individuals of all ages (Nguni, Bottomley, Kleinschmidt, Sander & Newton, 2010).

Though epilepsy has generally been understood as a medical problem that mainly receives the attention of medical doctors (McQueen & Swartz, 1995), studies have indicated that, cultural factors influence health seeking strategies that individuals and their families adopt to deal with their problem (Reis, 1994). Such cultural factors may drive these individuals to seek help from traditional healers, instead of consulting Western trained health care professionals. For example, a study by Obijiofor (2002) found that about 70-80% of the African population uses traditional medicine. In South Africa, it is estimated that as high as 80% of the black population consult traditional healers (Stafford, Pedersen, Van Staden & Jager, 2008) at some point in their lives.

According to the International League against Epilepsy/ International Bureau for Epilepsy/ World Health Organization, (1999) and Meinardi, Scott, Reis and Sander, (2001), people with epilepsy could leave normal lives if their conditions are properly managed. However, it has been found that the majority of people with epilepsy do not receive any effective treatment. Most people living with chronic disorders such as epilepsy share a common set of challenges including complex medication regimes,

lifestyle adjustments, symptom management, emotional struggles, disability and stigma (Wagner, Austin, Davis, Hindmarsh, Schafer, & Benomi, 2001).

## **1.2 Research problem**

In South Africa, the burden of non-communicable diseases including epilepsy is reported to be growing (Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009; Sander, 2003). It is suggested that about 1 in every 100 South Africans suffer from epilepsy (Spangenberg & Lalkhen, 2006; Ackermann & Van Toorn, 2011). Approximately 70% of patients with epilepsy can successfully achieve seizure freedom with Western medical treatment (Meyer et al, 2010; Baskind & Birbeck, 2005; Diop, De Boer & Mandlhatec, 2005; Coleman, Lopy & Walren, 2002). In resource poor countries, however, many patients with epilepsy remain untreated due to factors such as a lack of trained health care workers, poverty, illiteracy, socio-economic factors, inaccessible health facilities, and inadequate supply of epilepsy medication, cultural beliefs, stigma and myths about epilepsy (Mushi et al., 2011).

Treating people with epilepsy in developing countries may be different from developed countries (Jiamjit, Suwana, Jitpinan, Kittisak & Somsak, 2012). According to, Jager, Mototo, Van Heerden and Viljoen (2005), in some African cultures, some forms of diseases including epilepsy may be perceived as punishment by ancestors who feel disregarded by the living. In other words, epilepsy and other conditions of ill health may be understood as a way that the ancestors communicate their displeasure to the living. In view of these kinds of cultural views that might influence health behaviour, it becomes crucial to investigate the causal explanations that individuals in African communities attach to their illness, including how they respond to these illnesses. The present study is therefore a response to the need to investigate illness and health behaviour in the context of culture.

### **1.3 Operational definition of concepts**

- **Epilepsy-**Epilepsy is a disorder of the brain characterized by recurrent seizures which are physical reactions to sudden, usually brief, too much electrical discharges in a group of brain cells (Khalid & Aslam, 2011). According to McQueen and Swartz (1995), epilepsy is characterized by recurrent seizures which occur in an apparently spontaneous fashion, and are the product of abnormal, paroxysmal discharges of cerebral neurons. In the context of this study, epilepsy is understood to mean two or more unprovoked, recurrent paroxysmal seizures resulting in any abnormal clinical behaviour or motor, sensory, psychic or autonomic dysfunction (Singh, 2006).
- **Causal Explanations-** According to Psillos (2007), causal explanation requires a specification of the relation between cause and effect in virtue of which citing the cause explains the effect. In the context of the present study, this concept is understood to mean the relationship between events where one set of events is a direct consequence of another set of events (Salmos 1998).

### **1.4 Purpose of the study**

#### **1.4.1 Aim of the study**

The aim of the study was to explore the experiences of people living with epilepsy in Nzhelele area which is located in the Limpopo Province, with a view to understanding their causal explanations and responses to this condition.

#### **1.4.2 Research objectives**

The objectives of the study were:

- To investigate the subjective meanings that people living with epilepsy attribute to their condition;
- To determine the causal explanations that people living with epilepsy attribute to their condition, and

- To understand and describe the psychological strategies that these individuals employ to manage the illness.

### **1.4.3 Research questions**

The study was guided by the following questions:

- What are the subjective meanings that people living with epilepsy attribute to their condition?
- What are the causal explanations that people with epilepsy attribute to their condition? and
- What are the understanding and description of the psychological strategies that individuals with epilepsy employ to manage the illness?

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

The following chapter will focus on the existing literature about the subject being researched. In the first part of the chapter, the neurological and psychological basis of epilepsy will be presented. This will be followed by a discussion on the management of epilepsy and a review of the literature that looks at meanings attached to living with epilepsy. The last part of the section will look at the selected theoretical perspectives on this subject. The theoretical framework that has guided the researcher in the present study will also be presented.

#### **2.2 Neurological and psychological basis of epilepsy**

Epilepsy is a neurological chronic disorder with episodic manifestations (Haut, Bigal & Lipton, 2006). In epilepsy, neurological attacks can be accompanied by headaches as well as by variant gastrointestinal, autonomic and psychological feature (Aydemir, Ozkara, Unsal & Canbeyli, 2011). It is suggested that epilepsy is an umbrella disorder which constitutes a heterogeneous family of disorders. In some cases, common drugs such as, valproic acid and topiramate are used in treatment of epilepsy (Aydemir, Ozkara, Unsal & Canbeyli, 2011). The essential feature of all epilepsies is the intermittent occurrence of epileptic seizure which is caused by abnormal synchronous discharges of large numbers of neurons (Muircheartaigh & Richardson, 2012). Muircheartaigh and Richardson (2012) further postulated that these discharges arise in or predominantly involve neurons of the cerebral cortex including neocortex, paleocortex and arcicortex.

The term epilepsy encompasses a number of different syndromes, the cardinal feature of which is a predisposition to recurrent unprovoked seizures (Elger & Schmidt, 2008). Seizures are sudden, brief attacks of altered consciousness: motor, sensory, cognitive, psychic, autonomic disturbances or inappropriate behaviour caused by abnormal excessive or synchronous neuronal activity in the brain. The

phenotype of each seizure is determined by the point of origin of the hyperexcitability and its degree of spread in the brain. The diagnosis of epilepsy requires that the patient has had at least two unprovoked seizures (Elger & Schmidt, 2008).

Epilepsy is characterised by recurrent derangement of the nervous system due to sudden excessive disorderly discharge of the cerebral nervous system. This discharge results in almost instantaneous disturbance of sensation, loss of consciousness or psychic function and convulsive movements. This contributes to deterioration of the patient's condition and development of complications (Kabir, Iliyashu, Abubakar, Kabir & Farinyaro, 2005).

### **2.2.1 Classification of epilepsy**

Epilepsies have traditionally been divided into a number of discrete categories including focal epilepsies, characterized by primary generalized seizures. It is suggested by Berg and Cross (2010) that all seizures probably have a focal onset. However, according to Tatum and Sheth (2002), focal and generalized epilepsy rarely occur independently in the same person. Cases of focal ictal evolution during seizures that are generalized in onset have been reported though these have included a small heterogeneous series of patients with generalized epilepsy. Seizures typically regarded as focal probably evolve relatively slowly in unilateral brain networks, whereas seizures typically regarded as primary may also arise focally but rapidly evolve in bilateral brain networks. Epilepsy can be classified in several ways, as either generalized or partial or localization related and idiopathic or symptomatic (Commission on Classification and Terminology of the International League against Epilepsy, 1989). In generalized epilepsy, the predominant type of seizure begins simultaneously in both cerebral hemispheres. In partial epilepsy, seizures originate in one or more localized foci, although they can spread to involve the entire brain. Most partial epilepsies are believed to be the result of one or more central nervous system.

While epilepsy can be classified as either symptomatic or idiopathic, several types of the disorder have been documented, for example, Jacksonian seizures which are seizures characterized by a progressive spread from one part of the body to another without alteration of consciousness (Tatum, William, Kaplan & Pierre, 2009). Other types of epilepsy include the following: generalized tonic seizure (that is, when a person loses consciousness and usually collapse); absence seizures (which cause a loss of consciousness with few or no other symptoms); myclonic seizures (which consist of sporadic jerks, usually on both side of the body); clonic seizures (are repetitive, rhythmic jerks that involve both side of the body at the same time) (Benbadies & Heriaud, 2009). Tatum, William, Kaplan and Pierre (2009) have also identified a few more types of epilepsy. These include: tonic seizures (characterized by stiffening of the muscles tone particularly in the arms and legs, which results in a fall; Simple partial seizure are futher subdivided into four categories according to the nature of their symptoms, motor,autonomic or psychological); and, complex partial seizure (which include imparment of awareness “patients seem to be out of touch).

The work of Alexander Romanovich Luria, one of the leading experts in the field of neuropsychology, encompassed many topics, including epilepsy (Christensen, Goldberg & Bougakov, 2009). In examining his writings, it is apparent that Luria was clearly familiar with epilepsy as a condition and its influence on behaviour. Luria found that the stimulation of the medical temporal zones in epileptic patients gave rise to general affective change and special states of consciousness and not so much to audioverbal disorder (Luria, 1966). Working memory and processing speed are facets of cognitive ability that are known to be sensitive indicators of neurological functioning in epilepsy (Hermann, Seldenberg, Bell, Rutecki, Sheth, Ruggles, Wendt, O’Leary & Magnotta, 2002; Hermann, Hansen, Seidenberg, Magnotta & O’leary, 2003). The frontal lobe epilepsy and temporal lobe epilepsies are two localization based syndromes that have undergone particular scrutiny (Gottlieb, Zelko, Kim & Nordi, 2012). Executive functions such as cognitive proficiency are generally attributed to frontal cortex structures whereas monastic functions are classically associated with the temporal lobe (Helmstaedter, 2001; MacAllister & Schaffer, 2007). Most direct comparisons indicate greater executive functions deficits in frontal than temporal lobe epilepsy (Chulhane-Shelburne, Chapleski, Hiscock & Glaze,

2002; Hernandez, Squerwein, Jambaquel, De Guise, Lussier, Lortie, Dulac, & Lassonde, 2003).

### **2.2.2 Effect of epilepsy**

One of the most debilitating aspects of being diagnosed with epilepsy is the impact that recurrent seizure can have on cognitive functioning and daily life (McCagh, Fisk & Baker, 2009). In a study by Fisher, Vickery, Gibson, Hermannj, Penovich, Scherer and Walker (2000), people with epilepsy ranked cognitive impairment as one of the biggest problems with having epilepsy. Common cognitive deficits in people with epilepsy are intellectual decline, reduced information processing speed, reduced reaction time and memory (Corcoran & Thompson, 1993; Aldenkamp, Dreifuss & Renier, 1995; Moore & Baker, 2002; Helmstardter, Kurthen, Lux, Reuber & Elger, 2003). According to Aminoff, Boller and Swaab (2012), the most common symptoms of epilepsy are seizures, recurrent headaches, anorexia, vomiting, myoclonus, ataxia, exercise intolerance, muscle weakness, episodic coma, short stature, hearing loss, peripheral neuropathy, diabetes, cardiomyopathy, ophthalmoplegia, pigmentary retinopathy, hirsutism, gastrointestinal dysmobility and nephropathy. A study done by Kabir, Iliyashu, Abubakar, Kabir and Farinyoro (2005), in Nigeria, showed that convulsions and falling down were the most frequently mentioned perceived symptoms of epilepsy.

Characteristics of seizures vary and depend on where in the brain the disturbance first starts and how it spreads. Temporary symptoms can occur such as a loss of awareness or consciousness and disturbances of movement, sensation, mood and mental function (WHO, 2001). Because of these experiences, it can contribute in the impairment of function in daily life and therefore worsen health related quality of life (Gauffin, Flenser & Landtblom, 2011). Because of the sudden loss of movement and consciousness, cultures have consistently considered epilepsy as something similar to death (Mann, 2009). Epilepsy results in physical, intellectual, psychological and social limitation (International Bureau for epilepsy, 2010). In severe cases, epilepsy

results in disability and death due to burns, drowning and even depression induced suicide (Mungumbate & Mushonga, 2012).

People with seizures tend to have more physical problems as well as higher rates of other diseases or psychosocial issues and conditions such as anxiety and depression (WHO, 2001). More often people with focal epilepsy are affected, but milder neurocognitive deficiencies can be seen in those with generalized epilepsy (Carreno, Donarre & Sanchez-carpintero, 2008). Focal epilepsy either can be the result of an underlying condition or can be a postoperative consequence. Temporal lobe epilepsy is more often associated with memory problems (Helmstaedter, 2002; Helmstadter & Elger, 2009). The most common type for 6 – 10 people with epilepsy is called idiopathic epilepsy and has no identifiable cause and in many cases there is an underlying genetic basis (WHO, 2001). Epilepsy with a known cause is called secondary epilepsy or symptomatic epilepsy and the causes could be brain damage from prenatal injuries, congenital abnormalities or genetic conditions with associated brain malformation, a stroke that starves the brain of oxygen and infection of the brain such as meningitis, encephalitis, neurocysticercosis, certain genetic syndrome and brain tumour (WHO, 2001).

The sudden, unexpected and recurrent interruption of the brain function produced by seizures, the cognitive side effect of therapies, and the comorbidities associated with epilepsy all have serious psychosocial consequences for people with epilepsy (Canadian Neurological Sciences Federation, 2009). Some of the psychosocial problems appear to have a direct correlation with seizure frequency. People without seizures for one year, those with less than one seizure per month, and those with more than one seizure per month have a corresponding gradient of ascending prevalence of psychosocial problem such as impaired social activities, inability to sustain paid work, poor self-perceived health, inability to make friends, poor planning for the future and low standards of living (Baker, Jacoby, Buck, Stalgis & Monnet, 1997). People with epilepsy are three times more likely to be hospitalized following an injury than those without epilepsy (Tellez-zenteno, Hunter & Wiebe, 2008). Multiple seizures occurring in a 24-hour period or an episode of status epilepticus

are considered a single event (Khedr, Shawky, Ahmed, Elfeton, Attar, Ali, Kandil & Farweez, 2013). Individuals who have had only febrile seizures or only neonatal seizure (seizures in the first 30 days of life), and people with acute symptomatic seizures (seizures associated with acute systemic illness, intoxication, substance abuse or withdrawal, or acute neurological insults), and individuals with a single unprovoked seizure are not considered to be having epilepsy (Banerjee, Filippi & Allen-Hause, 2009).

### **2.2.3 Causes of epilepsy**

According to Eastman (2005), common causes of epilepsy in South Africa are likely to include infectious diseases, such as neurocysticercosis, HIV/AIDS and trauma. The larval stage of the pork tapeworm taenia solium infects the human nervous system causing neurocysticercosis which is a major cause of epileptic seizure in many developing countries (Garcia, Gonzalez, Evans & Gilman, 2003). Epilepsy is a frequent manifestation of central nervous system disorders in patients infected with HIV, particularly in more advanced stages of the disorder (Garg, 1999). Crepin, Godet, Chassan, Preux and Desport (2009), postulated that, malnutrition early in life has irreversible effects on the development of the brain and early under-nutrition may increase susceptibility to seizures later in life

The proposed International League against Epilepsy classified 48 lists of epilepsy syndrome which many start in childhood or adolescence (Engel, 2001). The various epilepsy syndromes of childhood and adolescence differ greatly in terms of cognitive and behavioural outcomes. A study by Besag (2001), shows that mental retardation has been reported in 71-80% of children with epilepsy. Cognitive arrest or loss of skills appears to occur around the time the spasms are first observed. Regression has been described as being autistic in a proportion of cases. Autistic and hypertnesis were said to occur in equal numbers. Speech problems and impaired visiospatial skills have, in particular been reported (Besag, 2006). The cognitive and behavioural problem in this syndrome may arise from a combination of factors including the epilepsy itself, especially the varying but frequent typical absence

seizures, reactions injury, which is common in this syndrome, the stigmatizing effect of having to wear protective helmets, which are frequently used, the effects of medication, particularly polypharmacy involving the benzodiazepines that may occur when these children emerge from the disabled state of frequent seizures and are able to misbehave as a result of treatment that is at least partly effective in achieving seizure control (Besag, 2001).

Seizures are defined as the behavioural manifestation of a sudden change in electrical activity in the brain (Titus, Kanive, Sanders & Blackburn, 2008). Epilepsy is diagnosed in children who have seizures that are associated with high fevers or other physiological alterations are typically treated or diagnosed with epilepsy. According to Jager, Mohoto, Van Heerden & Viljoen (2005), epilepsy can be caused by imbalance in the GABAergic system.  $\gamma$ -aminobutyric acid (GABA) is the major inhibitory neurotransmitter in the mammalian central nervous system, where it exerts its physiological effects by binding to three different receptor types in the neuronal membrane: GABA<sub>A</sub>, GABA<sub>B</sub> and GABA<sub>C</sub> receptors.

People with epilepsy have increased risk of fractures (Petty, 2011). The morbidity and mortality associated particularly with hip fractures make this an important clinical issue for people with epilepsy. People with epilepsy have at least twice the fracture risk of the general population (Vestergaard, 2005). Multiple triggers have been shown to provoke seizures in reflex epilepsy, among these are the external stimuli (flickering light and hot water), actions (chewing, reading) and even mental task (Gilboa, 2012). Emotional stress causing specific thoughts or fear may also trigger seizure (Zifkin, 2010).

### **2.3 Management of epilepsy**

Perception and treatment for epilepsy have been found to vary across cultures. A study by Khan, Huerter, Sheikh and Thiele (2009), suggests that knowledge, attitudes and practices surrounding epilepsy in developing countries appear to be

different from those in developed countries (Senevirante, Rajapaske, Pajapakse & Seetha, 2002). Although in many cases the precise origins and causes of epilepsy remain unknown, the idea that seizures are a result of sin possession by spirits can still influence people's conceptions of the cause of their disease and treatments (Tekle-Haimanot, Abebe & Forsgren, 1991; Jilek-Aall, Jilek, Kaaya, Mkombachepa & Hillary, 1997; Conrad, 1992). Traditional medicine, including Ayurveda in India, Kampo medicine in Japan, herbal medication in China and traditional herbs in Africa, has continued to play a significant role in the treatment of epilepsy and other medical disorders in many societies around the world (Khan, Huerter, Sheikh & Thiele, 2009). A South African study found that some people with epilepsy combined western and traditional treatments for their conditions (Keikelame & Swartz, 2007).

An estimated percentage of 80 to 90% of people with epilepsy in developing countries do not receive adequate medical treatment (Meinardi, Scott, Reis & Sander, 2001). Poor infrastructure, insufficient availability of drugs and scarcity of trained medical personnel are some of the factors found to be contributing to this situation (Preux, Tiemagni, Fondzo, Kandem, Ngouagong, Ndonko, Macharia, Dongmo & Dumas, 2000). Modern treatment for epilepsy is often unavailable in many countries in Africa. The reason for this might be a lack of treatment facilities, but also the general belief that epilepsy is a result of supernatural causation and therefore not treatable by Western medicine (Aall, 1962; Danesi, 1984; Jilek-Aall & Jilek, 1989). In spite of effective biomedical treatments that can substantially reduce and even prevent seizures entirely, few epileptics in low income societies are in biomedical treatment. For example, it has been suggested that, in Pakistan and the Philippines, greater than 90% of those with epilepsy are not receiving biomedical treatment (Kleinman, Wang, Li, Cheng, Dai, Li & Kleinman, 1995). In these communities, traditional healers are sought out for treatment in order to counteract the witchcraft and evil forces that are perceived to be the causes of conditions like epilepsy (Kleinman et al., 1995).

### **2.3.1 Role of traditional healers**

Traditional healers play an important part in the management of epilepsy in many lower and middle income countries (Newton & Garcia, 2012). In Africa, traditional healers are seen as one of the main sources of health care (Van der Geest, 1992). There are more traditional healers than biomedical health facilities in the developing countries (Baskind & Birbeck, 2005). Traditional healers are not only accessible, but they have also been found to provide culturally acceptable explanation for the seizures. They have also been found to provide culturally appropriate psychosocial support to epileptic sufferers and their families (Kendal- Taylor, Kathomi, Rimba & Newton, 2008). Traditional healers are a heterogonous group that includes herbalists, diviners and spiritualists (Newton & Garcia, 2012). Even with the expansion of modern medicine, traditional healers are still popular (Bojuwoye & Sodi, 2010; Sodi & Bojuwoye, 2011). A possible explanation is that healers have access to valuable and effective therapies unavailable to modern providers (Sobieck, 2002). According to Leonard (2003), such therapies involve living with, cared for and fed by the traditional healer during treatment with no extra charges expected. According to Sodi and Bojuwoye (2011), traditional health care approaches and methods, have been in existence since time immemorial.

Efforts made toward bringing the treatment gap and reducing the burden of epilepsy in developing countries are continually threatened by socio-cultural constraints which include local perceptions of cause and treatment, stigmatization, discrimination, negative cultural attitudes, poor health care system infrastructure, poverty, scarcity of trained medical personnel and inadequate supplies of drugs among others (WHO, 2001).

The majority of the population in South Africa use traditional health care to treat various mental conditions (Stafford, Pedersen, Shaden & Jager, 2008). The use of traditional medicine in South Africa is widespread, and it is estimated that as high as 80% of the black population consult traditional healers. A study by Christianson, Zwane, Manga, Rosen, Venter & Kromberg (2000), showed that 22.5% of epileptic

children in South Africa received only traditional medical management, 20% received both forms of management, and 34.6% received no treatment at all.

Traditional practice may include psychological, spiritual and cultural elements, as well as medical elements (Stafford, Pedersen, Shaden & Jager, 2008). A study conducted in Zimbabwe by Mugumbate and Mushonga (2012), indicated that villagers hold the belief that epilepsy is not treatable by medical means, hence the need for people with epilepsy to seek therapy from traditional means. This is also because of the belief that epilepsy is caused by their ancestors and therefore treatment should follow traditional methods where ancestors are consulted by a traditional healer.

The indigenous people of Southern Africa have a long history of traditional plant usage for medical purposes, with about 4000 taxa being so employed. Traditional medicines continue to play a significant role in the treatment of life threatening diseases (Deurtschlander, Lall & Van der venter, 2009). Traditional healers are often part of a local community, culture and tradition and continue to have high social standing in many places exerting influence on local health practices (Cheikhyoussef, Shapi, Matengu & Ashekele, 2011). Most African people still rely heavily on traditional medicines and traditional healers are often the first and last line of defence against most diseases (Matsheta & Mulaudzi, 2008). One advantage in preferring traditional medicine is that traditional healers are found within a short distance, are familiar with the patient, culture and the environment and the costs associated with treatment are negligible (Rinne, 2001). Traditional leaders work on body and mind together to help cure an illness.

Epilepsy in Kenya is known as *Kifafa* (Kendal-Taylor, Kathomi, Rimba & Newton, 2008). In a study done by Kendal-Taylor, Kathomi, Rimba & Newton, (2008), one healer described epilepsy as a problem that comes when a person falls on the ground and shakes. When such a person wakes up, he does not remember what has happened. It is epilepsy if it comes again and again. Traditional healers attribute

epilepsy and other illnesses to natural spirits, curses and ancestral spirits. Healers employed a different treatment ideology for each of the three spirit-based causes of childhood epilepsy. The natural spirit is the most common cause of epilepsy in the traditional system. Seizures are believed to occur when the spirit comes to a child, and they subside when the spirit departs.

Healers accounted for the tremors and shaking associated with seizures in terms of efforts of the affected individual to break free of the spirit's hold on them (Kendal-Taylor et al, 2008). The common looks of surprise or screams prior to the onset of the seizure were rationalized as the individual's reactions to the spirit's sudden appearance. Traditional healers also reported that epilepsy might be transferred between family members via ancestral spirits. Ancestral spirits are believed to cause problems because of unfulfilled desires. If specific rituals are not performed following the death of a family member with epilepsy, the spirit of the dead relatively may return to the family, bringing epilepsy. According to the traditional system, the family's next child will have the disorder (Kendal-Taylor, Kathomi, Rimba & Newton, 2008).

Traditional health care is utilized by the majority of the population in Southern Africa and this is especially true of treatment for mental health problems (Jager, Mohoto, Van Heerden & Viljoen, 2005). This is partly due to severe lack of facilities for treatment of mental disease in the Western health care system, but also because these diseases in their cultural context are better handled by traditional healers (Jager, Mohoto, Van Heerden & Viljoen, 2005). In African culture, mental diseases are the result of disregard for the ancestors, who can inflict an individual. This means that cultural/ psychological/ spiritual elements nearly always are a part of the treatment (Jager, Mohoto, Van Heerden & Viljoen, 2005).

## **2.4 Living with epilepsy**

Stigma has been found to be a major factor associated with the burden of individuals with epilepsy (Pallavi, Daya, Hacue & Nishant, 2009). Stigma has been variously defined, but is essentially the feeling of being different and usually inferior to others (McQueen & Swarts, 1995). The orthodox viewpoint of stigma argues that stigma originates from people who do not have epilepsy (outsider), who project a stigmatized image into persons with epilepsy (Scambler & Hopkins, 1988). For many patients, the fear of stigma makes them keep their disorder a secret. According to Giri and Shankar (2006), individuals with epilepsy refrain from discussing their sickness openly and try to minimize their difficulties.

The stigma associated with epilepsy is common in many cultures (Jacoby, Snaper & Baker, 2005) and is considered to be the most important factor that influences the lives of people with epilepsy and their families (Baker, 2002; Morrel, 2002; Mclin & De Boer, 1995; Jacoby, 1992). Epilepsy erodes the individuals' social status, social networks and self-esteem; all of which contribute to poor outcomes such as isolation, unemployment, lower prospects of marriage and not seeking treatment (Collings 1990; Jacoby, 1992). People with epilepsy report that dealing with the stigma and the associated prejudicial responses from others are the biggest challenges associated with the condition (Austin, Shafer & Deering, 2002).

People with epilepsy sometimes cannot conform to usual social norms as a result of the unpredictable nature of seizure. Consequently society may fear dealing with an epileptic person (Fernandes, Salgado, Noronha, De Boer, Prilipico, Sander & Li, 2007). Goffman (1963), has pointed out that stigma has been conceptualized as an attribute that is deeply discrediting. The stigmatizing nature of epilepsy and its associated psychological distress have been reported to have a significant impact on the quality of life of individuals with epilepsy. However, the degree of the felt stigma and its consequences are not equal in every individual (Schneider & Conrad, 1981).

People with epilepsy often struggle to overcome low self-esteem and the stigma that is attached to having epilepsy. According to Atadzhanov, Haworth, Chomba, Mbewe and Birbeck (2010), among people with epilepsy, stigma is experienced mostly by people reporting contagious beliefs of themselves or their neighbourhood and in people with forced disclosure. The stigma is due in part to a lack of understanding by people. To suffer from epilepsy in Africa often means to also suffer from a very specific psychological and social trauma (Billington, 1968; Dada & Odeku, 1966; Jilek-Aall & Jilek, 1989; Orley, 1979). Epilepsy drastically changes the way a person perceives life and his/her position within the family unit. Because of the belief that epilepsy may be contagious or caused by supernatural forces, epilepsy sufferers are in some cases shunned and feared by others around them (Jilek-Aall, Jilek, Kaaya, Mkombachepa & Hillary, 1997). The psychosocial problems that are faced by person with epilepsy particularly in relation to employment and relationships are not always a consequence of seizure activity but more often the results of discrimination and misconceptions about the disorder (ILAE, 2003; McCagh, Fisk & Baker, 2009; Fisher, Vickrey, Gibson, Hermann, Penovich, Scherer & Walker, 2000).

Epilepsy is often viewed with a degree of fear and risk of contagious effect due to the cultural attitudes and belief in South Africa (Stafford, Pederson, Staden & Jager, 2008). Studies conducted in township by Stafford, Pederson, Staden & Jager (2008), showed that the parents of epileptic children believed that the disorder is caused by various parameters including bewitchment, fear or evil spirit. And epilepsy is viewed as a shameful disorder and has severe social implications in African communities as it carries a stigma. This cultural influence is also prominent in the treatment of the disorder where many people seek treatment by traditional healers and traditional medicine. Epilepsy can have profound physical and psychological consequences in older patients (Besocke, Rosso, Valiensi, Garcia, Gonorazky & Romano, 2013). The stigma surrounding the diagnosis can be hard to address at the time of life. Elderly people are particularly vulnerable to physical injury as a consequence of seizures. The situation may be complicated by a range of neurodegenerative, cerebrovascular and neoplastic comorbidities. Quality of life can be adversely affected and unpredictable nature of the seizure can lead to social withdrawal, loss of confidence and reduced independence can result in premature admission to nursing homes and

residential care facilities (Besocke, Rosso, Valiensi, Garcia, Gonorazky & Romano, 2013).

Attitudes towards epilepsy can also be influenced by the individual's socioeconomic background, knowledge and the illness perception of epilepsy (Lim, Lim & Tan, 2011). For example, people from rural areas with lower educational level and socioeconomic status have been found to have more negative attitude towards epilepsy, as well as old age and gender (Neni, Latif, Wong & Lua, 2010). Names of epilepsy may reflect misconception and contribute to stigma in epilepsy (Lim, Li, Casanova-Gutierrez & Tan, 2012). Epilepsy in Chinese is associated with insanity and animals. Because of the influence of traditional Chinese medicine, the names of epilepsy in certain East and South-East Asian languages also convey the image of insanity and associated with animals.

The adolescence stage of life is important because it is associated with considerable mental, physical (puberty) and psychosocial (identity, autonomy) changes (Valizedeh, Barzegeer, Akbarbergloo, Zamanzadeh, Rahimnia & Fergurson, 2012). Children with chronic epilepsy can have a poor psychological prognosis which may increase the risk for behavioural, academic, social, psychiatric and family difficulties (Besag, 2006; Camfield & Camfield, 2007). People with epilepsy experience a higher degree of social isolation and some of this relates to or is exacerbated by restrictions in activities, and for adults, restrictions related to employment where many social networks are found. More people with epilepsy live alone than in the general population, and for families with children who have epilepsy, support networks may shrink with seizure severity (Nolan, Camfield & Camfield, 2006) along with leisure activities (Shore, Austin, Huster & Dunn, 2002).

Children with epilepsy often grow into adults with significant social problems including decreased employment, marriage, social relationship and independent living arrangements (Camfield & Camfield, 2001). The prevalence rate of epilepsy is estimated to be about 4 per 1000 children and adolescences (Hirtz, Thurman, Gwim-

Hardy, Mohamed, Chauduri & Zalutsky, 2007). Approximately 10 million people are affected in Africa (Lugthart, 2011). The daily life of many people with epilepsy is disturbed and endangered by seizures and the stigma the disease carries. People with epilepsy in Africa are disabled by stigma. A combination of traditional beliefs, poverty, lack of medical care and inability to fulfil social roles has a negative impact on the lives of people with epilepsy (Baskind & Birbeck, 2005). Stigma is not only felt by people with epilepsy. Courtesy stigma is the stigma by association experienced by people close to someone who is stigmatized (Baskind & Birbeck, 2005).

Seizure during cooking with open fire may frequently leads to burns. A study conducted by Allorto, Oosthuizen, Clarke and Muckart (2009) in South Africa showed that 50% of the adults admitted with burns had epilepsy. Scars, especially on the face, are visible to other people and lead to shame and discrimination. One aspect influencing stigma is that many people in Africa believe epilepsy to be contagious and that it can be spread by urine, saliva, flatus or faeces or during a convulsion (Sanya, Salami, Goodman, Buhari & Araoye, 2005). This can result in isolation and unwillingness of witness to touch the patient and protect from injury during seizure. The belief that seizures are a sign of bewitchment leads to stigma too. People with epilepsy seek care from traditional healers who often emphasizes these beliefs and medical care is delayed. As a consequence of the seizures and the related stigma people with epilepsy might be unable to find a partner or are at risk of abandonment after disclosure (Birbeck, 2010).

At the time of diagnosis, life expectancy has been reported as reduced, particularly in people who develop seizure before the age of 40 (Wilson, 2011). There is an increased risk of suicide shortly after diagnosis and elevated rate of co-morbidity and psychosocial difficulties (Jacoby & Baker, 2008). Multiple triggers have been shown to provoke seizure in reflex epilepsy (Gilboa, 2012). Among these are external stimuli (flickering light, hot water), action (chewing, reading) and even mental task. Seizures in reflex epilepsy may be spontaneous or precipitated by identifiable external or internal trigger (Engel, 2001). Some known triggers are listening to music, bathing, chewing, reading and other cognitive tasks. Many people with epilepsy

suffer from depression, which also impairs quality of life and introduces additional problems (Gilliam, Santos, Vahle, Carter, Brown & Hecimovic, 2004).

The impact of childhood cognitive impairment on the ultimate success of adjustment into normal adult life may be modified by social factors such as educational provision and family support, as well as behavioural comorbidities such as attention-deficit/hyperactivity disorder and autism spectrum disorder (Chan, Badleweg & Cross, 2011). Children with epilepsy have a high incidence of problems with attention and executive function compared with controls, even at diagnosis (Hermann, Jones, Sheth, Koehn, Becker, Fine, Allen & Seidenberg, 2008). Sleep problems in children with epilepsy are widespread, and range from behavioural and sleep hygiene issues to electrophysiological changes in sleep macro and microstructure (Parisi, Bruni, Villa, Verrotti, Miano, Luchetti & Curatolo, 2010). Children with epilepsy may also suffer from related breathing disorders, which have themselves been implicated in neurocognitive and behavioural problems (Kheirandish & Gozal, 2006).

The negative consequences of epilepsy are further compounded by the fact that a large proportion of people with epilepsy in Africa are not taking antiepileptic drugs and continue to have frequent seizures (Scott, Lhatoo & Sander, 2001). Sillanpaa, Jalava, Kaleva and Shinner (1998), have reported on the socioeconomic aspects of neurological intact individuals who are in long term remission from seizure. As compared with people without epilepsy, these individuals have a higher prevalence of low socioeconomic status, unemployment, inability to drive, limited education, non-married marital status and childlessness (Canadian Neurological Sciences Federation, 2009).

Stress has been considered the most frequently self-reported precipitant of seizures in people with epilepsy (Arida, Scorza, Terra, Scorza, Carlosde-Almerda & Cavalherro, 2009). Not knowing when, where or if a seizure will occur has been identified by people with epilepsy as the aspects of the disorder of greatest concern (Fisher, Vickrey & Gibson, Hermann, Penovich, Scherer & Walker, 2000). People

with epilepsy report that the frequency of their seizures increases if they are exposed to emotions caused in the person's internal or external circumstances (Browne & Holmes, 2001).

## **2.5 Theoretical perspectives**

### **2.5.1 Learned helplessness and epilepsy**

The theory of learned helplessness was developed by the American psychologist Martin Seligman in 1967. The theory consists of three essential components, namely: contingency, cognition and behaviour. Contingency refers to the objective relationship between the person's action and the outcomes that he/she then experiences. Cognition refers to the way the person perceives, explains, and extrapolates the contingency. Behaviour refers to the observable consequences of (non) contingency and the person's cognitions about it. The theory has proposed that epilepsy is a high psychological risk disorder because persons with epilepsy are vulnerable to the powerful behavioural ramifications of exposure to unpredictable, uncontrollable, aversive events. According to Peterson, Mainer and Seligman (1995), people with epilepsy are more depressed and tend to perceive themselves as having less control over events in their lives. According to the learned helplessness theory, people with epilepsy who have learned that the occurrence of a seizure is beyond their control can develop passive, helpless attitude towards many aspects of life (Svoboda, 2004; Hermann, 2004).

### **2.5.2 Psychodynamic theory and epilepsy**

Psychodynamic theory was developed by Sigmund Freud (1856-1939). This theory emphasizes the subjectivity of individual experiences based on the person's internal world. According to this theory, symptoms and behaviours are believed to be the external manifestations of internal process, with childhood experience considered to be crucial to the development of persistent maladaptive behaviour pattern (Ettinger & Kamer, 2007). According to the psychodynamic theory, epilepsy may be understood as a manifestation of the repressed and offensive thoughts and memories that may find an outlet in physical symptoms that allow the person to relieve their unconscious

selves and to keep the offending content or thoughts further repressed. The primary pathology (in this case, the epileptic condition) is the unresolved intrapsychic conflict and eventually this leads to secondary gain from obtaining attention and avoiding responsibility (William & Hermann, 2012). Psychodynamic theory assumes that mental illnesses are a result of unconscious psychological conflicts originating in childhood and that both normal and abnormal functioning are motivated by irrational drives and determined by childhood experiences. Further, psychological disorders are caused by an imbalance in the structure of personality (id, ego and superego) (Mufamadi & Sodi, 2010).

### **2.5.3 Cognitive-behavioural theory and epilepsy**

According to the cognitive-behavioural theory, the thought a person has about his illness can have a major effect on behaviour towards the illness (Wright, Turkington, Kingdon & Basco, 2009). The cognitive-behavioural theory looks at the inter-relationship between environment, thoughts, feelings, physical sensations and behaviour (Kaslow & Terence, 2002). This theory postulated that disturbance in the thoughts of an individual determine the way they will react towards the illness. In other words, the thought that an epileptic sufferer has towards his/her condition will have an impact on how they relate to the illness.

### **2.5.4 Health belief model and epilepsy**

The health belief model attempts to explain the thought process behind individual's decisions related to health behaviour change and maintenance (Remocker & Shea, 2011). This model suggests that individuals determine the feasibility, benefits and cost related to an intervention or behaviour change based on the following constructs:

- **Perceived susceptibility:** Beliefs about the likelihood of getting a disease/ condition.
- **Perceived severity:** Beliefs about the seriousness/ consequences of the condition.

- **Perceived barriers:** Belief about cost/negative aspects of the action.
- **Self-efficacy:** Belief in one's ability to take action to produce desired outcomes.

The health belief model was the first to postulate that a person's belief in his or her personal susceptibility to and the severity of a health condition are important variables influencing the decision to take action to prevent health problems (Rankin, Stalling & London, 2005). Based on this model, it can be suggested that the decision by an epileptic sufferer to take action to deal with his/her condition will be influenced by the severity of the illness.

### 2.5.5 Attribution theory and epilepsy

Attribution theory has been widely used to explain behaviour people attribute to their condition. The theory suggests that when people are faced with an illness which they have little control of, they will attempt to impose control by offering explanations of what is happening to them (Gehlert & Browne, 2011). Gehlert and Browne (2011), speaks of three dimensions of causal attributions:

- **Internality versus externality:** It is whether the cause is due to the person or to other persons or circumstances.
- **Globality versus specificity:** Whether the same explanations are used for variety of factors or are specific to one or a few factors.
- **Stability versus instability:** It has to do with whether a factor is long lasting or transient.

Based on the attribution theory, it can therefore be argued that individuals with epilepsy will tend to impose control by offering explanations of their conditions.

### 2.5.6 Cultural explanation of epilepsy

Every human society has its own culture and knowledge system for dealing with or responding to environmental conditions (Bojuwoye & Sodi, 2010; Simwaka, Peltzer & Maluwa-Banda, 2007). For example, one of the most important areas of African

culture in which the significant presence of traditional belief can be seen is through sickness and healing. In many traditional cultures, illness is thought to be caused by psychological conflicts or physical or mental problems. The indigenous African communities in South Africa perceive harmony between the individual and the ancestors as critical in maintaining good mental health. This harmonious situation is considered to exist if the individual and his/her family meet their socio-spiritual obligation to the ancestors. Some illnesses, including epilepsy and mental illness are believed to occur when this harmonious relationship between the ancestors and the living is disturbed. In such illnesses treatment by a traditional healer is aimed at restoring the balance between one's family and the ancestors (Sodi & Bojuwoye, 2011).

Each culture has its own knowledge systems for responding to diseases and restoring health to individuals who are ill. All cultures have their own unique explanatory models of health and illness that can be understood within their respective world views. Along with the explanatory models about health and ill-health or diseases, each culture also recognizes some of its members as competent healthcare providers because of their abilities to use culturally appropriate substances and methods to bring health and well-being to members of the community. Such talented individuals are believed to possess awareness or knowledge, skills, values and attitude acquired through timeless experiences and wisdom for helping people solve problems and make decisions (Sodi & Bojuwoye, 2010).

## **2.6 Theoretical framework: The Afrocentric perspective**

Schiele (2000) suggested that different societies have their own ways of describing what Western psychiatry refers to as mental illness. Similarly, different societies tend to have their own ways of describing and managing epilepsy and other neurocognitive conditions. It is recognized that this has an influence in moulding the presentation and natural history of different illnesses (Mkhize, 2003). The interaction of illness characteristics and socio-cultural variables is acknowledged, together with

the importance of taking into account the socio-cultural factors both in understanding an illness and planning treatment (Sodi & Bojuwoye, 2011).

In the present study the researcher was guided by Afrocentrism. The Afrocentric perspective examines topics with the eye of African people as subjects of historical experiences. It seeks to re-locate the African person as an agent in human history in an effort to eliminate the illusion of the fringes (Schiele, 2000; Mio & Iwamasa, 2003).

The perspective views manifestations of most illnesses as a result of conflicts between the patient and other individuals, dead or alive, spirits and the non-material forces that pervade society (Mkhize, 2003). Therefore, in order to understand the African perspective on epilepsy, it is important for one to have an understanding of the African concepts of the causes of illness (Bojuwoye & Sodi, 2010), including how conditions of ill health are treated. The Afrocentric approach is therefore considered a suitable theoretical framework for the present study, as the aim of the study is to explore the experiences of epileptic sufferers in a rural community in South Africa.

## CHAPTER 3

### RESEARCH METHODOLOGY

#### 3.1 Introduction

In this chapter, the methodology used in the study will be presented. The research design, and in particular the phenomenological approach that was adopted, is briefly described. The sampling and the data collection methods are also presented. The steps followed in data analysis are outlined whilst ethical considerations are also discussed.

#### 3.2 Research design

In this study, the qualitative method will be followed. Qualitative research is designed to explore the human elements of a given topic, where specific methods are used to examine how individuals see and experience the world and it often provides an unparalleled understanding of the motivations behind human behaviour, desires and needs (Given, 2008). In this study a phenomenological approach was used. According to McMillan (2010) and Von Eckartsberg (1998), phenomenology as a research approach seeks to examine and clarify the human situation, events, meanings and experiences as they spontaneously occur in the course of daily life. In addition, the purpose of the phenomenological research is to illuminate the specific and to investigate phenomena as they are perceived by actors in a situation (Lester, 1999). David (2000) and Smith (2004), define phenomenology as the exploration and description of phenomena, where phenomena refer to things or experience as human being experience them. One of the advantages of the phenomenological approach is that it clarifies the meaning of phenomena from the lived experience, and as such it, offers an important shift from a positivist cause effect to one of human subjectivity and discovery of the meaning of actions (Giorgi, 2005).

The goal of phenomenological research is to describe experiences as they are lived. Phenomenological research further examines the particular experience of unique individuals in a given situation thus exploring not what it is but what is perceived to

be (Burns & Grove, 1998; Langdrige, 2007). Another goal of phenomenological research according to Pollio (1997) is to describe human life rigorously as it is lived and reflected upon in all of its first person concreteness, urgency and ambiguity. In line with the goals outlined above, the present study sought to use the phenomenological approach in order to uncover the meanings that people with epilepsy attribute to their lived experiences.

### **3.3 Sampling and setting for the study**

Snowball sampling also known as chain referral sampling was used to identify and select participants for the present study. According to Babbie (2010), snowball is one of the non-probability sampling techniques where a researcher collects data on the few members of the targeted population that the researcher manages to locate. Once located and approached, these few members are asked to refer the researcher to other members of the population who also have the same characteristics. Voicu and Babonea (2009) describe the snowball method as the identification of an initial set of respondents who will be interviewed and who will be requested at the end of their interview, to recommend potential subjects who share similar characteristics, and who are relevant for the purposes of the subject. This procedure is appropriate when the targeted population is difficult to locate. Snowball is extremely useful when the focus of the research question is to do in-depth investigation of a small population, or when the researcher is performing a preliminary explanation study (Schutt, 2006). For the purposes of this study, the researcher targeted 6 participants who were drawn from Nzhelele area in Vhembe District (Limpopo Province).

Nzhelele village is a rural district situated in Limpopo Province in the northern part of the country (See Figure 1). Most of the people in this area speak Tshivenda as their home language. Nzhelele has an estimated population of about 516031 people. The growth rate of the in the area population is estimated to be 0.43%. Only 4.4% of population is said to have tertiary qualification and it's a low socioeconomic area with only 36.7% population employed (<http://beta2.statissa.gov.za/makhadomunicipality>).

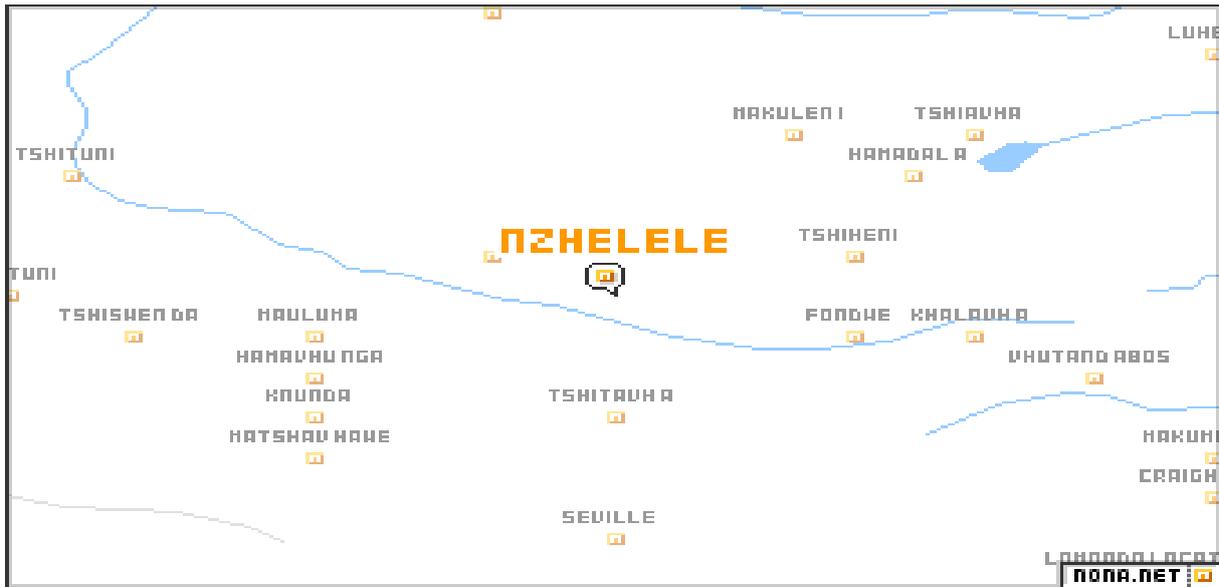


Figure1. Map of Nzhelele area, Limpopo Province ([www.nona.net/features/map/placedetail.1016508/nzhelele](http://www.nona.net/features/map/placedetail.1016508/nzhelele))

### 3.4 Data collection techniques

The qualitative research interview was used to conduct data for the present study. According to Kvale (1996), the main task in qualitative interviewing is to understand the meaning of what the interviewees say. A qualitative research interview seeks to cover both the factual and the meaning level, though it is usually more difficult to interview on a meaning level. In addition, interviews are particularly useful for getting the story behind a participant's experiences (McNamara, 1999). According to Burns and Grove (1998), the advantage of an interview is that: a) it is a flexible technique that allows the researcher to explore greater depth of meaning; b) interpersonal skills can be used to facilitate co-operation and elicit more information; c) there is a higher response rate to interviews than questionnaires, leading to a complete description of the subject under study; d) it allows collection of data from participants unable or unlikely to complete questionnaires such as those whose reading, writing and ability to express themselves is marginal.

The researcher opted to use open-ended and semi-structured questionnaires as recommended by Clifford, French and Valentine, (2010) and Wengraf (2001). Open-

ended questions are used because they give the respondent time to answer the question in detail and clarify the response. Semi-structured interviewing has a guide with questions and topics that must be covered. Semi-structured interviewing is often used when the researcher wants to delve deeply into a topic and to understand thoroughly the answers provided (Harrell & Bradley, 2009). Similarly, in the present study, the researcher developed an interview guide that was used where all the participants were interviewed in Tshivenda (see Appendix 1a)

Dawson (2002) argued that the semi-structured interview is perhaps the most widespread type used in qualitative research, and is the kind of interview where the researcher pre-establishes a set of questions to know more information about specific issues, and sometimes identify new issues that were not originally part of the interview. It is also characterized by its flexibility in which the researcher can add or remove some questions from the schedule based on the results of each interview. The semi-structured interview gives the researcher the opportunity to probe for more detailed information by asking the respondent to clarify the answer.

### **3.5 Data analysis**

Data analysis for the present study was analysed in accordance with the following steps that are recommended by Connor and Gibson (2003):

#### **Step 1. Organizing the data**

The best way to organize data is to go back to the research interview guide. In this regard, the researcher used ATLAS/ti software to organize the data. ATLAS/ti is a computer-based package designed to aid researchers in managing and organizing qualitative data. According to Woolf (2007), ATLAS/ti is a fundamental concept database where a researcher creates and enters names of concepts or “codes” to be used for conceptualizing chunks of data. The programme allows the researcher to organize and relate these concepts in a way that support the analysis. This method of organizing and displaying the data enables the researcher to look at the

responses to each topic and the specific question individually in order to make it easier to identify concepts and themes.

Lewis (2004), describes Atlas ti as a Microsoft Windows- based product that enables the researcher to associate codes or labels with chunks of text, sounds, pictures or video to search these codes for patterns and to construct classifications of codes that reflect testable models of the conceptual structure of the underlying data. It is a tremendously flexible programme that can be readily applied in a wide range of applications.

## **Step 2. Finding and organizing ideas and concepts**

When looking at the various responses for one particular question, the researcher may find specific words or ideas keep appearing. The researcher made notes of the different ideas as the different responses were read through. The ideas coming from these words and phrases were then organized into codes or categories. Kumar (2005) suggested that the researcher can count the number of times words have occurred in an interview and select a few responses and identify the main themes. In line with Kumar's recommendation, the present researcher continued to identify themes from the same questions until saturation point was reached. This then enabled the researcher to write the themes and assign a code to each of them.

## **Step 3. Building themes in the data**

All response categories that have one or more associated themes that give deeper meaning to the data and different categories were collapsed under one main overarching theme. As recommended by Dawson (2002), the researcher went through the descriptive responses given by the respondents to each question in order to understand the meaning that the respondent intends to communicate, and from these responses, the researcher developed broad themes that reflect these meanings. This was done given that people use different words and language to express themselves (Dawson, 2002).

#### **Step 4. Ensuring reliability and validity in data analysis**

As themes and patterns emerge from the data, the researcher will go through the data, carefully searching for negative instances of the patterns. According to Miles & Huberman (1994) this step is taken to ensure reliability and validity in data analysis. Validity is concerned with two main issues: whether the instruments used for measuring are accurate and whether they are actually what they want to measure (Winter, 2000). Reliability means to what extent the research findings can be replicated if another study is undertaken using the same research methods. The reliability of the findings depends on the likely recurrence of the original data and the way they are interpreted (Ritchie & Lewis, 2003). Polit and Hungler (1993) refer to reliability as the degree of consistency with which an instrument measures the attribute it is designed to measure. Reliability is a measurement of the consistency of the data with the research background and is also a measurement of the suitability of the data for analysis (Saunders, Lewis & Thanhill, 2009).

Ritchie and Lewis (2003) indicate that the validity of research is conceived as the precision or correctness of the research findings. According to Trochim and Donnelly (2006), validity refers to the best estimate of the truth of any proposition or conclusion described in the research. Validity plays a significant role in a qualitative study in that it is a powerful source used to determine the accuracy of the study findings (Creswell, 2003). Validity and reliability involve checking the status of the data collected to determine if they are valid and reliable (Struwig & Stead, 2004). Reliability refers to the measurement of the quality of the data collected in any research (Behling & Law, 2006).

In the present study the questions asked, more than two participants answered the same. The data collection was conducted the researcher only and this insured that all participants were asked the questions which are in line with the interview guide presented in the study. A conducive environment was created to make the participants feel comfortable to the questions freely. The questions were

administered in the participant's language (Tshivenda) to ensure that they understood every question.

### **Step 5. Writing the report**

This includes not only the results, but how the entire research process was conducted. In the final report, the researcher summarizes the findings and the implications of those findings. Recommendations, and strategies and areas of future research are also identified. The report informs what the researcher has done and what the researcher has discovered, what conclusion has been drawn from the findings (Dawson, 2002).

### **3.6 Ethical considerations**

Before the study was undertaken, the researcher submitted the proposal to the University of Limpopo's Research and Ethics Committee for ethical approval.

#### **3.6.1 Informed consent**

Before the interviews could be done, participants were requested to sign a consent form to insure that they agreed to participate in the study. Prospective participants were informed that participating in this study was voluntary and that they could withdraw from the research at any time they wished as suggested by Morse and Field (1998). Furthermore, the participants were advised that they were not forced to answer any question they were not comfortable with. According to Natasha, Woodsong, MacQueen, Guest and Namey (2005), informed consent is one of the most important tools for showing respect for the research participants, and is a mechanism for ensuring that people understand what it means to participate in a particular research study, allowing them to decide in a conscious and, deliberate way whether or not they want to participate.

### **3.6.2 Anonymity and confidentiality**

All research participants have a right to privacy and the right to remain anonymous and to have the confidentiality of their credentials protected (Walsh & Wiggins, 2003). Confidentiality protects participants in a study so that their individual identities cannot be linked to the information that they provide and that such information will not be publicly divulged (Lobiondo-Wood & Haber, 1997). Confidentiality means that any information that the informants divulge is not made public or available to others. Similarly, the participants in the present study were assured that their information would remain confidential and that it would not be shared with anyone.

### **3.6.3 Referral of respondents**

It is acknowledged that research of this nature has the potential to affect the participants emotionally. In view of this, the present researcher undertook to refer those participants who seemed to be experiencing some emotional problems during the interviews to psychologists in the local hospital for counselling and therapy. In this regard two participants (participant 2 and participant 5) showed some emotional reactions and were subsequently referred to psychologists for counselling.

## CHAPTER 4

### RESULTS

#### 4.1 Introduction

This chapter starts by first presenting the demographic profile of the participants. This will be followed by phenomenological explication of the participants' experiences. In this regard, the following themes are presented:

- Participants' explanations of epilepsy;
- Participants' own understanding of the causes of epilepsy;
- Pathways taken by participants when realizing that they are sick, and
- The psychological strategies the participants used to manage epilepsy.

The chapter is concluded by giving the summary of the findings from the study.

#### 4.2 Demographic profile of participants

The sample of this research consists of 6 participants who are living with epilepsy. They are all residents of Nzhelele where the research was conducted. All the participants are speakers of Tshivenda and all the interviews were conducted in this language so that the interviewees could express themselves. The interviews were translated into English, but making sure Tshivenda expression and the way of speaking are represented.

**Table 1: Demographic profile of the participants**

Participant's No	Gender	Home language	Residential area
1	Female	Tshivenda	Biaba
2	Female	Tshivenda	Maangani
3	Male	Tshivenda	Matanda
4	Male	Tshivenda	Matanda
5	Female	Tshivenda	Harabali
6	Male	Tshivenda	Tshirolwe

### **4.3 Phenomenological explications**

#### **4.3.1 Participants' explanations of epilepsy**

The participants were all able to explain what they understood epilepsy to be. These explanations appear to have been based on the participants' own experiences as is evident from the following extracts:

*"Epilepsy is a sickness where a person falls". [Participant 1]*

*"Epilepsy is a sickness that you fall down and become unconscious for a few minutes and there is no sign that you are about to fall down so it can happen anytime and everywhere even if you are sitting or standing up. Even all the scares on my head is because of falling and you fall in the all the angle. This is a very dangerous disease because sometimes you can fall and you die instantly. When you fall you need to be in a safe environment because the body becomes very stiff and biting the tongue and the body will be jiggling so you need to be with someone so that they can hold you tight so you cannot hurt yourself and thereafter put a spoon in the mouth so you cannot bite yourself and you will regain conscious after sometimes. This sickness can even disturb the mind". [Participant 2]*

*“Epilepsy is a sickness where a person fall and it’s a chronic disease; the only way to gets healed it’s only if you die”. [Participant 3]*

Participants seemed to believe that heat and stress led to seizures and that these experiences tended to occur unannounced. The following extracts demonstrate thi belief:

*“Now that is summer it gets worse, this sickness does not need heat that’s why I do not cook or do laundry”. [Participant 1]*

*“Every time when in scared or when it is seriously hot or when I am near the fire”. [Participant 3]*

*“Every time when I get angry or when I am near the fire and there are no sign when it want to start because sometimes it’s just happen even in front of people”. [Participant 6]*

*“Heat always makes it worse and sometimes it just start the problem is that there is no sign that shows that it’s about to start”. [Participant 5]*

Based on the above extracts, it does appear that what the participants consider as epilepsy is closely linked to their own experiences of the condition. Some of the participants tend to believe that extreme heat and stress are critical factors that can be triggering the onset of an epileptic seizure.

#### **4.3.2 Participants’ own understanding of the causes of epilepsy**

The participants seemed to have different views regarding the causes of epilepsy. Some participants believed that epilepsy is hereditary, as is evident in the following extracts:

*“You might have inherited it from a family member because it looks like in my father’s family there is a history of this sickness”. [Participant 1]*

*“Sometimes you can inherit it if there is someone in the family who have the same problem but in our culture we are able to prevent it to pass to the next generation”. [Participant 2]*

For other participants, epilepsy seemed to be a condition that could be attributed to some supernatural powers as reflected in the following:

*“I am not sure but sometimes you have bewitched or you have problems and you’re too much stressed, just like me I was bewitched because I was supposed to be the next chief”. [Participant 2]*

*“Being bewitched”. [Participant 6]*

Some participants also believed that the factors such as stress can cause epilepsy. The following statements confirm this:

*“Some say you can have it because of stress or taking injection for family planning when you’re still young”. [Participant 1]*

*“Nothing, it’s something that just comes because you cannot be born with it, and there is a shortage in your body I don’t know what kind of a shortage but that can cause a person to have epilepsy”. [Participant 3]*

*“I don’t know but as for me I was not born with it, it started when I was in grade 8 and it started to be worse when I was in grade 10 till today I have the sickness and it all started when I was at school”. [Participant 4]*

Based on the above extracts, it does appear that the participants understood epilepsy to be a result of hereditary factors, stress and supernatural factors. In other words, internal factors (like heredity) and external factor (like witchcraft) are perceived as possible causes for epilepsy.

### 4.3.3 Pathways taken by participants when realising they are sick

The results of this study revealed that almost all the participants use both traditional and Western healing systems together with spirituality to manage epilepsy. The following extracts demonstrate this:

*“I went everywhere using traditional medicines and I got healed for 5 years and I was bewitched again and it came back so the woman who helped me the first time didn’t want to help me again because she said she doesn’t heal one person twice with the same problem. I even spent time at church being treated there”. [Participant 2]*

*“Yes, when it started I went to the hospital and I was even admitted and when I came back I then went to traditional healers even when I was still using the pills I got from the hospital even now I use both.....Epilepsy cannot be healed even if you can go to a traditional healer, you can only maintain it by taking pills and traditional medicine”. [Participant 4]*

*“I went to the clinic and then I got admitted at the hospital and thereafter when I came back I went to traditional healer and then to prophets. I also went to church”. [Participant 6]*

*“I use traditional medicines and pills I got from the clinic because these things should help each other”. [Participant 3]*

*“I use everything, traditional medicines and pills and I am also treated at church when I get a chance to go to church because at home they don’t believe in it”. [Participant 6]*

*“I trust in God but my mother took me to the doctor and even took me to traditional healers and every time I go there they always ask if I have burned because they say if you get burned you won’t be healed and they always tell me that I will be cured but I will only take time”. [Participant 5]*

*“Yes, my mother and my grandmother took me all over to traditional healers but they always say I won’t be cured because I have been burned”.*  
[Participant 3]

Based on the above extract, it can be revealed that people with epilepsy try all forms of healing (traditional system, western system as well as spirituality) system to maintain the illness though some were taken by close family members.

#### **4.3.4 Psychological impact of epilepsy and coping strategies**

It does appear that the unpredictability associated with seizure generate greater levels of distress to the participants, as reflected in the following statements.

*“Epilepsy is a sickness that you fall down and become unconscious for a few minutes and there is no sign that you are about to fall down so it can happen anytime and everywhere even if you are sitting or standing up”.* [Participant 2]

The company of people that one is familiar with seems to be militating against the distress that can potentially result from the epileptic seizures. The following extract demonstrates this:

*“Everywhere I go I should have company for in case it start I won’t be able to help myself because most of the time it just happen with no sign..... I don’t like going out of too much because I am afraid that it can start while I am with people who don’t know me and who will not know what to do when it starts”.* [Participant 3]

*“Everywhere I go I should be with someone therefore I don’t leave my life alone..... I can live like anybody else because even my family have accepted that I am sick the only problem I have its only when it start when I am around people I can shy be and that’s the reason why I don’t go out often”.*  
[Participant 4]

*“My mother always makes sure that where ever I am I should be with someone who can help whenever it starts”. [Participant 1]*

*“I feel comfortable being with people I know and my family”. [Participant 5]*

Some of the participants perceived their condition to be making them impatient when they relate to other people. This appears to be a problem that they have learnt to accept and live with. The following extract demonstrates the issue of impatience and acceptance of the condition:

*“I am not a talkative person so I am very impatient but the support I get from my family helps me a lot.....At home they have accepted that I am not well and this sickness it cannot be cured, the only way to be free from this sickness is to die”. [Participant 1]*

*“I have accepted that I am sick and I always try not to worry and be stressed because if I am angry it starts..... I am very impatient and because of this problem I had to leave my job so I cannot be able to support my family”. [Participant 2]*

*“I have accepted because even my family supports me”. [Participant 3]*

*“It took my mother time to accept that I am sick because is not something I was born with it just started but I have accepted and I don't like to think too much”. [Participant 5]*

*“Everybody at home knows that I am sick and they have accepted and that makes it better for me to deal with this problem”. [Participant 6]*

Some participants feel the anxiety of having a seizure in front of people because sometimes when they recover from it they find out that they have wet themselves. This was expressed as follows.

*“Sometimes when it attacks me I will wake up and find that I have wet myself and make me to feel ashamed even if I am around people who know me”.*

[Participant 1]

*“Sometimes when I fall, when I wake up I will find that I have wet myself and that disturb me a lot”.* [Participant 3]

Some of the participants were of the view that their condition has negatively affected their education. This resulted in them dropping out of school, leading to loss in career opportunities. The following extract demonstrates this:

*“Because of this sickness I had to leave school in primary because it was worse. This sickness has affected my eye sight, I cannot see properly and I am very moody sometimes”.* [Participant 1]

*“Sometimes if I think too much ill even think of committing suicide because is suffering because I had to leave my job because it was affecting my job”.*

[Participant 2]

*“I used to be intelligent at school and never failed but ever since it started I have been failing and my performance has gone down”.* [Participant 5]

*“I get bored when I think that people my age are far in life because I had to leave school because it was worse”.* [Participant 6]

Based on the above extract, it does appear that epilepsy generates a great amount of distress for the individuals concerned. Some of the participants ended up having interpersonal problems as they tended to be impatient when relating to others. It does appear that the epileptic condition also leads to anxiety and considerable levels of fear. Many of those who participated in this study held the view that health problem they were facing could be minimised if their relatives or friends were present when the seizure happened. Also, as many of them had to leave school because of their condition, they came to attribute their inability to carry on with their education and to find employment.

#### **4.4 Summary of the findings**

It appears that what the participants consider as epilepsy is closely linked to their own experiences of the condition. Some of the participants tend to believe that extreme heat and stress are critical factors that can trigger the onset of an epileptic seizure. It also appears that the participants understood epilepsy to be a result of hereditary factors, stress and supernatural factors. In other words, internal factors (such as heredity) and external factor (such as witchcraft) are perceived as possible causes for epilepsy. The study also revealed that people with epilepsy try all forms of healing, traditional system, Western system as well as spirituality, system to maintain the illness. The Participants also reported that the epileptic condition generates a great amount of distress for the individuals concerned. Some of the participants ended up having interpersonal problems as they became impatient when relating to others. It does appear that the epileptic condition also leads to anxiety and considerable levels of fear. A number of participants believed that these unpleasant psychological experiences could be lessened if one were in the company of people one knew. It emerged from the interview that some participants attributed their poor academic achievement and limited career prospects to their epileptic condition.

## **CHAPTER 5**

### **DISCUSSION**

#### **5.1 Introduction**

In this chapter the researcher discusses the themes that emerged in the context of the existing literature. Specifically, the following themes are discussed: Participant's explanations of epilepsy; participants own understanding of the causes of epilepsy; pathways taken by participant when realising they are sick; and, psychological impact of epilepsy and coping strategies.

#### **5.2 Participants' explanations of epilepsy**

Participants perceived epilepsy as a disease of "falling" and it was observed that cultural understanding influenced the way epilepsy is understood by participants. Epilepsy among participants was accepted as a deadly chronic disease which is associated with supernatural causes and injury. The participants mostly believed that this condition does not have a cure. The findings of the present study seem to be consistent with the results of a study conducted in China by Jacoby, Wang, Dang, Wu, Snape, Aydemir, Parry, Reis, Begley, De- Boer, Prilipko and Baker (2008). In that study, it was also found that, informants generally accepted epilepsy as a pernicious chronic disease that could not be cured. Religious and socio-cultural beliefs influence the nature of treatment and care received by people with epilepsy. Many communities in Africa believe that epilepsy results from witchcraft or possession by evil spirits and therefore treatment should be through the use of herbs from traditional doctors, fetish priests and religious leaders. People turned to religious spiritual treatments in desperation for a cure, often under the influence of their families after the perceived failure of Western medicine (Sidig, Ibrahim & Hussen, 2009).

### **5.3 Participants' own understanding of the causes of epilepsy**

In the present study, it was found that some of the participants tended to associate epilepsy with witchcraft and as supernaturally caused. In an earlier study, Mushi, Hunter, Mtuya, Mshana, Aris and Walker (2011) postulated that most people attributed epilepsy to spiritual powers and witchcraft. Similarly, a study conducted by Mbewe, Haworth, Atadzhanov, Chomba and Birbeck (2007) revealed that epilepsy in many societies is not thought to be a biomedical illness affecting the brain, but a debilitating, sometimes contagious condition that is caused by spiritual beliefs.

Stress and injury was also identified as one of the causes of epilepsy. Heat and anger were perceived by the participants in the present study as some of the possible triggers for epileptic seizures. A study conducted in Malawi by Mushi, Burton, Mtuya, Gona, Walker and Newton (2012), categorized the causes of epilepsy into external and internal agents. External agents were perceived as spiritual forces such as witchcraft and direct injury such as head injury and birth trauma.

Other participants in the present study reported that epilepsy can be hereditary. This finding seems to be consistent with the results of previous studies. For example, a study conducted in Nigeria by Ogunrin, Adeyekun and Adudu-Philomene (2013), reported that family history of epilepsy was obtained in people living with epilepsy patients, all of them with primarily generalized seizures, 6 of the 34 gave history of epilepsy in first-degree relations (siblings and parents), 17 reported epilepsy in second-degree relations (uncles, aunts and grand-parents) and 11 reported epilepsy in third-degree relations.

### **5.4 Pathway taken by participants when realising they are sick**

Nzhelele village is a community where traditional healers still play a major part in the healing system of the community. In the present study, it was found that when the participants realized that they were sick, they go to traditional healers before seeking the services of Western trained health care practitioners. The findings of the present

study appear to be consistent with the results of an earlier study by Lughart (2011) who also found that, people with epilepsy seek care from traditional healers who often emphasize their traditional beliefs. In Zambia, for example, only 4% of people with epilepsy sought medical care while the majority sought traditional healers. The findings of the present study and those by Munthali, Braathen, Grut, Kamaleri and Ingstead (2013), in which traditional methods of healing were mostly mentioned, seem to lend support to the conclusion that the use of traditional healers is widespread in Africa and other developing communities.

Traditional healers are often consulted by people with epilepsy and their families and provide explanations for the development of epilepsy that the people with epilepsy and their families can understand and find more acceptable than the biomedical explanations (Carter, Molyneux, Mbuba, Jenkins, Newton & Hartley, 2012). In one southern province of Cameroun, patients can choose between healers, church (mission) hospitals and clinics and government hospitals and clinics. Traditional healers provide high levels of effort compared to government facilities and provide particularly appropriate levels of effort when patient effort is important.

One significant finding of the present study was that most participants (three participants) tended to consult traditional healers first. Only when they found that their condition was not improving, would the participants consider going to the medical clinic. In the final analysis, it was found that participants found it helpful to use both Western and traditional medicine to manage their illness. Studies in developing countries in Asia and Africa have found that a large percentage of epileptic patients are seen by native or traditional healers at the beginning of their illness. This tendency often results in patients being delayed to get specialized treatment (Apprah-poku, Laugharne, Mensah, Oseyi & Burns, 2004). Indigenous or traditional healers provide a substantial proportion of the care delivered to people with epilepsy in developing countries. Such healers are more numerous and equitably distributed than physicians and often are more affordable (Berbeck, 2010). The health seeking behaviour of people with epilepsy has been associated with their knowledge of disease causation, prevailing socio-cultural factors and beliefs

especially myths surrounding epilepsy and availability and proximity of a health facilities. The practice of using traditional healing methods for the treatment of epilepsy is common in sub-Saharan African societies, especially in rural communities (Ogunrin, Adeyekun & Philomene, 2013).

### **5.5 Psychological impact of epilepsy and coping strategies**

The quality of life of people with epilepsy is low as compared to the whole community. Epilepsy and the accompanying psychosocial comorbidities are capable of impairing quality of life. People with epilepsy tend to have lower quality of life compared with matched healthy individuals (Liou, Chen, Chen, Chiu, Chang & Wang, 2005). Self-esteem of people with epilepsy is very low because it is viewed as a shame to have the disease. Epilepsy is seen as a highly contagious and shameful disease in the eyes of the public in the country (Awaritefe, 1989). Some of the participant's symptoms such as wetting themselves and jiggling behaviour as the seizure occurs have brought them shame in the society. The fear of going to public places is very common to all the participants. Therefore the participants always depend on family members in everything they do.

Epilepsy is a chronic disorder marked by intermittent, often unpredictable seizures with associated significant psychological and social consequences for everyday living (Akinsulore & Adewuya, 2010). People with the condition report a significant impact of the disease and its management in terms of family dysfunction, reduced social and leisure opportunities and increased level of psychiatric comorbidity and poor self-esteem compared with people without the condition (Jacoby, Baker, Steen, Potts & Chedwick, 1996). Research in Nigeria has similarly documented that people with epilepsy are more likely to experience anxiety, depression and low self-esteem (Adewuya & Ola, 2005). Epilepsy has been observed to significantly impact on the quality of life of the sufferers (Mosaku, Fatoye, Komalafe, Lawal & Ola, 2006). The concept of quality of life in epilepsy encompasses physical health, mental and social health (Akinsulore & Adewuya, 2010). The general attitude toward patients with epilepsy is negative. In Nigeria most diseases affecting the brain which include

epilepsy are assumed to be due to affliction by evil spirits (Kabir, Iliyasu, Abubakar, Kabir & Farinyaro, 2005). This belief is responsible to a large extent for patients with seizure disorders seeking treatment from traditional healers (Akinsulore & Adewuya, 2010)

In the present study, it was found that some participants' education and employment were negatively affected as a result of epilepsy. In an earlier study focusing on Nigerian adolescents with epilepsy, it was found that 20% of these young people were withdrawn from school because of the condition (Nuhu, Fawole, Babalola, Ayilara & Sulaiman, 2010). Similarly, in the present study, one participant reported leaving school due to the worsening seizures. A study by Nuhu, Yusuf, Sheikh and Eselgbe (2012), shows that more adolescents reported missing school frequently because of their illness, some stayed at home to avoid being mocked by schoolmates should they have a seizure at school. In addition, some of them had stopped going to school, either on the advice of their teachers or school authorities. Another participant gave an account of how he had to be escorted home by a teacher and how the seizure has also affected his thinking. A community-based study of children with active convulsive epilepsy in rural Kenya found half of children with epilepsy were not attending school; more frequent seizures and cognitive impairment were associated with non-attendance (Munyoki, Edwards & White, 2010). Epilepsy has a profound effect on the children in terms of education and wider cultural integration (Mushi, Burton, Mtuya, Gona, Walker & Newton, 2012). A study conducted in Malawi shows that access to education is a problem for children with epilepsy as they would always need to be escorted. Some patients with epilepsy started school and did quite well, but when the seizures were severe they dropped out of school (Munthali, Braathen, Grut, Kamaleri & Ingsted, 2013)

Previous studies have found that epilepsy does negatively affect job performance and workplace safety. Similarly, in the present study, one participant was found to have had a work related problem that cost him his job. The findings of the present study found that uncontrolled convulsion raise the possibility if direct damage to the sufferer. The loss of consciousness or the lack of control of bodily movements often

results in poorer work performance and the potential to damage themselves, equipment or colleagues (Gwandure & Thatcher, 2006).

Epilepsy has been found to put a strain on family members. The pressure of the family goes to an extent that they do not allow epileptic people to go out and be with people. This was evidenced by Wilmshurst, Kakooza-Mwesig and Newton, (2014) who found that the impact of epilepsy appears greater in the poorer regions, particularly in Africa, where the stigma often results in people with the condition being hidden by their families. Childhood epilepsy impacts on the entire family, because the demands for change and the use of family resources increase (Spangenberg & Laikhen, 2006). This may lead to an increase in family stress and disruption. A chronic illness with unpredictable characteristics such as epilepsy puts a family at risk for poor communication, poor cohesiveness and poor integration. The burden of care may fall more heavily on one member which may lead to resentment and increased family tension. Plans for the future are often placed on hold. The family may spend less time enjoying activities outside the home, fearing that the child may have a seizure and inviting friends to the home may come to an end (Ellis, Upton & Thompson, 2000). Childhood epilepsy has serious and far-reaching psychosocial sequelae for the patient and his/her family.

## CHAPTER 6

### SUMMARY AND CONCLUSION

#### 6.1 Summary

The aim of the present study was to explore the experiences of people with epilepsy in Nzhelele area (Limpopo Province) with a view to understanding their causal explanations and responses to this condition. Specifically the objectives were:

- To investigate the subjective meanings that people living with epilepsy attribute to their condition;
- To determine the causal explanations that people living with epilepsy attribute to their condition;
- To understand and describe the psychological strategies that these individuals employ to manage the illness.

Six participants with epilepsy were approached and requested to participate in the present study. All the participants were not married, neither where they employed. They also did not go to school. Among others, it was found that the heat and stress triggered the seizure.

Most participants use both Western and traditional form of treatment to manage their epileptic conditions. Traditional healers are considered the most important people in the community and their opinions are highly considered.

The quality of life of people with epilepsy in the community of Nzhelele where this study was conducted as compared to that of their peers was observed by the present researcher to be low. There were also indications that there is a stigma that is associated with epilepsy. This appears to result in some families in this community preferring to hide their epileptic patients. Some participants reported that in the process of the seizure they wet themselves and that embarrasses them. Based on these findings it does appear that epilepsy lead to considerable psychological distress and has disruptive effect on an epileptic person's educational and

occupational functioning. Furthermore, it does appear that epilepsy is associated with a stigma that results in some families having to hide the members that suffer from this debilitating condition.

## **6.2 Implication for theory**

The Afrocentric model explores the natural responses which would occur in the relationship, attitude towards the environment, type of religion and historical referent for African people if there had not been any intervention of colonialism or enslavement. The Afrocentric model answers this question by asserting the central role of the African subject within the context of African history, thereby removing Europe from the centre of the African reality. In this way, Afrocentric becomes a revolutionary idea because it studies ideas, concepts, events, personalities, and political and economic processes from a standpoint of black people as subjects and not as objects, basing all knowledge on the authentic interrogation and location (Molefe, 2009). In reference to this model, the reaction to epilepsy and the understanding of the condition is shaped by cultural belief of the illness. Epilepsy is mostly attributed to spiritual forces that can only be cured by traditional healers. The pathway that the participants took in treating the condition is also based on the traditional belief of the condition.

## **6.3 Limitations**

The following are some of the limitations that could be associated with the present study: Firstly, translating the interview data from Tshivenda into English may have led to omissions or inappropriate substitutions of the original material provided by the participants. Secondly, this study depended on the participants' view of their conditions and how they coped with the epileptic condition. It is therefore possible that some of the participants' level of psychological distress caused by the illness may have affected their cognitive ability to respond appropriately to the question. Lastly, the results of this study cannot be generalized to the larger South African population since the study was conducted on very small sample of individuals in Vhembe district (Limpopo Province) suffering from epilepsy.

## **6.4 Recommendations**

Based on the findings of the present study, the following recommendations are made:

- There is a need to conduct quantitative studies based on larger samples in order to get a fairly representative view of epilepsy in this rural community.
- Given the stigma associated with epilepsy, there is a need for more community education regarding this and probably other chronic conditions.

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### **Appendix 1(a): Interview guide**

- Can you share with me your understanding of epilepsy?
- In your own understanding, what do you think are the causes of epilepsy?
- Can you describe to me how you went about seeking help for you condition including the people that you consulted when you realized that you were ill?
- Currently what form of treatment are you receiving for your illness?

### **Appendix 1(b): Nyendedzi ya nyambedzano.**

- Vha humbelwa uri vha talutshedze nga kupfesesele kwavho uri tshifakhole ndi mini?
- Ngaku pfesesele kwavho vha vhona unga Tshifakhole tshivhangwa nga mini?
- Vha dalela nnyi musu vha tshi wana uri vha khou lwala?
- Zwa zwino vha shumisa mini u lafha tshifakhole?

**Appendix 2(a) Participants consent letter**

Department of Psychology  
University of Limpopo (Turfloop campus)  
Private Bag X1106  
Sovenga  
0727

Date: \_\_\_\_\_

Dear participant

Thank you for agreeing to take part in this study which focuses on epilepsy in Nzhelele, Limpopo Province. The purpose of this study is to explore the experiences of people living with epilepsy with a view to understanding the causal explanations and responses to this condition.

Kindly answer all the questions as honestly as you can. Your responses will remain strictly confidential. You are free to ask any question. Participation is voluntary and you are therefore free to withdraw from this study at any time.

Thank you for your time and cooperation.

Yours sincerely

.....

.....

Siriba R. M

Masters Student

Date

.....

.....

Prof. T. Sodi

Supervisor

Date

## Appendix 2 (b) Linwalo la thendelo la vhashelaho mulenzhe

Muhasho wa zwamihumbulo

Yunivesithi ya Limpopo

Private bag X 1106

Sovenga

0727

Datumu

.....

Kha vhashelaho mulenzhe

Ri khou livhuwa u tenda havho u shela mulenzhe kha ino ngudo yo lavhelesanaho na tshifakhole kha la Nzhelele vunduni la Limpopo.

Ndivho ya ngudo iyi ndi u todulusa tshenzhemo ya vhathu vhane vha tshila na vhulwadze ha Tshifakhole, ri tshi tama u pfesesa thalutshedzo na vhupfiwa nga ha nyimele iyi.

Vha humbelwa uri vha fhindule nga vhungoho nahone phindulo dzavho dzi do vha dza tshiphirini zwihulu. A vha pfe vho vhofholowa u vhudzisa mbudziso dzine vha sa dzi pfesese. U shela mulenzhe kha ngudo iyi ndi ha u tou di vhudinangeli nahone vha a di bvisa tshifhinga tshinwe na tshinwe tshine vha funa.

Ri khou livhuwa tshumisano yavho.

Wavho a fulufhedzeaho

.....

.....

Siriba R.M

Datumu

Mugudiswa wa Masitasi

.....

.....

Phurofesa T. Sodi

Datumu

Mutoli

### Appendix 3 (a) Participants consent form

I \_\_\_\_\_ hereby agree to participate in a masters research project that focuses on the experiences of people living with epilepsy with a view to understanding the causal explanations and responses to this condition.

The purpose of this study is fully explained to me and I understand that my participation in this study is voluntary and that I am not forced to participate. Furthermore, I understand that I can withdraw from participating in this study at any time. I also understand that my responses will be kept strictly confidential.

I understand that this research project is not necessarily going to benefit me personally.

Signature.....

Date.....

### **Appendix 3 (b): Fomo ya thendelano ya vha shelaho mulenzhe**

Nne..... ndi khou tenda u shela mulenzhe kha thandela ya thodisiso ya masitasi ine yo lavhelesana na tshenzhemo ya vhatu vhane vha khou tshila na tshifakhole hu na u tama u pfesesa thalutshedzo ya zwivhangi na vhupfiwa kha iyi ngudo.

Ndivho ya ngudo iyi yo talutshedzwa nga vhudalo nahone ndi a pfesesa uri ushela mulenzhe hanga ndi ha u tou di netshedzela nahone a thi kombetshedzei u shela , ndi nga di bvisa kha u shela mulenzhe kha ngudo iyi. Ndi dovha hafhu nda pfesesa uri mihumbulo yanga i do vha ya tshiphiri tshihulu nahone a i nga tumetshedzwi na zwinwe.

Ndi a pfesesa uri hei ndi thoduluso ine ndivho ya yo a si u vhuedza nne.

Tsaino.....

Datumu .....

## **Appendix 3: Transcripts**

### **Participant no 1:**

**10 October 2013**

#### **What is epilepsy?**

- Epilepsy is a sickness where a person falls

#### **What do u thing cases epilepsy?**

- You might have inherited it from a family member because it looks like in my father's family there is a history of this sickness. Some says you can have it because of stress of family planning when your still young

#### **When did you start having this problem?**

- It started when at school in primary, the principal brought me home. My mother thereafter took me to traditional healers and even took me to prophets and when the sickness start to worsen, she then took me to a doctor but now it has even disturbed the mind that's the reason why I am gating grant.

#### **It means that you stated going to traditional healers when you realise you were sick**

- Yes, I started going to the doctor when we realise that the sickness is getting worse

#### **What are you using at the moments?**

- I am using medicine from the traditional healer and from the doctor which I take once a day but when it gets worse my mother gives me twice a day because now that is summer it gets worse, this sickness doesn't not need heat that's why I do not cook or do laundry

#### **How are you coping with this sickness?**

- I am not a talkative person so I am very impatient but the support I get from my family helps me a lot. My mother does not want me to go out or get married. Because of this sickness I had to leave school in primary because it was worse. This sickness has affected my eye sight, I cannot see properly and I am very moody sometimes
- Sometimes when it attacks me I will wake up and find that I have wet myself and makes me to feel ashamed even if I am around people who knows me.
- At home they have accepted that I am not well and this sickness it cannot be cured, the only way to be free from this sickness is to die

- My mother always make sure that where ever I am the should be with someone who can help whenever it starts
- Everybody knows that I am sick even in the village

**What do u think make you impatient and moody**

- I don't know I just get easily irritated

**Participant no 2:**

**05 November 2013**

**What is epilepsy according to your understanding?**

- Epilepsy is a sickness that you fall down and become unconscious for a few minutes and there is no sign that you are about to fall down so it can happen anytime and everywhere even if you are sitting or standing up
- Even all the scares on my head is because of falling and you fall in the all the angle
- This is a very dangerous diseases because sometimes you can fall and you die instantly
- When you fall you need to be in a safe environment because the body becomes very stiff and biting the tongue and the body will be jiggling so you need to be with someone so that they can hold you tight so you cannot hurt yourself and thereafter put a spoon in the mouth so you cannot bite yourself and you will regain conscious after sometimes
- This sickness can even disturb the mind

**What do you think are the causes of epilepsy?**

- I am not sure but sometimes you have bewitched or you have problems and your too much stressed, just like me I was bewitched because I was supposed to be the next chief
- Sometimes you can inherit it if there is someone in the family who have the same problem but in our culture we are able to prevent it to pass to the next generation

**Who did you consult when you find out you were ill?**

- I went everywhere using traditional medicines and I got healed for 5 years and I was bewitched again and it came back so the woman who helped me the first time didn't want to help me again because she said she doesn't heal one person twice with the same problem
- I even spent time at church being treated there

**Are you still using traditional medicines even now?**

- When it came back for the second time it became very serious that I had to go to the doctor, even now I am taking treatment from the clinic and it's better because when it starts it does no longer take much time as it used to be

**How often do you get these attacks?**

- Every month, sometimes when I am too much stressed it can happen even twice a day

- Sometimes when I fall and after that I start thinking that people were watching me I get bored and it will start all over again

### **How are you coping with the sickness?**

- I have accepted that I am sick and I always try not to worry and be stressed because if I am angry it starts
- I am very impatient and because of this problem I had to leave my job so I cannot be able to support my family
- Sometimes if I think too much I even think of committing suicide because this is suffering because I had to leave my job because it was affecting my job
- Sometimes I have faith that I will be healed someday
- Maybe because of the pills I am taking I am even losing my strength, I no longer do the things I used to do, I am always tired so I spend most of my time sleeping
- Where ever I am there has to be someone accompanying me even when I go to the clinic to take my treatment

**Participant no 3:**

**08 November 2013**

**What is epilepsy according to your understanding?**

- Epilepsy is a sickness where a person fall and it's a chronic diseases the only way it gets healed its only if you die

**How did you find out that you were sick?**

- I am not born with this disease it's something that just came when I am all grown and when it start it happened that I got burned so every time I go to sick for help I am always told that the sickness won't be curable because I got burned

**It means that you went to a traditional healers when you find out you were sick**

- Yes, my mother and my grandmother took me all over to traditional healers but they always say I won't be cured because I have been burned

**How many times do you get these attacks?**

- Every time when in scared or when its seriously hot or when I am near the fire

**How do you cope with this sickness?**

- I have accepted because even my family supports me
- I don't like going out of too much because I am afraid that it can start while I am with people who don't know me and who will not know what to do when it starts
- Everywhere I go I should have company for in case it start I won't be able to help myself because most of the time it just happen with no sign

**What are you currently using to treat this sickness?**

- Traditional medicines and pills I got from the clinic because this things should help each other

**What do you think are the causes of this sickness?**

- Being poisoned or bewitched

**How are you coping with this sickness?**

- I am always thinking that all my peers are far in life because I had to leave school because of this problem
- I am always with someone so that if it start I should be assisted
- Sometimes when I fall, when I wake up I will find that I have wet myself and that disturb me a lot.

**Participant no 4:**

**08 November 2013**

**What is epilepsy?**

- Epilepsy is a sickness where a person falls and it happens all the time

**What do you think are the causes of epilepsy?**

- Nothing, it's something that just come because you cannot be born with it, and the is a shortage in your body I don't know what kind of a shortage but that can cause a person to have epilepsy

**Do you believe that epilepsy can be healed?**

- Epilepsy cannot be healed even if you can go to a traditional healer, you can only maintain it by taking pills and traditional medicine

**It means that you're using pills and traditional medicines?**

- Yes, when it start I went to the hospital and I was even admitted and when I came back I then went to traditional healers even when I was still using the pills I got from the hospital even now I use both

**How are you coping with this sickness?**

- Everywhere I go I should be with someone therefore I don't leave my life alone
- I am impatient and I get easily irritated I can fight with people at home and at home there are used to it now
- I think too much and that makes me to get even more sick
- I can live like anybody else because even my family have accepted that I am sick the only problem I have its only when it start when I am around people I can shy and that's the reason why I don't go out often

## **Participant no 5:**

**10 November 2013**

### **What is epilepsy?**

- Epilepsy is a sickness where a person falls and to other people it affects the mind

### **What do you think causes epilepsy?**

- I don't know but as for me I was not born with it, it started when I was in grade 8 and it started to be worse when I was in grade 10 till today I have the sickness and it all started when I was at school

### **Do you think you can inherit epilepsy?**

- I don't know but in my family I have never heard of anyone having this problem

### **How often do you have the attacks?**

- Every month more especially when I am writing exam it gets worse
- Now I have memorised that every month during 15 it starts but last month I didn't experience anything
- Sometimes they bring me back from school because it happens everywhere
- Even when it starts it all started at school, because my mother didn't know it took her time to accept and the second time when it happens I was at home and I was cooking fortunately when I fall inside the fire because if you get burned you will never be healed
- Heat always makes it worse and sometimes it just start the problem is that there is no sign that it's about to start

### **Who did you consult when you realise you are sick?**

- I trust in God but my mother took me to the doctor and even took me to traditional healers and every time I go there they always ask if I have burned because they say if you get burned you won't be healed and they always tell me that I will be cured but I will only take time

### **What are you currently using?**

- I am using pills from the clinic and traditional medicines even at church they are always praying for me

### **How are you coping with this problem?**

- My mother took her time to accept because it is not something I was born with it just started but I have accepted and I don't like to think too much
- I am just tired of the up and down we do going to healers
- I used to be intelligent at school and never failed but ever since it started I have been failing and my performance has gone down

### **How do you feel?**

- I get easily worried when I think that all my peers are far and I am remaining behind
- I feel comfortable being with people I know and my family
- My family support me a lot so it makes it easy to deal with it

**Participant no 6:**

**11 November 2013**

**What is epilepsy?**

- Epilepsy is a sickness where a person falls and it a sickness that affects the mind

**What do you think causes epilepsy?**

- Being bewitched

**When did it start?**

- It has been long and it started when I am here at home

**Where did you go when you realise you were sick?**

- I went to the clinic and the I got admitted at the hospital and thereafter when I came back I went to traditional healer and then to prophets
- I also went to church

**How often do you get attacks?**

- Every time when I get angry or when I am near the fire and the are no sign when it want to start because sometimes it's just happen even in in front of people.

**How are you coping with this problem?**

- Everybody at home knows that I am sick and they have accepted and that makes it better for me to deal with this problem
- But I get angry very easily and I am short tempered, I don't feel comfortable with people who don't know me
- Everywhere I go I should be with someone for in case something happen I should find help
- I get bored when I think that people my age are far in life because I had to leave school because it was worse

**What are you currently using to treat this sickness?**

- I use everything, traditional medicines and pills and I am also treated at church when I get a chance to go to church because at home they don't believe