

# **CHAPTER 1**

## **PROBLEM, AIMS AND PLAN OF STUDY**

### **1.1. Introductory Orientation**

Epilepsy (called “switshetshela” in Xitsonga) is one of the illnesses which is still viewed with suspicion in African communities. Depending on the cultural and/or religious orientation of the family and society, it is perceived as witchcraft, possession by demons, punishment for sins, etc. Children with epilepsy therefore, face society’s negative stereotypes. As a result of such stereotypes, most children living with epilepsy have accompanying psychological problems. This could result in social and academic problems. Stores in Williams, Sharp, Bates, Griebel, Lange, Spence and Thomas (1996: 143) assert that learning and behaviour problems are common in children with epilepsy. This could be related to low self-esteem.

### **1.2. Problem analysis**

#### **1.2.1. The pre-scientific problem**

The research was initiated while visiting schools in Ritavi District in Region 5 of the Limpopo Province. The researcher is currently working as a co-ordinator of Psychological and Special Education Services (Psyses) in the Department of Education in the above-mentioned district. While visiting schools to provide Psyses services, the researcher discovered that some children who were referred to the Department due to learning difficulties suffered from epilepsy. In this district, there is also a special school called Letaba which has 13 children living with epilepsy.

Children who are placed in the special school may also have other disabilities such as mental disabilities or physical disabilities. The researcher wondered how learners living with epilepsy in the mainstream schooling system, especially those who get seizures at school, experience their condition in relation to themselves, others and academic work.

### **1.2.2. Exploration of the problem**

In the Third World countries of Africa, epilepsy is viewed with suspicion, Its definition depends largely on the superstition which is held by a particular community. According to Ahmad (in Wiechers 2001: 1-2), in Cameroon it is believed that epileptic convulsions are caused by evil spirits that have possessed the sufferer, in Liberia epilepsy is attributed to witchcraft while in Swaziland, sorcery is viewed as the cause of epilepsy. The way in which a particular society perceives epilepsy determines the measures to be taken in trying to control it.

In rural areas of South Africa, like in the rest of the African countries, epilepsy appears to be less controlled medically. A study conducted by Christianson and Kromberg (2000: 262-266) in the district of Bushbuckridge, Limpopo Province, revealed that out of the 49 children who had epilepsy, 35 had associated developmental disabilities. It was also found that half of the children with epilepsy did not receive anticonvulsant medication. This renders the seizures uncontrollable. Wiechers (2001:2) quotes Ebrahim Malick Samba, the Regional director for Africa of the World Health Organisation, who says that “the reason why most epileptic children remain untreated is social rather than economic.” This implies that lack of seizure control is not caused by poor socio-economic conditions but to a larger extent, by values, attitudes and a lack

of knowledge. People of Senegal, for example, seem to hold people with epilepsy in high esteem because they have particular beliefs about spirit possession. As a result of various beliefs, “eighty percent of the 3 to 4 million people who suffer from epilepsy in Africa do not receive medical treatment” (Ahmad in Wiechers 2001:2).

When viewed from the First World perspective, epilepsy can be defined as a disorder that is characterised by intermittent and brief periods of altered consciousness, often accompanied by seizures and excessive electrical discharge from brain cells. It is regarded as the most common of the neurological disorders and it also seems to be one of the earliest recognised cognitive disorders ( Sue, Sue and Sue 1994: 487). Christianson and Kromberg (2000: 263) define epilepsy as “...a history of recurrent, unprovoked seizures, occurring in the absence of an identified acute brain or systemic insult”. They maintain that epilepsy could however, occur subsequent to, or as a direct consequence of, such cerebral insult. Insult refers to anything that causes trauma to the brain for an example, traumatic brain injury or infections such as meningitis or encephalitis, or tumours. Spiegel, Cutler and Yetter (1996: 34) maintain that when the cause is unknown, the etiology is considered idiopathic. On the basis of the above information, epilepsy can be defined as a chronic brain disorder characterised by spontaneous, recurrent seizures, the causes of which cannot always be determined. It can be controlled but usually cannot be cured.

Some studies conducted indicate that epilepsy is often accompanied by a disability in one or more areas of functioning, especially if the seizures are not under control. Williams et al (1996: 143) assert that “findings suggest that seizure type did not appear to affect academic or

behavioral function, but lack of seizure control had a negative impact on reading achievement, attention span and social withdrawal.”

In South Africa, children living with epilepsy who are admitted to special schools are those who have accompanying severe disabilities and/or other illnesses which require constant monitoring and medication. The rest of these learners are admitted to ordinary public schools in terms of The National Education Act of 1996. This Act requires ordinary public schools to admit learners with special educational needs, where this is reasonably practical. According to the Act, “schools are encouraged to make necessary arrangements, as far as practically possible, to make their facilities accessible to such learners” (Education Labor Relations Council 1999: 14). This idea was also emphasized in the Education White Paper 6 (2001: 15). The White Paper indicates that “...learners who require low intensive support will receive this in ordinary schools...learners who require high intensive support will continue to receive such support in special schools.”

The question is whether teachers and learners in the mainstream schooling system are prepared to include and nurture learners with epilepsy as Learners with Special Educational Needs (LSEN). In order to explore this problem, Wiechers (2000: 11 - 14) conducted a research on the experiential world of the epileptic learner. Interviews were conducted with a group of adolescents living with epilepsy, and with parents of learners living with epilepsy. The subjects came from families in affluent areas in the Gauteng Province, South Africa. The findings from the focus group interview with adolescents indicate that they experience prejudice and isolation. Results from the interview with parents reveal that they perceive teachers as ignorant and harsh towards their children.

As indicated above, Wiechers looks at the experiential world of learners with epilepsy from families in an affluent urban area. This study focuses on the experiential world of epileptic learners from families in a poor rural area.

### **1.3. Statement of the problem**

#### **1.3.1. The general scientific problem**

The central problem of this study is as follows: How does a child living with epilepsy in rural South Africa experience mainstream schooling? To what extent does his/her condition affect relations to himself/herself, others and academic performance?

#### **1.3.2. Subsidiary problems**

- How was epilepsy seen in the past?
- How is epilepsy seen in the modern rural areas?
- How does a child suffering from epilepsy relate to others?
- How does he/she perceive himself/herself?
- How does he/she experience academic tasks?

## **1.4. Objectives of the study**

### **1.4.1. The general objective**

The general aim of the study is therefore:

- to investigate the lifeworld of the child living with epilepsy and attending an ordinary school in the rural areas of the Limpopo Province.

### **1.4.2. Subsidiary objectives**

The subsidiary objectives are as follows:

- to find out about modern perspectives on epilepsy.
- to investigate the child's social world.
- to explore the intrapsychic structure i.e. the I/self of the child suffering from epilepsy.
- to investigate the impact of the lifeworld of the child living with epilepsy on academic tasks.

## **1.5. Research methodology**

Epilepsy is interpreted differently in various communities depending on the cultural and religious norms and values of the families concerned and the society at large. The researcher is going to employ a qualitative method as it emphasizes the importance of the social context within which thoughts and actions of people occur. Neuman (1997: 331) asserts that qualitative researchers "...hold that the meaning of a social action or statement depends, in an important way, on the

context in which it appears”. He further maintains that the same events or behaviours can have different meanings in different cultures or historical eras. This implies that the way in which people experience reality depends largely on how it is perceived in their social context. In investigating the child’s experience of epilepsy, the researcher should view it in relation to other aspects in the child’s environment, for a example, the socio-economic background, family history, societal perceptions, attitudes and values. Neuman (1997: 331) further asserts that “qualitative researchers place parts of social life into a larger whole...otherwise the meaning of the part may be lost.”

The case study approach will be used. A case study gives the researcher an intimate familiarity with people’s lives and culture. The researcher “looks for patterns in the lives, actions and words of people in the context of the complete case as a whole” ( Neuman 1997:331). The case study approach in this study will enable the researcher to understand how and why a rural child living with epilepsy in a mainstream school experiences epilepsy the way he/she does, in relation to the patterns in his/her community i.e. the context. Questions which may arise could be:

- How do children, teachers, family members, relatives and other members of the community react when the child has a seizure? What do they say? What do they do about it?
- Why do they react in that particular manner? In other words, what is the motive behind the reaction?

These patterns will enable the researcher to understand the lifeworld of a child living with epilepsy as he/she explains it. Understanding involves assigning meaning, which cannot be separated from people’s subjective interpretations and intentions.

Waghid (2000:26) maintains that interpreting and communicating clear meanings to others is an essential component of qualitative research. This implies that as a researcher, one needs to understand and communicate clearly, the way in which the child experiences reality from the child's frame of reference. The researcher should therefore, try his/her best to access the child's intrapsychic structure.

In order to gather as much relevant information as possible concerning this case study, the Focus Group Interview Technique will be implemented. Krueger (in Kingry, Tiedje and Friedman 1990:124) defines a focus group as a carefully planned discussion in a group setting, "designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment." This implies that the researcher should carefully select the participants, design questions to be asked and create an environment which is conducive to openness. According to Kingry et al (1990: 443), the underlying principle in forming a focus group is homogeneity. This is based on the notion that participants feel more comfortable and safe in the company of people who are similar to them in such aspects as problems, feelings, opinions, attitudes and behaviour. The group provides a stimulating and secure setting for members to express ideas without fear of being criticized (Kingry et al 1990:125). Homogeneity is determined by the purpose of the research.

Focus group sessions will be recorded on audio tape to enable the researcher to listen to the discussions several times and to make verbatim transcriptions. All psychological indicators will be noted. Psychological indicators refer to any cue that communicates thoughts and feelings. These include cues such as sighs, hesitations and silences.

After transcribing, findings which will include important quotations will be organized and reports will be written. Results will be analysed and interpreted. Then the final report will be prepared.

## **1.6. Demarcation of the research**

The case study focuses on a group of learners living with epilepsy from the following primary schools in the Ritavi District in Region 5 of the Limpopo Province: Banana, Gavaza and Sebone. Eleven such learners have been chosen to participate in this study. The group was chosen because they have a similar health condition and are all at the primary school level.

Four Focus groups to be involved in this study will be constituted as follows:

- 11 learners suffering from epilepsy
- 11 parents of these children
- 6 teachers from the three primary schools involved in this study
- 8 peers of learners living with epilepsy from the above-mentioned schools.

## **1.7. Clarification of concepts**

### **1.7.1. Epilepsy**

This is a disorder of the central nervous system characterised by periodic loss of consciousness with or without convulsions. In some cases it is caused by brain trauma such as injury, but in others the cause is unknown (Sue et al 1994: 489). Fenton in Fendell and Zealley (1993:343)

defines epilepsy as a disorder of brain function that is characterized by recurring fits. He further asserts that it is a symptom of the malfunctioning of the brain that can be caused by “diverse disease processes, the final common pathway of expression being an intermittent, paroxysmal, excessive and disorderly discharge of cerebral neurones”.

### **1.7.2. Focus Group**

It is a group of people selected by a researcher for participation in a planned discussion. The purpose of such a discussion is to obtain perceptions on a particular area of study (Kingry et al 1989: 124).

### **1.7.3. Homogeneity**

This refers to similarity in kind or nature (Sinclair 1999:439). A homogeneous group of people therefore, refers to a group of people who share similar aspects e.g. gender, grade, ideas, problems, opinions, values and attitudes.

### **1.7.4. Idiopathic**

This is an adjective which comes from the word idiopathy. The concept Idiopathy refers to any disease of unknown cause. In some cases of epilepsy, the etiology is unknown therefore, it is considered idiopathic (Spiegel et al 1996: 34).

### **1.7.5. Seizure**

This refers to the recurrence of an epileptic convulsion or an absence. A seizure occurs as a result of “a sudden electrical discharge of cerebral neurones” (Fritz in Allwood and Gagiano 1997: 205).

### **1.7.6. Convulsion**

A convulsion is an attack in which the child becomes unconscious and usually stiff, with jerking of arms and legs. It is caused by unusual electrical activity of the brain. The concepts convulsion and fit are usually used interchangeably (The Royal College of General Practitioners 1996:1).

### **1.7.7. Absence**

An absence is an epileptic seizure without convulsions. It is characterised by a momentary loss of consciousness during which the sufferer stares blankly and have a slight twitching or blinking ( Sue et al 1994: 487).

## **1.8. Research Programme**

The content of the research programme will be allocated to chapters as follows:

Chapter 1: Problem, aims and plan of study.

Chapter 2: Epilepsy in childhood and adolescence is discussed.

Chapter 3: Epilepsy and human development is analyzed.

Chapter 4: The research design is outlined.

Chapter 5: The research findings are recorded, conclusions are presented and recommendations are made.

## **1.9. Summary**

Epilepsy (called “switshetshela” in Xitsonga) is still viewed with suspicion in African Third World countries. It is perceived as witchcraft, spirit possession, punishment for sins, etc. From the First world perspective, it is defined as a neurological disorder which is characterised by spontaneous, recurrent seizures.

In South Africa, learners living with epilepsy who do not have accompanying severe disabilities and/or other severe illnesses are admitted to ordinary public schools in terms of The National Education Act of 1996. According to the findings of research conducted in the Gauteng Province, it appears that learners suffering from epilepsy and their parents believe that teachers and learners in the mainstream schooling system are not prepared to accept and nurture learners living with epilepsy.

The general problem of this study is how a child living with epilepsy in rural areas experiences mainstream schooling system. The general objective is therefore, to investigate the lifeworld of a rural child living with epilepsy in the ordinary school and how it impacts on his/her academic performance. A qualitative research method has been chosen for this study. A Focus Group Interview technique will be implemented.

The case study to be used in this research is a group of learners living with epilepsy from the following primary schools in the Limpopo Province: Banana, Gavaza and Sebone. There will be four focus group sessions selected as follows: learners living with epilepsy, parents, teachers and peers.

## **CHAPTER 2**

### **EPILEPSY IN CHILDHOOD AND ADOLESCENCE**

#### **2.1. Introduction**

The purpose of this literature chapter is:

- to investigate the concept ‘epilepsy’ and indicate how it affects young children and adolescents.
- Furthermore, to serve as the background upon which the research will be based. This implies that the research findings will be compared to information gathered from the various literature sources.

The following aspects will be discussed: the prevalence of epilepsy, diagnosis, classification, causes of epilepsy in childhood, triggers, therapy and prognosis.

#### **2.1. Prevalence**

According to Christianson and Kromberg (2000: 263) epilepsy affects individuals throughout the world irrespective of age, ethnicity, socio-economic class or geographical location. They further maintain that the prevalence is higher in developing countries. Thiele, Gonzalez-Heydrieck and Riviello (1999: 672) provide an overview of the prevalence of epilepsy worldwide. They assert that epilepsy is common, with a lifetime prevalence of up to 10% of individuals having at least one afebrile seizure at some stage in their lives. An afebrile seizure is the convulsion that occurs without high fever.

A febrile seizure is the convulsion that is brought on by fever in a child. It can happen to a child between six months and five years of age (The Royal College of General Practitioners 2000:1). Febrile seizures can be triggered by any illness that causes high temperature, usually a cold or other virus infection. A febrile seizure therefore, is not epilepsy and it rarely leads to epilepsy. The Royal College of General Practitioners (2000:1) maintains that 99% of children with febrile convulsions never have convulsions after they have reached school going age, and they never have afebrile seizures.

Latchman from Epilepsy South Africa (2002: 28 July), assert that 1% of the world population suffer from epilepsy. He further maintains that there is no current statistical data on the prevalence of epilepsy in South Africa. Christianson et al (2000: 262) agree with Latchman. They emphasize that “no information is currently available on the prevalence of epilepsy in rural South African children”. This calls for more research on the subject.

The incidence of epilepsy worldwide is reportedly higher in children than in adults, with the greatest incidence occurring within the first year of life. Fenton in Kendell and Zealley (1993: 345) maintain that the onset of epilepsy occurs before the age of five years in approximately a quarter and before school-leaving age in more than half of the cases. Thiele (1999: 672) quotes Lennox et al who maintain that 75% of the seizures have their onset before 20 years of age and 30% occur between birth and 4 years of age.

### **2.3. Diagnosis**

A clinical diagnosis of epilepsy can mostly be made from the history alone (Chabalala 2002: Personal Interview, see Appendix VI) . Thiele et al (1999: 676) support this assertion when they say that the description of what occurs to the patient, or the way in which the patient behaves when having a seizure, determines the seizure type. Thiele et al (1999:676) further maintain that electroencephalograms (EEG's) and Neuroimaging studies may be helpful in the diagnosis, however, they might not be accurate. Neuroimaging for an example, only helps to show the absence of underlying causes of a seizure, not to make a diagnosis. The EEG is usually abnormal in many epileptics, however, some epileptics may have a normal EEG, especially between seizures. The most reliable way of making a clinical diagnosis is therefore, to check the symptoms.

Nonepileptic paroxysmal events can be mistakenly diagnosed as epilepsy. These are periodic events which resemble epilepsy. According to Thiele et al (1999:675), these disorders must always be suspected in patients with intractable epilepsy, or someone with a normal EEG. They further warn that “ a persistently normal EEG in a patient with a diagnosis of epilepsy...should always raise suspicion about the diagnosis”. Paroxysmal events include pseudoseizures, breath-holding spells, syncope, narcoplexy and cataplexy. This is by no means an exhaustive list of non-epileptic events. Many such events do exist. The following is a brief discussion of these events.

- Pseudoseizures

Neppo (1997: 1) defines pseudoseizures as phenomena that resemble epileptic seizures but which are in reality psychogenically induced. According to Chabalala (2002: Personal Interview), people can fake seizures to avoid responsibility or to get attention. Two decades ago, the following concepts were used by clinicians to refer to these events: hysterical epilepsy, hysteroepilepsy or hysterical seizures (Neppe 1997: 1)

- Breath-holding spells

These are dramatic, involuntary episodes that occur in children who are otherwise healthy (Jennette 2002: 1). Chabalala (2002: Personal Interview) defines them as temper tantrums during which the child stops breathing and in some cases, the child turns blue. In corroboration with this assertion, Jennette (2002: 1) explains that the breath-holding episode usually begins when a child becomes upset, is startled or suffers a minor injury which is followed by crying. This stage is immediately followed by a dramatic change in skin colour. The skin then becomes cyanotic (blue) or pallid.

- Syncope

Hain (2002: 1) defines syncope as a sudden fall of blood pressure resulting in loss of consciousness. It is commonly referred to as fainting.

- Narcolepsy

This is a sudden attack characterised by loss of muscle tone resulting in a person falling to the ground. It is usually caused by excitement (Chabalala 2002: Personal Interview). Shapiro in Kendell and Zealley (1993: 547) defines narcolepsy as “a condition with a classical tetrad of features”. These features include among others, hypersomnolence, sleep paralysis and hypogogic hallucinations”.

- Cataplexy

This is a sudden seizure during which a person just stops movement. Unlike with narcolepsy, the person experiencing by cataplexy does not lose muscle tone and it is a very brief seizure which lasts for a few seconds (Chabalala 2002: Personal interview). Shapiro (in Kendell and Zealley 1993: 548) maintain that cataplectic seizures occur especially in the context of strong emotions such as mirth, anger or distress. He further maintains that such attacks can be dangerous in certain situations, for example, in a swimming pool.

## **2.4 Classification**

In the DSM IV-TR (Diagnostic and Statistical Manual of Mental Disorders-Text Revision) classification system, epilepsy is classified as one of the diseases of the nervous system under Axis III ( General Medical Conditions). According to the ICD-9CM ( International Classification of diseases, 9<sup>th</sup> Revision, Clinical Modification), the coding for epilepsy is as follows:

345.10 Epilepsy, grand mal

345.40 Epilepsy, partial with impairment of consciousness (temporal lobe)

345.50 Epilepsy, partial, without impairment of consciousness (Jacksonian)

345.00 Epilepsy, petit mal (absences)

(American Psychiatric Association 2000: 868)

Thiele et al (1999: 672) provide a classification system proposed by the International League Against Epilepsy (ILAE). This classification system is based on three factors: clinical seizures manifestations, EEG ictal patterns and EEG interictal patterns. Ictal patterns refer to events during a seizure, whereas interictal patterns refer to events between seizures. Fenton (in Kendell and Zealley 1993: 348) assert that interictal symptoms occur between attacks and “in a setting of clear consciousness”. The interictal disorders in children include neurotic disorders, antisocial disorders and on very rare occasions, psychosis. The following is the classification system as proposed by the ILAE:

I. Partial (Focal, Local) Seizures

- The first clinical and/or EEG changes indicate initial involvement of part of one hemisphere.
- Partial Seizures are classified on the basis of an impairment of consciousness.
  - A. Simple partial seizures (no impairment of consciousness)
  - B. Complex partial seizures (with impairment of consciousness)
  - C. Partial seizures with secondary generalization (the discharge spreads locally, and also to the brain stem structures, which spread the discharge through the entire brain).

## II. Generalized seizures

- The first clinical and/or EEG changes indicate initial involvement of both hemispheres.
- Consciousness is impaired.

### A. Absence / atypical absence

An absence is also referred to as a “petit mal” attack ( Fenton in Kendell & Zealley). A child with an absence looks blank, stares and may have slight twitching or blinking (Chappell 1987:208). This assertion is supported by Sue et al (1994:488) when they say that absences involve a momentary dimming or loss of consciousness and the sufferer stares blankly. After an attack, the person may carry on with whatever activity he or she was engaged in, unaware that a seizure has occurred and that he or she had momentarily lost consciousness. An absence may be mistaken for day dreaming.

### B. Myoclonic

These are brief jerky movements. Allwood and Gagiano (2000: 211) define myoclonic seizures as “intermittent brief generalized jerks”.

### C. Clonic

Sue et al (1994: 490) define clonic seizures as violent jerky movements which are usually characterized by bruising the head on the ground, biting the tongue and vomiting.

### D. Tonic

These are generalized seizures which are characterized by spasms only (Allwood & Gagiano 2000: 211).

### E. Tonic-clonic

The tonic-clonic seizures are also referred to as “grand-mal” seizures (Fenton in Kendell & Zealley 1993: 344). The patient becomes stiff and adopts a strained body posture during which they may fall (Sue et al, 1994:490).

### F. Atonic

When a patient has an atonic seizure, he/she collapses or slumps, due to loss of muscle tone. According to Allwood and Gagiano (2000: 211), during an atonic seizure, there is a “complete loss of tone”.

### III. Unclassified seizures

An unclassified seizure is the seizure for which there is not enough information available to indicate what type of a seizure it is. According to Fenton in Kendell and Zealley (1993: 344), these seizures “are unclassifiable because of incomplete clinical and EEG data. Clinical information is usually clouded by the beliefs of the person giving the history (Chabalala 2002: Personal Interview).

#### **2.5. Causes of epilepsy in childhood**

As already mentioned in Chapter 1, some parents in Third World countries are still labouring under misconceptions regarding the causes of epilepsy. It is attributed to sorcery, evil spirits and witchcraft. These misconceptions should be addressed in order to assist people living with epilepsy to obtain relevant medication to control the seizures.

The following are causes of epilepsy as viewed from the scientific First World perspective: idiopathic or cryptogenic, congenital, trauma, genetic vascular, neoplastic, and infection. These causes will now be discussed briefly.

##### - Idiopathic

In cases of epilepsy where the etiology is unknown, it is considered idiopathic or cryptogenic (Spiegel et al 1996: 34).

- Congenital

A disease of congenital nature is one which the patient was born with ( Mohlaba 2002: Personal Interview, see Appendix VII). Kumar, Cotran and Robbins (1992: 85) define the concept congenital as follows: “The term congenital simply means present at birth”. They further emphasize that not all congenital diseases are genetic and that not all genetic diseases are congenital. This implies that epilepsy of congenital nature is not necessarily genetic, and vice versa. In support of this assertion, Louis and Jones (2002: 8) maintain that congenital lesions “are not often inherited but may be malformations or wrong migration of brain tissue”. If some pieces of the brain tissue fail to move (migrate) to their more permanent position as the fetus grows, they may not function properly and can cause seizures due to misconnection of cells.

- Genetic

If epilepsy is genetic, it means that it has been biologically inherited from parents and/or ancestors. In corroboration with this explanation, Louis and Jones (2002: 4) say that some types of seizures are usually inherited in the sense that they have been related to one or more chromosomes, for example, myoclonic seizures.

- Trauma

Trauma in this case refers to an injury to the brain. Injury is considered to be the most common cause of seizures in teenagers and young patients ( Louis and Jones 2002: 2). They further assert that seizures often happen when there is damage to the grey matter of the brain which is referred to as the cortex. According to Chabalala (2002: Personal Interview), trauma usually occurs in the process of giving birth, for example, use of forceps in difficult labour. He further asserts that trauma can also occur as a result of accidents involving head injury, or even deliberate action on children, for example, hitting with a hard object.

Epilepsy can also be iatrogenic. This means that it can be post-surgery or post-operative. Louis and Jones (2002: 2) assert that “surgery to the brain can be considered another type of injury”. In corroboration with this assertion, Chabalala (2002: Personal Interview) says that all operations that involve the brain carry a potential to result in epilepsy.

- Vascular

If epilepsy is considered vascular, it implies that it originated from the blood vessels. The concept vascular refers to a large group of conditions including diseases of the blood vessels which are caused by fat accumulation, damage of the blood vessel walls and blood clotting disorders (Louis and Jones 2002: 8). Mohlaba (2002: Personal Interview) agrees with this assertion and explains that epilepsy can be caused by blockage of the blood vessels in the brain.

- Neoplastic

Neoplastic causes are those that emanate from tumors growing in the brain. Kumar et al (1992: 172) assert that the concept “neoplasia literally means new growth”. A neoplasm is an abnormal mass of tissue the growth of which exceeds and is uncoordinated with that of the normal tissues. It also persists in the same manner after the stimuli which evoked the change has ceased. Kumar et al (1992:172) further assert that neoplasms do not respond to regulatory influences that control normal cell growth.

The following are characteristics of neoplasms:

- They seem to behave like parasites, and compete with natural normal cells and tissues for their metabolic needs.
- They have a certain degree of autonomy because they steadily increase in size regardless of their host’s nutritional status and other factors in their environment.

Neoplastic epilepsy can be divided into two types: benign and malignant. According to Kumar et al (1992:85), a tumor is said to be benign when its characteristics are considered innocent, meaning that it will remain localized and will not spread to other sites. It can be removed surgically and the patient can survive. Malignant tumors are very dangerous and could be fatal. They are collectively referred to as cancers. Kumar et al (1992: 172) maintains that malignant tumors can invade and destroy normal structures and spread to distant sites (metastasize) to cause death. They further assert that “the designation ‘malignant’ constitutes a red flag”. This implies that it is a sign of danger.

- Infection

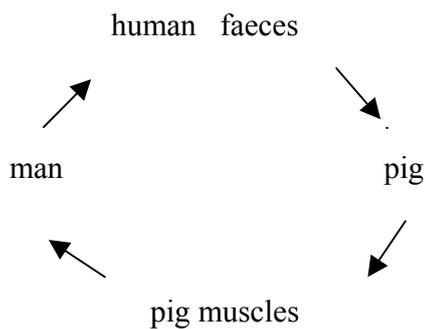
Infection refers to the presence of harmful micro-organisms which could cause brain abscesses or inflammation (Chabalala 2002: Personal Interview). Kumar et al (1992:44) assert that abscesses are localized collections of pus, which is caused by pyogenic bacteria for a example, staphylococci. Mohlaba (2002: Personal Interview) asserts that meningitis can also result in epilepsy. Hope et al (1987:364) define meningitis as “an infection of the pia mater and arachnoid” which are coverings of the brain . Mohlaba (2002: Personal Interview) agrees with this definition and says that these brain coverings are called meninges. He further explains the concepts ‘pia mater’, ‘arachnoid’ and ‘dura mater’. He says that the pia mater is the innermost covering which is very soft, the arachnoid is the middle covering and the dura mater is the outer covering which is hard.

Ahmed (2002: Personal Interview, see Appendix V) maintains that poor hygiene (for a example, eating without washing one’s hands properly or eating unwashed vegetables) and eating pork which is not well-cooked can result in epilepsy. This assertion is supported by Chabalala (2002: Personal Interview) when he says that in the Third World countries, the most contributory factor in the development of epilepsy is cysticercosis. The pork tapeworm which is referred to as “*Taenia solium*” or its eggs can be consumed by a human being by eating pork. This assertion supports that of Fripp (1983: 82) when he maintains that human cysticercosis is caused by “*cysticercus cellulosae*”. If an egg of a “*Taenia Solium*” referred to as an “onchosphere” is ingested, “it hatches in the duodenum and penetrates the mucosa”. After a migratory phase it develops into a cysticercus, most commonly in muscular tissues. Epilepsy usually results from

cerebral cysticercosis which occurs when the oncospheres settle in the ventricles and grow to an extent that they block the flow of cerebro-spinal fluid (Fripp, 1983: 83). In support of this assertion, Chabalala (Personal Interview: 2002) says that from the human intestines, the eggs of a “Taenia solium” can get to the brain. In the brain the eggs are encapsulated into cysts which can remain there for many years. The cysts in the brain can become the starting point (focus) of the seizures. The following is an illustration of the route it takes:

pork → human intestines → human liver → blood stream → brain

Eggs which are not absorbed into the blood stream leave the human body with the faeces, and later develop into tapeworms. When the pig eats the faeces with the tapeworms, the tapeworms incapsulate in the muscles of the pig. Then it perpetuates a cycle which can be illustrated as follows:



## **2.6. Triggers**

Seizures in people who are susceptible to the development of epilepsy or who have epilepsy can be triggered by the following factors: alcohol, lack of sleep (insomnia), fever, low blood sugar level (hypoglycaemia), brain lesions or injury, general fatigue, particular musical tones, flickering lights (e.g. TV), emotionally charged situations and everyday stress (Sue et al 1994: 488).

## **2.7. Therapy**

### **2.7.1. The Third World Perspective**

In Third World African countries, many of the children living with epilepsy do not receive antiepileptic medication because of the misconceptions held by various communities regarding the causes of epilepsy. The sufferers of epilepsy in rural black communities are usually taken to traditional healers (previously referred to as witchdoctors) and spiritual healers such as priests, prophets and evangelists for help. Seape (in Allwood and Gagiano 2000: 5) maintains that when a cure for mental illnesses is sought in these communities, the question asked by the patients and their families is usually “who has caused the illness and why”. If the disease is attributed to sorcery and witchcraft, the traditional healer (called “mungoma” in Xitsonga) will reveal this and prescribe a ritual or sacrifice to correct whatever he says is wrong in the family. It is also important to indicate that some traditional healers do point out the person responsible for the disease or the witch. In some communities, the suspect is then murdered or instructed to leave

the village. In Christian families, epilepsy is usually interpreted as possession by demons. Such families rely on prayer for a cure. Therapy is therefore, aimed at “chasing away the evil spirits”.

If the patient’s body is perceived as a dwelling place of the spirits of the ancestors, seeking cure can be “regarded as interference that may anger the spirits” (Seape in Allwood & Gagiano 2000: 5). If the family or community holds people with epilepsy in high esteem, the sufferer might not receive any treatment at all. A study conducted by Christianson et al (2000:262-266) indicate that half of the subjects involved in their research in rural South Africa do not receive medication.

## **2.7.2. The First World Perspective**

The following First World types of therapy will be discussed: Antiepileptic Drug Therapy and Alternative Therapies.

### **2.7.2.1. Antiepileptic Drug Therapy**

Allwood and Gagiano (2000: 214) maintain that “pharmacological management is the cornerstone of therapy”. The choice of an antiepileptic drug to be administered depends on the correct identification of the seizure type and cause. The medication which is chosen is the one that has shown to have the highest efficacy and fewest adverse effects (also called side effects) to the particular seizure type (Thiele et al 1999: 676).

Antiepileptic drugs are divided into two types: the standard first-line antiepileptic medications and the second-line antiepileptic medications. Thiele et al (1999:677) maintain that treatment should always be started with a single antiepileptic medication and the dosage should be increased slowly until the seizures are under control or until intolerable side effects occur. This assertion is supported by Allwood and Gagiano (2000: 214) when they say that patients should “use one drug at a time to full dosage”. If the first drug is not effective, then the patient should consider trying a second one. According to Thiele et al (1999: 677) “the benefits of monotherapy include limited drug interactions, fewer side effects, lower cost and greater compliance”. First-line antiepileptic drugs include carbamazepine, phenobarbital, phenytoin, valproic acid and clonazepam. Generalized seizures can be controlled by phenytoin, carbamazepine, diazepam, clonazepam, phenobarbitone and valproic acid. Partial seizures can be controlled by phenyton, carbamazepine and valproic acid. Ethosuximide is used to control absences (Allwood & Gagiano 2000: 215).

If patients have not responded to the above-mentioned drugs, the second-line antiepileptic medications are administered. These include chlorazepate, methuximide, acetazolamide and ethotoin. New antiepileptic medications which have become available in recent years include felbamate, gabapentin, lamotrigine, topiramate, tiagabine and vigabatrin. Most of the new drugs differ from the standard ones in their mechanisms of action, pharmacokinetics and side effects (Thiele et al 1999: 677). Pharmacokinetics refer to what the drug does to the body. What the body does to the drug is referred to as pharmacodynamics (Mohlaba 2002: 15 August).

To prevent seizures effectively, the above-mentioned medicines must be taken regularly so that a steady level of medication is maintained in the body.

Allwood and Gagliano (2000: 214) assert that pharmacological management is successful in 70% of the patients. Thiele et al (1999: 677) maintain that although some types of seizures are harder to control than others, about half of the patients who take medication gain complete control over their seizures, 30% have fewer seizures than before, while the remaining 20% do not benefit from drug therapy. When a patient does not respond to antiepileptic drug therapy, he/she is said to have “medically refractory epilepsy”.

### **2.7.2.2. Alternative Therapies**

Other treatments which are available for the management of epilepsy are: the ketogenic diet and surgery. Diets which are high in fats but low in carbohydrates (sugars and starches) are considered to be helpful to people with epilepsy. Thiele et al (1999:681) maintain that retrospective studies of the ketogenic diet have shown a significant reduction in seizure activity in more than 70% of children who had seizures which were difficult to control.

They further warn that such diets may have unpleasant side effects which include weight loss, dehydration, abdominal pain, acidosis and lethargy. These factors should be taken into consideration before subjecting children to ketogenic diets.

When all other therapies have failed, surgery is considered. Surgery however, is a rare and controversial procedure. It is done only when other therapies could not help and when an operation will not seriously interfere with the normal functioning of the brain or with the patient’s personality (Chabalala 2002:Personal Interview).

Because of its complexity, the patient is admitted to hospital so that a presurgical evaluation can be done. This is done by means of continuous video-EEG monitoring, neuroimaging and

neuropsychological evaluation. Surgery is performed after the area from which the seizure arises has been identified. This area is referred to as “the epileptogenic zone” (Thiele 1999: 682). Viljoen (2002: Personal Interview, see Appendix VIII) agrees with this assertion when he says that before surgery is performed, “mapping” is done to identify the focus. He further maintains that surgery can then be performed in which the corpus callosum is severed in order to prevent seizures from spreading to the entire brain. The two brain hemispheres then become disconnected. It is therefore, “a palliative procedure rather than a curative one” (Thiele et al 1999: 682). This type of an operation is referred to as corpus callosotomy.

A hemispherectomy can be performed when the epileptogenic zone is large, localized to one hemisphere and when the child already has a contralateral neurologic deficit (Thiele et al 1999: 682). When a child has a contralateral neurologic deficit, the other side of the brain does not function. The child therefore, cannot function properly (Chabalala 2002: Personal Interview). Thiele et al (1999:682) further assert that the success rate of this type of operation is high, but they also warn that it has a greater chance of leaving the patient with postoperative deficit. This is also referred to as iatrogenic deficit (Mohlaba 2002: Personal Interview). Viljoen (2002: Personal Interview) maintains that the results of this type of operation depends on the location of the epileptogenic zone. He further asserts that if it is localized in the motor cortex for example, surgery can be dangerous. The type of surgery to be performed is determined to a large extent, by the presurgical evaluation.

## **2.8. Prognosis**

Epilepsy is a long term problem that needs to be addressed at pharmacological and psychological levels. This calls for involvement of people at the three levels: the macro level in which the national and the provincial educational structures and policies are involved , the meso level which is the school and the community and finally, the micro level in which the family and the individual are involved. The support system at all these levels should be strong in order to help them to function meaningfully.

According to Ahmed (2002: Personal Interview), children can “outgrow” epilepsy. Some patients may have epilepsy throughout their lives, but without experiencing seizures . This implies that even if epilepsy is not curable, seizures can be controlled. This is supported by Sue et al (1994: 488) when they assert that “epilepsy cannot be cured but it can be controlled”.

## **2.9. Conclusion**

Epilepsy is a complicated neurological disease the causes of which vary from one child to another. It is even more complicated and difficult to control when it is medically refractory. Triggers of this disease also differ from one patient to another. It is usually very difficult to identify a trigger for a particular child. Understanding and support is essential to enable the child living with epilepsy to function meaningfully. Although it is usually difficult to change people’s beliefs, misconceptions should be addressed at all the levels: the macro level, the meso level and the micro level.



### **AMBER'S POEM**

THESE EYES ARE NOT LIKE YOURS OR HIS,  
THESE EYES ARE PHOTO SENSITIVE.  
FAST MOVING ADS ON THE TV SCREEN.  
THE FLICKERING, BLINKING LIGHTS SEEM MEAN.

WITH THEM COMES, SPACE IN MIND,  
THE BLANK STARE, THE LOST TIME.  
THE NIGHTS ARE MY HAVEN, MY ESCAPE.  
HOW TO EXPLAIN, HOW TO COPE.  
WHAT ARE THE ODDS OF THIS GOING AWAY.

THIS IS MY FATE AND SO I WILL PRAY  
THAT AS TIME GOES ON THIS WILL GO TOO  
AS THIS AFFLICTION IS KNOWN BY VERY FEW.

**BY MARLYN SEARLES**

DEDICATED TO HER GRANDDAUGHTER, AMBER

## **CHAPTER 3**

### **EPILEPSY AND HUMAN DEVELOPMENT**

#### **3.1. Introduction**

This chapter aims at explaining the learning and behavioural problems of children and adolescents with epilepsy. Children and adolescents with epilepsy experience emotional and relationship problems at school. They are usually described as bullies or as being rebellious which may be strategies they use in order to survive in what they regard as a hostile world. According to Regan et al (1993:18), “behavioural disorders in children with epilepsy are not a constitutional feature of epilepsy but an adaptive response to those around them”. They further maintain that about one in every three children with epilepsy do not achieve according to their learning ability. This indicates that their academic performance is also affected.

As an attempt to place the child with epilepsy in greater perspective, the following aspects will be discussed:

- Stages of psychosocial development in order to describe learners living with epilepsy within their developmental phase
- Epilepsy and the learning process in order to describe how epilepsy affects the learning process.

### **3.2. Erikson's stages of psychosocial development**

All eight phases will be discussed briefly. However, only the possible effects of epilepsy in the childhood and adolescent phases will be discussed in fuller detail.

#### **3.2.1. The theory**

Erikson (in Meyer 1997:208) asserts that human development takes place according to a genetically determined plan. He employs an epigenetic principle to explain this "plan". According to this principle, development takes place in both visible and invisible ways. As a person grows up, each personality characteristic continues to develop even though their development might not be evident at a particular age, but will be evident later in life. Aspects of personality such as cognitive abilities and social skills are examples of such covert development. He further asserts that social influences also affect human development by making certain demands on the child while at the same time providing opportunities for growth. In a nutshell, Erikson (in Meyer 1997: 208) believes that human development is a result of two simultaneous and complex influences which are: genetic and social factors.

According to Erikson, human life is divided into stages through which every person has to progress. Each developmental stage grows out of the preceding one. These stages are critical periods during which certain qualities and characteristics develop (Van Niekerk et al 1998:44).

This implies that all the experiences of the child in each stage plays an important role in his/her life. These stages determine the child's functioning later in his life. In this study, the development of the child with epilepsy will be discussed in relation to this psycho-social theory.

### **3.2.2. The eight psychosocial stages of development**

Although only the first five stages deal with childhood and adolescence, all eight stages will be discussed briefly.

#### **3.2.2.1. Trust versus mistrust**

This is the first year of the child's life. Erikson (in Sue et al 1994:88) stresses that parental love and attention are important for the child to develop a sense of trust. Without this trust, the child is likely to view the world as dangerous, hostile and threatening. Erikson (1977: 224) says the following about this stage:

“Let it be said that here the amount of trust derived from the infantile experience does not seem to depend on absolute quantities of food and demonstrations of love, but rather on the quality of maternal relationships.”

A child who experiences the world as threatening might eventually avoid social interactions later in life. The personality and identity of children experiencing epilepsy depend largely on the attitudes of their parents towards the disease. The disease might bring fear to the parents and the child and as a result, the child can experience the world as cruel and threatening.

Prinsloo and Wiechers (1994:47) maintain that “the critical requirement in this period is that babies should experience their world as secure, reliable and caring- not as threatening, unpredictable and treacherous.” Pianta et al (1994: 1415) assert that characteristics of epilepsy directly affect the relationship between the parent and the child by increasing the parent’s overprotective responses, anxiety and intrusive interactions. Even when the seizures are under control, parental fears for the next seizure, expectations and the stigma attached to the disease cause recurring anxiety to both the parent and the child. This contributes to long-term problems of adjustment.

#### **3.2.2.2. Autonomy versus shame and doubt**

These are the second and third years of life. If the children have developed a sense of trust, they learn to be autonomous that is, to explore the world on their own as opposed to shame and doubt. Erikson (1977:227) asserts that “He who is ashamed would like to force the world not to look at him, not to notice his exposure. He would like to destroy the eyes of the world. Instead, he must wish for his own invisibility.” He further maintains that “Doubt is the brother of shame...this finds its adult expression in paranoid fears concerning hidden prosecutors and secret persecutions threatening from behind”.

Epilepsy can hinder the child’s autonomy. Because of its nature, especially if it involves convulsions, the child remains dependent on parents and other people for security and support. It is therefore, important for parents to provide reasonable levels of security and support. This implies that children should neither be under-protected nor over-protected.

This however, is not an easy task. Pianta et al (1994:1415) emphasize that “parents’ tendencies toward over- and under-regulation can undermine the child’s autonomous problem-solving efforts”. They further assert that such children might later experience among others, the following negative outcomes: academic performance below expected levels, increased psychiatric and behavioural disturbances, poor self-esteem and excessive dependency. The ultimate result of these negative outcomes is lack of self-reliance throughout the child’s life. Scroufe (in Pianta et al 1994:1417) conceptualizes self-reliance as a “relationship construct, which...is viewed as the way in which the child-parent relationship supports the autonomous problem-solving and coping efforts of the child”. From the above definition, it becomes clear that self-reliance does not mean total independence but rather well-guided critical thinking and creative coping skills.

Erikson (1977:228) describes this phase as follows: “This stage therefore, becomes decisive for the ratio of love and hate, cooperation and willfulness, freedom of self-expression and its suppression. From a sense of self-control without loss of self-esteem comes a lasting sense of goodwill and pride; from a sense of loss of self-control and of foreign over-control comes a lasting propensity for doubt and shame”.

### **3.2.2.3. Initiative versus guilt**

These are the third to the sixth years of life. It is the stage during which children acquire a sense of initiative while overcoming a sense of guilt. They begin to assume a certain amount of responsibility for themselves and for their environment. They are also eager to care for their

siblings and for pets. This is the stage at which children psychologically become rudimentary parents and care-givers. These tasks , especially if done successfully, help in building their self-esteem and eventually, in giving them the sense of initiative (Prinsloo and Wiechers 1994:53). The social circle also broadens and the child develops a new initiative in language and play. This indicates that acceptance by peers plays an important role. Erikson (1977: 230) asserts that “Social institutions therefore, offer children of this age economic ethos, in the form of ideal adults recognizable by their uniforms and their functions, and fascinating enough to replace the heroes of picture book and fairy tale.”

Erikson (1977: 230) further maintains that “The usual failure leads to resignation, guilt and anxiety”. If the child’s sense of self-reliance has been hampered by epilepsy, problems in social interactions are likely to occur. It is also during this stage that children become aware of their gender roles. Gender is of significant importance in determining adjustment. Pianta et al (1994:1417) maintain that adjustment problems in children with epilepsy are higher in boys than in girls. This could be due to societal emphasis on self-reliance in boys as a sign of masculinity.

#### **3.2.2.4. Industry versus inferiority**

These are the primary school years which are approximately between six and twelve years of age. The children in this stage want to be actively involved in their environment and want to use their energy in constructive and socially acceptable activities. They try to understand the technological society in which they are living and to make a positive contribution to it.

If they accomplish something in their endeavors and receive recognition for it, they experience a sense of industry (Prinsloo & Wiechers 1994:54). They develop a sense of proficiency which according to Meyer et al (1997:218), is the ego quality through which a healthy balance in life is reached. The peer group becomes a major focus and it is a stage which plays a vital role in the development of personality. The children compare their achievements with those of their peers. As already discussed, many children who experience epilepsy also underachieve academically (Pianta 1994: 1416). In a nutshell, their academic performance is usually lower than expected. If children have not developed a sense of initiative and they underachieve, they might experience a sense of inadequacy and inferiority. This can lead to social isolation. Erikson (1977: 233) says the following concerning the child during this phase: “If he despairs of his tools and skills or of his status among his tool partners, he may be discouraged from identification with them and with a section of the tool world”.

Because this study focuses on epileptic learners in the primary school, the effects of epilepsy on learning will be discussed in greater detail in the next section (3.3).

#### **3.2.2.5. Identity versus identity diffusion**

This is the stage of adolescence. Prinsloo and Wiechers (1994:55) assert that a sense of self-identity means that the adolescent has managed to overcome childhood problems to a great extent and that he/she increasingly has the ability to live and function like an adult. For a learner with epilepsy, it implies that his/her condition did not hinder his/her ability to build sound relationships with significant others (parents, teachers and peers) during all the previous stages.

“Elements of each phase are discernible in the adolescent’s identity” (Prinsloo & Wiechers 1994: 55). Identity includes those characteristics of other people with which the child can identify.

Erikson (in Prinsloo and Wiechers 1994:56) asserts that adolescents are in a “psychosocial moratorium”. This means a period of grace during which society allow adolescents to commit childhood errors while practicing adult roles. Erikson (in Meyer et al 1997:218) says that it is of the utmost importance for adolescents to ask themselves the following questions:

“What am I in the eyes of other people?”, “How do others’ images of me correlate with my self-image?”, and “How can my previously acquired roles and skills fit into the career world and my projected future”.

During this period, each of the preceding phases is manifested at a higher level. Each phase as reviewed by Prinsloo and Wiechers (1994: 56) will be briefly looked at:

- The search for basic trust in significant others turns into a search for people and ideals in which to believe. This means that this is the stage during which religious, cultural and political ideals are chosen. In relation to the child’s identity, it means: “I am that which I believe”. For an epileptic child who has lost trust in the world, forming such an identity can be a very difficult process.
- The sense of autonomy and independence turns into a sense of having freedom to choose tasks and duties. In terms of the child’s identity, it means: “I am the services which I voluntarily choose to render”. For a child with epilepsy, such a freedom of choice is limited. A child who is, for example, sensitive to flickering lights, cannot obtain information from

electronic media therefore, the choice of learning aids is limited for him/her. Epilepsy may also lead to deterioration of mental functioning, which results in learning disabilities. Such learners also lack self-reliance. A study conducted by Jones et al (1998: 247) indicates that children with epilepsy have poorer life skills particularly in the area of independent functioning.

- The sense of initiative becomes an ambition and a striving towards self-actualization. The identity in this regard would be: “I am the goals towards which I aspire”. Actualization of one’s potentials can be hindered by epilepsy to the extent that they could be regarded as having significant barriers to learning. A child with barriers to learning has limited chances of actualizing his/her potential. It should however, be borne in mind that a child with epilepsy whose seizures are under control and/or whose mental functioning has not been significantly affected, can overcome childhood problems. Such a child can progress normally through the developmental stages and attain self-actualization.
  
- The sense of industry forms the basis for the selection of the right career. In terms of identity formation, this means that: “I am what my occupation is”. Epileptic seizures can be triggered by exhaustion. This implies that some children with epilepsy are forced to choose careers which are “friendly” to their condition. Some for example, may not drive a car and others may not be allowed to work with equipment which could be dangerous if they have absences.

As has been said, the following three stages are beyond the focus point of this script. However, in view of the fact that these are the developmental phases towards which the child and adolescent are developing, they are important. They will therefore, be discussed very briefly.

### **3.2.2.6. Intimacy and solidarity versus isolation**

This is the period between approximately 23 and 35 years of age. The focus during this stage is to form a close relationship with a single member of the opposite sex. It is a period of choosing a life partner, which enables one to develop a communal sense of identity. This refers to sharing one's identity with another person. Meyer et al (1997: 219) assert that in most cultures, the most intimate relationship is marriage, although other forms of committed relationships between lovers do exist. If the previous phases were successfully handled, a person enters this phase with a sense of trust for others. The aspects of the previous phases will enable him/her to build an intimate relationship with his/her life partner and to share emotions and ideals genuinely with this significant other person. If the previous stages were not resolved successfully, which may well happen to people with epilepsy, the person might just desire to have an intimate relationship but will be unable to build it because of a low ego and lack of social skills. All these eventually lead to frustration and loneliness in both partners (Prinsloo & Wiechers 1994: 58).

Erikson (1977:237) maintains that "The counterpart of intimacy is distantiation: the readiness to isolate and, if necessary, to destroy those forces and people whose essence seems dangerous to one's own, and whose 'territory' seems to encroach on the extent of one's own intimate relations".

### **3.2.2.7. Generativity versus self-obsession and stagnation**

This is the period between approximately 37 and 59 years of life and involves most of the individual's adult life. Meyer et al (1997:220) maintain that this stage "spans generations".

While an adult continues to develop himself or herself, he/she is at the same time involved in the development of the next generation. A person becomes generous and cares for other people, for example, children and grandchildren. Generativity also involves doing good work for the benefit of his/her community. Prinsloo and Wiechers (1994:58) assert that this sense of generativity helps to prevent feelings of stagnation and ego-centricity. The main focus during this stage is "the belief that life is meaningful and human species are valuable" (Prinsloo & Wiechers 1994: 58).

A person needs to feel that other people need him/her and wants to pass on the knowledge and traditions to other people. This is the ego strength of care which is defined as "man's love for his works and ideas as well as his children" (Erikson in Meyer 1997:220). If early childhood crises are unresolved especially if there is lack of trust in mankind and in the future, the person becomes stagnant and obsessed with the self.

### **3.2.2.8. Integrity versus despair**

This is the period around the 60<sup>th</sup> to the 80<sup>th</sup> or 90<sup>th</sup> year of life. The person during this phase accepts and adjusts to the "frailties" of age. This is the final stage and the aged come to terms with the inevitability of the approaching death. Prinsloo and Wiechers (1994:58) assert that

elderly people who have successfully tackled the previous phases face death with confidence because of the feeling that their lives were happy and useful. To Erikson (in Meyer et al 1997: 221) this ego strength of wisdom as “detached concern with life itself, in the face of death itself”. Elderly people who are not content with this stage “generally develop a morbid fear or unrealistic denial of death” (Prinsloo & Wiechers 1994: 58).

Erikson maintains the following concerning this final phase: “Only in him who in some way has taken care of things and people and has adapted himself to the triumphs and disappointments adherent to being,...only in him may gradually ripen the fruit of these seven stages. I know no better word for it than ego integrity.”

### **3.3. Epilepsy and the learning process**

As the focus of this study is the learner with epilepsy in a primary mainstream school, it is important to look at how the child in this stage is affected by his/her condition.

This section will be discussed under the following subheadings:

epilepsy and mental functioning, seizure types and their effects on learning, emotional and behavioural disturbances and their impact on learning, relationship problems at school and their effects on learning, and the effects of medication on learning.

### **3.3.1. Epilepsy and mental functioning**

Children with epilepsy have the same distribution of intelligence as children without epilepsy. The majority of children with epilepsy, except those with severe brain damage, fall within the normal distribution curve of intelligence. Kapp et al (1991: 261) quotes Livingstone when he emphasizes that there is no constant relationship between epilepsy and mental ability. They further quote Svoboda (1991:261) when he says that in some children however, epilepsy leads to mental deterioration. This is attributed to the destruction of the nerve cells as a result of the seizures, continuous use of medication, unfavourable reactions to medications and the nature of the brain disturbance which is the original cause of the seizures. Seidenberg and Gunstof (in Austin 1998:248) assert that past research findings have consistently shown that academic performance of children with epilepsy is poorer than could be expected in relation to their intellectual ability. Epilepsy can also lead to secondary mental handicap. This is the category of handicap that occurs as a result of epilepsy whereas primary handicap is the disability that a child was born with. In the case of a primary handicap, the child was born with a mental ability far below average (Kapp et al 1991:262).

### **3.3.2. Seizure types and their effects on learning**

The type of a seizure determines the type of learning disability the child is likely to experience. Regan et al (1993:17) maintain that impaired performance associated with epilepsy is seen particularly in the following areas: concentration, memory, mental processing and alertness.

Problems are usually manifested in reading, spelling and mathematics. The following is a brief discussion of each seizure type in relation to the learning process.

Absences disturb the child's continuity of consciousness and as a result, his/her ability to pay attention is disrupted. Unlike the other seizure types, an absence occurs suddenly without any prior warning sign and it involves both hemispheres of the brain. Kapp et al (1991:262) assert that the child's consciousness is therefore, abruptly stopped. In some cases, the following are the symptoms during the absence: an empty, glazed expression in the eyes; sometimes the eyes are turned upwards and a sharp cry is uttered. In other cases, there are no motor symptoms therefore, the only symptom is the disruption of the activity the child is involved in for example, reading, writing or speaking. It is also reported that there are disturbances of the thought processes before and after the seizure. Kapp et al (1991:262) again quote Svoboda when he says that "his (the child's) thought processing may be slowed, distorted or tenuous" before and after an absence.

Convulsive general seizures, especially the tonic-clonic seizures, usually exhaust the child to such an extent that he/she experiences difficulty in thinking afterwards. The after effects include confusion, headaches, restlessness, disturbed speech and sometimes temporary paralysis.

The child may also experience what Barnard (in Kapp et al 1991:263) refers to as "retro-active amnesia". This means that the child might not remember events that occurred immediately before the seizure. This explains the inconsistency in some epileptic children's thoughts and achievements. According to Kapp et al (1991:263), the child might know something today but cannot remember it tomorrow, only to remember it the day after tomorrow.

Aldenkamp et al (1999:130) conducted a study on how seizure types affect learning. The findings showed significantly lower school achievement scores for patients with idiopathic generalized epilepsy compared to patients with localization-related epilepsy. A study conducted by Williams et al (1996:151) indicates that children have more difficulty with scholastic achievement when seizures were poorly controlled. Aldenkamp et al (1999:130) support this assertion when they maintain that the key factor that contributes to learning disabilities in children with epilepsy is “uncontrolled epilepsy”. Uncontrolled epilepsy refers to an epilepsy with a high seizure frequency, which is not controlled by medication.

Partial seizures disturb the normal functions of that specific area in the brain which is affected. In the following table, the common localizations and the learning disabilities which are associated with these localizations are outlined.

Localization	Learning disability
<ul style="list-style-type: none"> <li>▪ Lesions in the frontal lobes</li>   <li>▪ Left temporal lobe focus</li>   <li>▪ Right temporal lobe focus</li> </ul>	<ul style="list-style-type: none"> <li>▪ inability to think and to work independently.</li>   <li>▪ Language and speech problems which eventually lead to problems in reading, spelling, writing and mathematical problems.</li>   <li>▪ Problems with: <ul style="list-style-type: none"> <li>• the recognition of form, form-</li> </ul> </li> </ul>

	<p>spatial relationships and the attribution of meaning to general non-verbal spatial information.</p> <ul style="list-style-type: none"> <li>• the meaningful interpretation of the overt behaviour of others.</li> <li>• The recognition and synthesis of musical perception and rhythmic activities.</li> <li>• Generally, the interpretation of environmental stimuli may be altered.</li> </ul>
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Adapted from Kapp et al (1991:263-264) and Fenton (in Kendell and Zealley 1997: 345)

**3.3.3. Emotional and behavioural disturbances: the impact on learning**

The child with epilepsy lives in a world which is different from the world in which the other children live. His perceptions of existence are unique to him/her in the sense that his/her whole existence is controlled by the condition. Kapp et al(1991:265) maintain that “the child’s epileptic condition permeates his whole existence. His life revolves around it”. They further assert that epilepsy fills the young child with the fear that he will die whereas to the older child (of school going age), it is an embarrassment. The child might conceal the use of medication, however, the seizures cannot be concealed. A lot of embarrassing things happen during the seizure, for

example, the child sometimes wets and soils himself/herself. These, together with the after effects of a seizure such as confusion, and speech paralysis, contribute to a larger extent, to the child's low self-esteem and poor social relations.

Carlton-Ford et al (1997:384) mention the following three sets of variables as independent causes of behavioural and emotional problems: seizure coupled with medication, perceived stigma and parenting. Livingstone (in Regan et al 1993:18) maintains that the greatest problem may not be the seizures per se, but the psychosocial, behavioural and learning problems associated with the condition. Svoboda (in Kapp et al 1991:265) says that "the recurrence of the seizure only reinforces his poor self-concept formation and his defences are shattered. The child's frustration is manifested in behavioural problems such as depression, quarrelsomeness, rebelliousness and loneliness. A depressed child has no motivation to work. Sue et al (1994:361) maintain that when a person is depressed, work responsibilities become "monumental tasks". The ultimate result of all these is poor academic performance.

#### **3.3.4. Relationship problems at school and their effects on learning**

The learner with epilepsy needs understanding and a positive attitude from the educator and other learners. As already discussed, his/her medical condition is usually accompanied by psychological problems, for example, a weak self-concept. A child with a weak self-concept experiences poor relations with other people and objects. Psychosocial problems in turn contribute to an increase in the frequency of seizures, which exacerbates school problems. This establishes what Regan et al (1993:18) refer to as a "self-perpetuating cycle".

If the educator has a negative attitude towards the learner it will contribute to the learner's negative attitude towards his/her academic tasks. Kapp et al (1991:264) maintain that the educator's attitude towards the children contributes significantly towards the children's attitude towards their school work. The relationship between the educator and the learner also determines the child's identity formation, which is a very important aspect of human development. If the children identify with the educator, they accept the educator's authority. They usually accept the content presented to them and the tasks which they are instructed to perform. The educator and the child must be reciprocally involved. "This involvement serves as a basis for the identification relationship between the teacher and the child...identification is not possible without mutual acceptance" (Kapp et al 1991:264). This implies that relationship problems between the educator and the child will negatively affect the child's learning.

Educators in mainstream schools do not know how to deal with learners with epilepsy, as a result, they sometimes become irritated with them. Other learners can also label them as "stupid", "different", etc. This results in learners with epilepsy becoming lonely and withdrawing from learning tasks ( Kapp et al 1991:265). In a nutshell, the child becomes less motivated to learn and eventually develops learning problems.

### **3.3.5. The effects of medication on learning**

A child with epilepsy often uses medication to control seizures. However, unpleasant side effects might result. Side effects include drowsiness (which might be mistaken for "laziness" or

“stupidity”), restlessness, irritability and agitation. Prolonged use might also affect the learners’ general health (Kapp et al 1991:266). All the above-mentioned factors negatively affect the child’s motivation to learn and his/her sense of industry.

### **3.4. Conclusion**

It becomes apparent from the above discussion that each and every stage of life plays an important role in the optimal development of a person. It should however, be borne in mind that although unresolved crises in each stage may lead to adjustment problems later in life, a person may recover during the following stages. Erikson has an optimistic view of human development. He believes that one can recover from developmental inadequacies of the past. This implies that a learner with epilepsy who has lost interest in learning and life in general, can still recover through the support of parents, teachers and peers. This support could help him/her to reconstruct the self-esteem and eventually, improve in academic and social functioning. The child’s significant others need to know the truth about the condition in order to enable them to break away from the misconceptions they might hold about it.

## **CHAPTER FOUR**

### **EXPLORATION OF RESEARCH DESIGN AND METHOD**

#### **4.1. Introduction**

The two preceding chapters, are based on the data collected from the study of literature and personal interviews. This chapter will focus on the following aspects:

- The specific research question
- Aims of the study
- The research method

#### **4.2. The specific research question**

The researcher is concerned about the way in which the child living with epilepsy in rural South Africa experiences mainstream schooling. The problem confronting the researcher is:

What information do teachers and learners in mainstream schools need about children with epilepsy in order to give the necessary support to these children?
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People in the rural areas of South Africa still hold myths concerning epilepsy. As already discussed in Chapters one and two, they attribute the disease to superstitious factors.

This study will be of assistance in the sense that the researcher will be able to find out from learners with epilepsy, their parents, teachers and peers, what they think and how they feel about epilepsy.

#### **4.3. The aims of the study**

The general purpose of social science research is to seek answers to questions which researchers have about the social world in order to produce knowledge. Social researchers employ a variety of methods in gathering the data with the aim of generating knowledge. Neuman (1997:327) maintains that social researchers systematically collect and interpret empirical evidence. This evidence helps them to understand and explain social phenomena. Mouton and Marais (1990: 7) define social science research as “a collaborative human activity in which social reality is studied objectively with the aim of gaining a valid understanding of it.”

Rosnow and Rosenthal (1996:12) assert that social science is included under the umbrella of behavioral science. All fields of behavioral science have the same objective which is : to describe and explain how and why people behave the way they do, including why they feel and think the way they do (Kimble in Rosnow & Rosenthal, 1996: 12).

The aims (objectives) of this study, as mentioned in 1.4., are:

- To state the modern perspectives on epilepsy.
- To investigate the social world of the child with epilepsy in rural South Africa.
- To explore the intra-psychic structure of the child with epilepsy.

- To investigate the impact of the life-world of the child with epilepsy on academic tasks.

#### **4.4. The research method**

##### **4.4.1. Qualitative research**

Qualitative methods of research emphasize that the meaning of a social action or a word, depends on the context in which it is used (Neuman 1997:331). These methods include observation of participants and conducting interviews in which the use of open-ended questions is encouraged. The focus is mainly on naturalistic inquiry and inductive analysis (Ryan et al 2001: 135).

The use of a qualitative method of research in this study will enable the researcher to understand the learners' conceptions of their behaviour in relation to their condition. This implies that the researcher attempts to understand the world of the learner with epilepsy from the learner's frame of reference. Halfpenny (in Neuman 1997:328) writes the following about qualitative research methods:

“They concern such matters as the...relativity of actors' accounts of their social worlds, and the relation between sociological descriptions and actors' conceptions of their actions”. Ryan et al (1997:135) assert that qualitative reports usually make use of quotes and descriptions and take the form of case portrayals.

#### **4.4.2. The case study**

Mathye (2000: 95) defines a case study as “a comprehensive investigation of the specific person, existing institutions or concrete entities”. When such an investigation is conducted, data is gathered regarding among other segments of knowledge, the biographical aspects, the environmental aspects and the psychological aspects that might assist in explaining that particular unit of study.

In this study, the researcher used a case study with the aim of exploring the life patterns, thoughts and statements of learners with epilepsy in a mainstream schooling system in rural South Africa. Neuman (1997:133) maintains that this type of an investigation is done in a holistic way. This means that the whole context of the unit of study is considered. As Mathye (2000: 95) asserts, research done through case studies emphasize aspects which are distinguishable and unique in that particular situation or event, therefore, findings are of significant contextual importance. The study takes into consideration all the factors which are involved in explaining such patterns and looks at the relationships among these factors.

Wallen and Fraenkel (1991: 290-291) say the following about a case study:

“The intent is to find out as much as possible about the characteristics, actions, ideas, and other attributes of a single individual or group”.

#### **4.4.3. The research technique**

The focus group interview technique was implemented with the aim of generating empirical data for this study. Focus group sessions are discussions which are usually held with people who share similar problems, beliefs, attitudes, opinions and even behaviour. The focus group is therefore, homogeneous in a certain way. This helps the participants to express their feelings and opinions freely, knowing that the other members of the group also have “something similar”, unlike talking to a researcher on an individual basis. Salend (1999: 47) maintains that this type of interview helps to foster the identification and discussion of issues, insights and recommendations which might not be revealed during individual interviews. Krueger (in Hunt 2000: 308) asserts that the focus group helps people to listen to themselves and receive feedback from other participants.

Folsch-Lyon and Trost (1981:443) believe that focus group sessions help in addressing questions of how and why people behave the way they do. In order to obtain such information, the researcher should in a sense probe into the participant’s sub-conscious by means of inference, since the person’s actual motivations and feelings are below the threshold of consciousness. Basch (in Kingry et al 1990:124) also supports the assertion that these sessions help in exploring the participant’s intra-psyche structure. He defines the focus group interview as “a qualitative approach to learning about the population subgroups with respect to conscious, semi-conscious and unconscious psychological and sociological characteristics and processes”. Kreuger (in Lewis 1995:2) suggests that the purpose of focus group sessions is “to obtain information of a qualitative nature from a predetermined and limited number of people”.

Most focus groups consist of approximately six to twelve people. According to Merton et al (in Lewis 1995: 3), there are two considerations which govern the size of the group:

- It should not be too large to the extent that it becomes cumbersome to adequate participation by most members.
- It should also not be so small that it fails to cover most of the aspects that the research is intended to cover. The coverage should significantly differ from an interview with one individual.

Depending on the topic of the research, several groups (three to four groups) should be convened for one study. One group is never enough to obtain sufficient data (Morgan in Lewis 1995: 3).

#### **4.4.4. The participants**

Prior to the focus group sessions, the researcher had telephonic discussions with the principals of the three primary schools which participated in the study. The schools are: Banana, Gavaza and Sebone. A letter of consent was sent to the parents of the learners concerned. Dates and venues were then arranged and the participants were invited.

The focus group interviews took place in the following sequence: Group A was a learner group which included eleven learners with epilepsy. This session was conducted in two languages namely: Xitsonga and Sepedi. Group B was a parent group in which participants were eleven parents of the learners who were involved in focus group A. The two languages mentioned above were also used during this session. Group C was a teacher group which included six

teachers of the learners with epilepsy from the three schools mentioned above. The medium of communication was supposed to be English, however, they indicated that they would also like to use mother-tongue, the discussion therefore, took place in the following three languages: English, Xitsonga and Sepedi. Group D was a peer group which included twelve classmates of the learners with epilepsy who are involved in this study.

#### **4.4.5. The structure and procedure of the focus group sessions**

The researcher welcomed the participants and indicated that all of them should feel free to express their views. In order to eliminate the problem of some participants' conforming to others' responses, the researcher clarified the purpose of the discussion. The researcher explained that the main aim was not to reach agreement but to determine how each one of them felt and what they thought about epilepsy in relation to themselves, their children, their learners or their classmates. Salend (1999:47) emphasizes the importance of making everything clear to the participants in this aspect. He says that the researcher should "inform focus group participants that the goal of the session is not to achieve consensus and that it is appropriate and necessary for them to form and express their own opinions and viewpoints". The participants were assured that they would remain anonymous and that the views and the experiences they related would be regarded as confidential. It was also mentioned that there were no right or wrong statements because their thoughts and experiences were unique to them. The use of the audio-tape was also explained and permission to tape the interviews was obtained.

The ground rules, as explained by Rees and Bath (2000: 238-239), were discussed. They included the following:

- Only one person should speak at a time.
- There is no particular order in which they should speak.
- They should state their viewpoints without negatively commenting on the opinions and experiences of other group members.
- Interruptions are not allowed, however, the researcher might interrupt and re-direct the conversation.

The participants were given a non-threatening environment in which they were encouraged to discuss freely, all issues which they felt were important to them. They were also asked to introduce themselves and tell the group where they came from. They were then asked open-ended questions in relation to the topic. Participants in Focus Group A were asked to discuss how they experience their epilepsy. Groups B, C, and D were asked to discuss their experiences of living or learning with, or teaching children with epilepsy. They were all asked what they thought and how they felt about the condition, and also to explain why they felt the way they did. The discussions were only interrupted and redirected when the researcher realized that the participants had diverted from the subject of inquiry. All four sessions were audio-taped and fully transcribed.

#### **4.5. Limitations**

Many participants in this study could not speak English well. As a result of this, the focus group sessions were conducted in mother-tongue. As has been stated, they speak two different languages namely, Xitsonga and Sepedi. The two tribes fortunately live together in the villages involved in this study, therefore they could understand each other, but preferred to speak in their own languages in order to express themselves more clearly. The researcher can speak both languages fluently.

There are direct translations in some words and phrases which might be grammatically incorrect in English. The word heart for example, is used interchangeably with the words mind and soul.

The other problem was the generation gap among the parents. During the session, the older parents wanted to act as counsellors and advisers to the younger parents. This is common practice in rural black communities. The researcher redirected the discussion back to the subject of inquiry.

#### **4.6. Conclusion**

This chapter gave an account of the research methodology which was used in this study. The focus group interview technique appears to be very effective in trying to understand social phenomena. The next chapter will give the qualitative analysis and interpretation of the data obtained from the focus group sessions.

## **CHAPTER 5**

### **FINDINGS, CONCLUSION AND RECOMMENDATIONS**

#### **5.1. Introduction**

This chapter aims at presenting findings from the empirical study and to provide recommendations on how to address the needs of learners living with epilepsy. The experiences of the participants in the four focus group sessions will be conveyed. The findings will be divided into three sections for each focus group: firstly, participants' characteristics, secondly, a qualitative enrichment of the findings by means of quotations that illustrate their experiences and finally, main themes which emerged from the focus group discussions. Names of participants and schools have been changed to protect their identity.

#### **5.2. Findings**

##### **5.2.1. Focus Group A – Learners with epilepsy**

###### **5.2.1.1. Participant characteristics**

Eleven learners with epilepsy participated in the study. They range from six years to fifteen years of age. There were five girls and six boys and two of the girls are sisters. All were Black and came from Xitsonga- and Sepedi- speaking families. The majority of them had at least one

epileptic seizure while they were at school. During the session, participants tended to stay superficial and to copy one another. This could be a sign of their lack of confidence. The six-year old remained silent throughout the discussion, even when her sister was crying. The researcher's colleague who has a vast experience in teaching learners with special educational needs also participated in this focus group, as in focus groups B and C.

#### **5.2.1.2. Quotations (see Appendix I which has more detail)**

What now follows are quotations from the focus group interviews with the epileptic learners. In brackets in italics is a brief psychological description of what it implies. This method will be followed in the discussions of all the groups.

- ◆ "...At school, when I want to raise up my hand to give an answer, my heart starts beating fast and I don't raise it." (*low self-esteem; anxiety*)
- ◆ "A certain teacher...often tells me about it and it hurts me." (*name-calling; humiliation*)
- ◆ "They accuse us of stealing ball pens." (*labelling; scape goating; blaming by peers*)
- ◆ "They say: 'This one who falls down often, scares us'." (*name calling; social isolation; feared by peers*)
- ◆ "They say: 'It's that thing that falls often'." (*humiliation*)
- ◆ "They always gossip about me". (*suspicion from peers; social isolation*)
- ◆ "I want it to be cured. It blocks my mind." (*longing for normality; feelings of cognitive incompetence*)

### **5.2.1.3. Main themes that emerged**

The themes mentioned here are taken from the interview and are wider than the quotations given in section 5.2.1.2. This method will also be followed concerning the other groups.

- ❖ Most of the respondents experience other physical problems as well.
- ❖ They often experience anxiety.
- ❖ They have a low self-esteem.
- ❖ Their lives are characterized by fear.
- ❖ They are feared by peers.
- ❖ They withdraw in the classroom situation.
- ❖ They experience some teachers as unkind to them.
- ❖ They are blamed by peers and are made scape goats.
- ❖ They are labeled and referred to as “the one with a sickness of falling”.
- ❖ They are ostracised and humiliated by teachers and peers.
- ❖ An absence is not regarded as epilepsy.
- ❖ Most of them would like to be medical practitioners when they grow up.
- ❖ They wish that their epilepsy could be cured because it disturbs their academic and social functioning.

### **5.2.2. Focus Group B – Parents**

### 5.2.2.1. Participant characteristics

Eleven parents of learners with epilepsy participated in the focus group. They range from twenty eight years to sixty years of age. There were ten females and one male. Most of the female parents are single mothers. The participants come from two tribes viz: the Vatsonga and the Bapedi tribes. They expected to find answers to their poverty after attending this session. The African values of respect for elders were reflected during the session. The two young mothers stopped crying immediately after they were told by older parents that it is taboo to cry for a child when he/she is sick. In the Black communities of the Limpopo Province, it is believed that if a parent cries when his or her child is sick, the child will become a moron after the sickness has been cured and remain like that forever. Throughout the session, the younger mothers were more emotional when talking about their children. This was the longest of the four sessions.

### 5.2.2.2. Quotations ( see Appendix II for more detail)

- ◆ “It hurts so much...” (*grief and pain*)
- ◆ “Two kids! It hurts me...” (*grief and pain*)
- ◆ “My wife can’t even go closer to him because I am afraid that she will cry and that will damage my child, you see.” (*superstition; beliefs prevent showing emotion and supporting the child emotionally*)
- ◆ “Even now as I am talking about it, I feel numb...I wish God could feel pity for us.” (*feelings of destitution*)
- ◆ “It’s just that prayer sometimes is able to make me strong.” (*finds solace in religion*)

- ◆ “He doesn’t want to be angered...he likes fighting.” (*sees the child as aggressive; the child exhibits faulty impulse control*)
- ◆ “I ask you to please plead with the school principal, to discuss with the teachers so that they should be able to see them as people like others.” (*experience teachers as unsympathetic; feels desperate*)
- ◆ “This disease should have attacked somebody else. I am poor.” (*sees it as punishment*)

### **5.2.2.3. Main themes that emerged**

The parents’ experiences can be grouped in the following themes:

- ❖ They experience grief and pain.
- ❖ Their superstitious beliefs prevent them from showing emotion - therefore their children lack emotional support.
- ❖ They often experience feelings of helplessness.
- ❖ Their children experience other medical conditions as well.
- ❖ They do not regard an absence as epilepsy.
- ❖ They perceive children with epilepsy as emotionally different from other children, and therefore, they need to be handled with care.
- ❖ They believe that it is taboo for parents to cry for their children when they are ill.
- ❖ They experience teachers as unsympathetic to their children.
- ❖ They believe that malnourishment contributes to lack of control of the seizures.
- ❖ They find solace in religion.

### 5.2.3. Focus Group C – Teachers

#### 5.2.3.1. Participant characteristics

Six teachers of learners with epilepsy participated in the focus group. Three were males and three were females. They ranged from thirty to fifty one years of age. One of the female teachers had epilepsy during her childhood. They also come from the two language groups, Xitsonga and Sepedi.

#### 5.2.3.2. Quotations (see Appendix III for more detail)

- ◆ “You find that the process of teaching in that particular classroom is disturbed”. (*perceives the seizures as disruptive*)
- ◆ “It is difficult to teach someone like that.” (*feels inadequate; stressed in the teaching situation*)
- ◆ “Dealing with these kind of learners means long-term suffering.” (*experience teaching children with epilepsy as a burden*)
- ◆ “They act as if they are attacked when they don’t want to write...and when they don’t understand that class work.” (*sees children as using epilepsy as an excuse; lack of sympathy; ignorance on the part of the teacher*)
- ◆ “Some of them beat others and others (learners with epilepsy) steal other learners’ properties, and all those kinds of things.” (*perceives them as aggressive and dishonest*)

- ◆ “Some of them are really bully.” (*perceives them as aggressive*)
- ◆ “They seek too much attention.” (*experiences them as attention seeking and manipulative*)
- ◆ “They are ignorant, as my friend has already said.” (*negative attitude; sees these learners as inadequate*)
- ◆ “He is so mean that one can say bad things about him.” (*aggression towards a learner with epilepsy*)
- ◆ “It’s the question of concentration. Yes, it is one of the problems.” (*a more realistic view*)
- ◆ “Parents are not co-operative.” (*experiences insufficient parental support*)
- ◆ “It also seems as if some families do not care.” (*experiences insufficient support from families*)
- ◆ “You find that their (the parents’) approach is bad even in front of that learner, listening to them trying to protect him.” (*perceives parents as being overprotective; feels that more demands (behaviorally and academically) can be made of these children*)
- ◆ “Some parents do contribute to the situation, to make the situation worse.” (*believes that some parents are to blame for these learners’ behaviour and attitude*)
- ◆ “The majority of these learners are from poor families.” (*links the high frequency of seizures to malnourishment*)
- ◆ “I don’t know if you have something in mind, to help these type of families because you find that they really do not have food at home.” (*high frequency of seizures is linked to malnourishment*)
- ◆ “I have no skills...I know nothing about the disease...I don’t know how to help him.” (*feelings of uncertainty, ignorance and helplessness*)

### **5.2.3.3. Main themes that emerged**

- ❖ Seizures disturb school activities.
- ❖ They experience fear and feelings of sadness when a learner is having a seizure.
- ❖ They often feel uncertain and helpless.
- ❖ They perceive learners with epilepsy as ignorant, stubborn, bullying and disrespectful.
- ❖ They believe that these learners sometimes use their condition to avoid academic tasks and to manipulate people around them.
- ❖ The main problem that they experience in the classroom is that these learners often don't concentrate.
- ❖ They believe that parents contribute to their children's unacceptable behaviour by spoiling them at home.
- ❖ They regard malnourishment as one of the contributing factors to the high frequency of seizures.
- ❖ They need skills which will enable them to deal with learners with epilepsy in an appropriate way.

### **5.2.4. Focus Group D – Peers**

#### **5.2.4.1. Participant characteristics**

Twelve classmates of learners with epilepsy participated in this focus group. They range from ten years to thirteen years of age. There were six girls and six boys. They also come from the two

language groups mentioned above. Some of these learners also live with their peers with epilepsy in their communities therefore, they also revealed their experiences with them at home.

#### **5.2.4.2. Quotations (see Appendix IV for more detail)**

- ◆ “I feel pain in my heart when he falls down.” (*empathy*)
- ◆ “I am scared of them.” (*fear*)
- ◆ “To be honest with you, he is cheeky.” (*interpersonal problems*)
- ◆ “He is a difficult person.” (*interpersonal problems*)
- ◆ “Some boys just hit him back.” (*counter-aggression; interpersonal problems*)
- ◆ “Mam Shisana’s work is difficult for her, but Mam Rivisi’s work is better because she talks to her nicely...Mam Shisana beats her.” (*aggression from the teacher*)
- ◆ “It is possible that Golden has been possessed by those who are underground because his grandmother had this disease.” (*superstition; spirit possession*)
- ◆ “He once provoked a certain old man who was riding on a bicycle. That old man was a wizard.” (*superstition; witchcraft*)
- ◆ “My wish is that they should help them at the clinic so that they can be like us.” (*pity; sympathy*)

#### **5.2.4.3. Main themes that emerged**

- ❖ They experience ambivalent feelings towards learners with epilepsy. They feel pity for them but also experience them as aggressive and dishonest.

- ❖ They are afraid of them.
- ❖ They describe learners with epilepsy as ignorant, difficult, stubborn and cheeky.
- ❖ They attribute the high frequency of seizures to ignoring medication. This could be a sign of poor management by parents.
- ❖ They believe that their peers with epilepsy underachieve because some teachers lack empathy. This could be a sign of ignorance on the part of the teachers.
- ❖ They attribute epilepsy to spirit possession and witchcraft. This could be a reflection of the beliefs of their communities.
- ❖ They do not regard an absence as epilepsy. This is a sign of lack of knowledge and ignorance regarding epilepsy.
- ❖ They have sympathy for their peers.

### **5.3. Conclusion**

Black rural communities of the Limpopo Province are not well-informed about epilepsy and how to handle people who are living with it. It became apparent in this study that communication between parents and teachers is not good. This study also made it evident that learners with epilepsy were just placed in mainstream schools without any further steps taken to ensure that teachers, parents and peers are equipped with relevant skills of dealing with these learners. In a nutshell, the needs of learners with epilepsy are not well catered for in mainstream schools.

#### **5.4. Recommendations**

On the basis of the findings of this study, the following recommendations are relevant:

- Community-based projects should be initiated with the aim of educating Black rural communities on epilepsy.
- Measures should be taken to ensure that mainstream schools keep constant contact with other professionals such as psychiatrists, neurologists, psychologists, social workers and educators in special schools. A team approach is thus advocated.
- Workshops should be held often in which particular problems related to learners with epilepsy which educators encounter can be addressed.
- In-service training of educators should be done to ensure that they are well-equipped to educate learners with Special Educational Needs (LSEN), including learners with epilepsy.
- Learners in mainstream schools should be motivated to be actively involved in projects which aim at educating the community on children with special needs, including epilepsy. This will promote empathy, respect and tolerance for their peers.
- Co-operative learning based on the principles of Outcomes Based Education (OBE) should be encouraged. Involving learners with epilepsy in group discussions and projects (facilitated

by a knowledgeable and sympathetic teacher) will help in building their self-esteem and eventually, in developing their social skills.

- Schools should be advised to organize health information weeks in which learners are encouraged to bring topics for discussions. Professionals from relevant fields should be invited to facilitate the discussions. This will help to eliminate myths and prejudices relating to various medical conditions.
  
- The attitude of the school staff (the principal and teachers) influence that of the learners. It is therefore, extremely important that they be well-informed and that they know how to accommodate children with epilepsy. They will then serve as role models for the learners.
  
- Epilepsy is a medical condition. The school community (staff and learners) therefore, need information about the causes, how to manage it and issues surrounding prognosis.

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