EXPERIENCES OF PEOPLE LIVING WITH EPILEPSY PRESENTING FOR TREATMENT AT UMLAZI CLINIC

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Declaration

This is to certify that the work is entirely my own and not of any other person, unless explicitly acknowledged (including citation of published and unpublished sources). The work has not previously been submitted in any form to the Durban University of Technology or to any other institution for assessment or for any other purpose.

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Abstract

Introduction

Epilepsy is one of the world’s most common neurological disorders of the brain. It is a condition that affects individuals in most countries worldwide. However, there is still stigma attached to epilepsy, and the condition is often misunderstood. However, there are people who understand the condition and the care that PWE need.

Aim of the study

The aim of the study was to describe the lived experiences of people with epilepsy.

Methodology

A descriptive phenomenological methodology was used. This study is guided by Parse’s Theory of Human Becoming. In-depth interviews were conducted with eight participants. The main research question that was asked in this study was: What are experiences of people living with epilepsy?

Results

The findings of this study revealed that people with epilepsy still face challenges unique to their lifestyles. The lack of knowledge among communities has led to negative experiences of people with epilepsy. Family members often provide support to people with epilepsy; especially female partners support their husbands.

Dedication

I dedicate this dissertation to my family and people with epilepsy.

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Glossary of Terms

Epilepsy: Epilepsy is a chronic disorder characterized by recurring seizures of unknown course (Walsh 2007:741).

People with epilepsy: People with epilepsy are people who have been diagnosed as having epilepsy and taking anti- epileptic drugs.

Primary Health Care: The essential care based on practical, scientifically sound and socially acceptable methods and technology, made universally accessible to individuals and families in the community through their full participation and at a cost that the community can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination (Dennill, King and Swanepoel 1999: 2).

Registered nurse: A person registered with the South African Nursing Council (SANC) as a nurse under Article 16 of *Nursing Act, No 33 of 2005,* as amended (Republic of South Africa 2005). The terms ‘registered nurse’ and ‘professional nurse’ are used interchangeably.

Seizure: Paroxysmal transient disturbance of the brain resulting from a discharge of abnormal electrical activity (Smeltzer et al. 2008: 2161).

South African Nursing Council: The body entrusted to set and maintain standards of nursing education and practice in the Republic of South Africa. It is an autonomous, financially independent, statutory body, initially established by the Nursing Act, No. 45 of 1944, and currently by the Nursing Act, No. 50 of 1978 as amended to the Nursing Act No. 33 of 2005 (Republic of South Africa 2005).

List of Acronyms

Acronym	**Full term**
AIDS	Acquired immune deficiency syndrome
AEDs	Anti-epileptic drugs
CHC	Community Health Centre
DoH	Department of Health
HIV	Human immunodeficiency virus
ILAE	International League Against Epilepsy
KZN	KwaZulu-Natal
PHC	Primary Health Care
PWE	People with epilepsy
WHO	World Health Organisation

CHAPTER 1

OVERVIEW OF THE STUDY

1.1 INTRODUCTION

Epilepsy is a chronic disorder of the brain that affects people in every country of the world (WHO 2012:1). It is classified as a neurological disorder of the brain (Suljic 2010: 77). Epilepsy can affect anyone at any age but most commonly develops before the age of 20 (Epilepsy South Africa 2008). Common causes of epilepsy especially in South Africa are likely to include infectious diseases, such as Human immune virus (HIV) Acquired immune deficiency syndrome (AIDS), nuerocysticercosis and trauma (Eastman 2005:9). Other causes of epilepsy may include trauma, infective collections or space occupying lesions, chemically induced changes, for example metabolic change or secondary to alcohol or recreational drugs, or idiopathic, where the cause is unknown (Cumisky 2009: 42). People with Epilepsy (PWE) express anxiety and embarrassment and perceive themselves as being different and inferior (Walsh 2007:741). Walsh (2007: 741) further states that this is because PWE feel that they are constantly under threat of experiencing a seizure. PWE also depend on daily medication to reduce the likelihood of/or prevent future seizures. Epilepsy has many non-medical effects on PWE, their family and community and they also have to cope with psychological and social consequences which have an impact on the person, their, education, and employment, their family and social relationships, on women, and on their quality of life (Hills 2007: 10).

1.2 BACKGROUND

Global population with active epilepsy is at least 45 million (Forsgren 2008: 22) and World Health Organization (WHO) has estimated the number at 50 million (WHO 2012:1). Of this estimation, WHO (2001) indicates that about

10 million PWE reside in Africa. According to Shibre et al. (2006: 170), about 1:100 people have epilepsy worldwide. The population prevalence of epilepsy varies across countries from 0.5 to 5%. Shibre et al. further state that higher levels tend to be seen in developing countries where less than 50% of cases receive medication. Hung (2009: 15) states that despite the fact that seizures may only last for a few seconds, it has many psychosocial repercussions for PWE and their family members. Due to a lack of understanding PWE feel stigmatised by their family and friends (WHO 2012:1). Some people mistakenly believe that epilepsy is a form of mental illness or mental retardation and that seizures are something to fear, that drastic first aid measures must be taken to help someone having a seizure, or that PWE cannot be valuable and productive employees (Suljic 2010: 80). The classification of mental illness includes the following conditions: mental retardation/ mental deficiency, delirium, dementia, schizophrenia, affective disorders, anxiety states, hysteria, phobias, obsessive compulsive neuroses, hypochondria, depressive personality, anti-social personality, socio-pathic personality, drug addictions and psychosomatic illness (De Haan, Dennill and Vasuthevan 2005). Therefore, epilepsy is not classified as mental illness (WHO 2012:1). This lack of community understanding fosters a sense of fear, misunderstanding and even discrimination in the community.

1.3 PROBLEM STATEMENT

PWE will conceal their epilepsy due to the fear of being stigmatized and discriminated against (Hung 2009: 15). Communities still do not have enough knowledge on how to live with PWE. Research studies conducted in South Africa after 2006 have not focused on experiences of PWE but on other aspects of epilepsy, for example, effectiveness of treatment. Therefore, this study seeks to describe people’s experiences of epilepsy in order to increase an understanding of epilepsy and the psychosocial impact it has on their lifestyles.

1.4 AIM OF THE STUDY

The aim of this study was to describe the lived experiences of PWE.

1.5 RESEARCH QUESTION

The research question for this study was:

- What are the experiences of people with epilepsy?

1.6 THEORETICAL FOUNDATIONS OF THE STUDY

The study was based on Parse's Theory of Human Becoming (Parse 1981). This formed a foundation from which to inform health care providers of their role in exploring the lives of people living with epilepsy. Parse's theory also formed basis from which health care providers could reflect on their own emotional responses from participation in the study.

According to Parse, the goal of practice with the Human Becoming Theory is that the person is the only one who can describe his/her quality of life. The basic factors that determine people's quality of life include a healthy and clean environment, good socio-economic conditions that promote good psychological and physical well-being of the individual. The theory focuses mainly on the lived experiences of the individual who can be considered as inseparable, unpredictable and ever changing because they make choices freely choosing meanings from the situations they perceive of their environment. The main themes underlying the theory are structured with the concept of language, valuing and imaging (Parse, 1981).

The community can assume that they understand what PWE feel about the condition but according to Parse's Theory, only PWE can describe their lived experiences. PWE can also have different experiences due to their environment and socio-economic conditions.

1.7 SIGNIFICANCE OF THE STUDY

The findings of this study will increase an understanding of epilepsy and the psychosocial impact that it has on PWE. Health care professionals will gain a better understanding of epilepsy, and the experiences that PWE face every day. This will assist in their psychological care (Parahoo 2006: 75). Communities where there are PWE will understand their experiences and accept them as part of the community.

1.8 STRUCTURE OF THE DISSERTATION

Chapter 1: Introduction

This chapter presents the background, problem statement aim of the study, research question, theoretical foundation and the significance of the study.

Chapter 2: Literature Review

In chapter two a detailed review of the types of epilepsy, impact of epilepsy, globalisation trends, extent of epilepsy in sub- Saharan Africa and South Africa.

Chapter 3: Methodology

Chapter three examines the philosophical underpinning of a phenomenological study, the rationale for using the phenomenological method for enquiry and analysis, study setting, study population, sampling process, data collection, conceptual framework, pilot study, data analysis, trustworthiness and ethical consideration.

Chapter 4: Presentation of the results

The results are presented in this chapter, excerpts to support the themes identified and the demographic data.

The five themes were

1. Experience of being diagnosed with epilepsy
2. Psychological experiences
3. Physical burden
4. Relationship burden
5. Support

Chapter 5: Discussion of the results

Discussion of the results, conclusion, recommendations and limitations of the study.

1.9 CONCLUSION

This chapter explored the background of experiences of PWE and their experiences. This chapter has highlighted the problem statement and explained the purpose of the study, theoretical foundation and significance of the study. In the following section, literature pertaining to people living with epilepsy will be discussed in detail thus contextualizing the study.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

PWE have different experiences that are determined by their age, gender, community and level of education. Their experiences may include psychological and social aspects. Wilson (2011: 16) found in her study of psychosocial outcomes of newly-diagnosed epilepsy patients that people react differently to the diagnosis of epilepsy. Wilson (2011:31) studied two groups of people who had been newly diagnosed with epilepsy and found that they experienced their diagnosis differently. The first group described a pervasive sense of loss of control, characterized by increased vulnerability and mortality, grappling with why the seizure occurred, a fear of seizure recurrence and lowered mood, and sense of loss of physical control. They also described their experience as traumatic and major life changing experience. The second group reported a more limited psychological reaction with a few features of loss of control. McQueen and Swartz (1995: 859) conducted a study in a rural South African village, it was revealed that most of PWE in that village accepted their epilepsy diagnosis and learnt to cope with it. However, some of the villagers felt stigmatized by their epileptic experiences and made various attempts to conceal it from outsiders. Problems which they experienced in this village were: fear of going out unaccompanied, forgetfulness and irritable mood as few of them had well controlled epilepsy (McQueen and Swartz 1995: 859).

According to the World Health Organization (WHO) (2005: 10) and International League Against Epilepsy (ILAE), an individual’s experience of epilepsy is not simply a direct result of the medical severity of the seizures, but also related to its social meaning and reality. Although in some countries PWE are protected by law, they are also subjected to legal discrimination, especially with regard to employment and driving

(Poochikian-Sarkissian et al. 2007:23). PWE are seen as somehow morally responsible for their condition and that family members are partly responsible for instilling a sense of guilt and shame into those with the disorder (WHO 2005:10).

2.2. TYPES OF EPILEPSY

According the WHO (2012: 1), epilepsy is the most common serious brain disorder worldwide with no age, racial, social class, neither national nor geographic boundaries. It is characterized by recurrent seizures. Epilepsy with a known cause is called secondary or symptomatic epilepsy (WHO 2012). It is commonly classified according to the areas involved that are partial and generalised varieties (Cumisky 2009: 42). In general seizures a person will lose consciousness whereas in partial seizures consciousness may be retained. The most common type of epilepsy is called idiopathic epilepsy, where there is no identifiable cause. It can usually be an underlying genetic basis (WHO 2012: 4).

2.3. IMPACT OF EPILEPSY

Friedman (2001: 225) states that epilepsy usually starts at childhood. Childhood epilepsy negatively affects educational achievement and regardless of the age of onset, it has an impact on the persons' eventual employment level. PWE experience various stressors that compromise the quality of life. These include unpredictable and uncontrolled seizures with or without loss of awareness, medication side effects, cognitive changes, reduced physical strength and memory, vocational problems, economic strains, inability to drive, dependency on medications or caregivers. Some people living with epilepsy report a significant personal impact of experiencing unpredictable seizures in terms of reduced social opportunities and leisure activities, limitations on activities and ambitions, family dysfunction, memory changes, increased anxiety and depression, and reduced personal control and self-esteem (Poochikian-Sarkissian et al. 2007: 20-23). PWE are believed to have a high risk of incurring accidental injury than those without a seizure (Wirrel 2006: 79). These injuries may include submersion injury, burns, fractures, head injuries, soft-tissue injuries, dental injuries and motor vehicle accidents. Wirrel (2006: 84) further states that these injuries can be sustained at home, street, work, school, or during sports, but the most common place of injury is at home.

PWE have to take anti-epileptic drugs (AEDs) to control their seizures. AEDs have a greater potential for cognitive and behavioural toxicity. This can be related to the dose given to an individual. Other AEDs can cause decline in concentration, memory, mental speed and intelligence (Kwan and Brodie 2001: 218). There have been reported cases of infants with birth defects in women who use AEDs (Friedman 2001: 226).

2.4 GLOBALISATION TRENDS

A study conducted in Hong Kong, China showed a negative attitude towards epilepsy (Fong and Hung 2002:311). Such misunderstandings, myths, negative attitudes or misbehaviour were significantly less in respondents with better education and younger ages (Fong and Hung 2002: 311). These authors further stated that PWE are regarded as being possessed by evil spirits. Even with the great advances in understanding epileptic disorders, the stigma attached to the term “epilepsy”, in some instances, has demonstrated to be a greater disability to PWE than that of the condition itself. Yang et al. (2011: 4) conducted a study on stigma of PWE in China which revealed that due to stigma associated with epilepsy, people have a negative attitude towards epilepsy. These people describe epilepsy as a ‘horrible’ condition which one has to take medication for the rest of his or her life and the condition is not curable. These authors states that other PWE conceal the condition due to the need to secure schooling, employment and equal marriage rights, as well as to reduce disparity in social life. Participants from rural areas tend to be more often concerned about the marriage prospects of PWE and so more often supported the concealment of epilepsy of younger people, whereas those from urban areas who approve concealment were more concerned about privacy rights of those with epilepsy, and also worried about the potential psychological harm of concealment (Yang et al. 2011:5). Jacoby and Austin (2007) state that stigma has three different levels which are internalized, interpersonal and institutional. In order to tackle stigma effectively, it should be addressed at all three different levels in which it operates. Poochikian-Sarkissian et al. (2008: 129-145) examined the impact of illness intrusiveness in epilepsy, the disruption of lifestyles and activities attributable to constraints imposed by chronic disease and its treatment. This study revealed that freedom of seizures whether achieved by surgical or pharmacological treatments was associated with maximal reduction of illness intrusiveness and improved quality of life. Poochikian-Sarkissian et al. further described illness intrusiveness as an important determinant of psychosocial impact and treatment of epilepsy.

A study conducted in Brazil by Fernandes, de Barros and Li (2009: 1280), among high school students, to evaluate the impact on attitude and perceived stigma of using different terms for referring to persons with epilepsy among teenagers showed that using the word ‘epileptic’ instead of PWE enforces stigma on an individual . This is further supported by the findings of the study that was conducted by Erichsen et al. (2009: 304) on young people living with epilepsy which revealed that PWE also experience psycho-social impacts due to epilepsy. About 50% of the participants reported that epilepsy made them feel useless and more dependent on others; 39% felt they were a burden to their families and friends; and 40% experienced a moderate or high degree of stigmatization. Some of these young people had difficulty in finding employment or permanent employment; some were even given disability grants (Erichsen et al.

2009:1280). Other young PWE developed behavioural problems, and many experienced considerable mal-adjustment at school. (Erichsen et al. 2009: 1280). So, this study seeks to describe the experiences of PWE so as to increase understanding of epilepsy and psychosocial impact this condition has on PWE.

2.5. EXTENT OF EPILEPSY IN SUB-SAHARAN AFRICA

Other factors that affect the management of seizures, which result in PWE narrating different experiences, like the use of traditional medicines (Chomba et al. 2010). A research study conducted in Zambia by Onwuekwe et al. (2009: 786) revealed that in Sub-Saharan Africa, epilepsy associated stigma is due to lack of access to anti-epileptic drugs (AEDs) and traditional belief systems which may worsen the burden of disease and stigma among PWE. Onwuekwe et al. (2009: 786) further explain that a problem may arise because PWE access care through traditional healers rather than the formal medical system. In other African countries like Nigeria, epilepsy remains a significant cause of morbidity and mortality. In a study conducted in Khayelitsha Township in South Africa, parents of children with epilepsy were of the opinion that epilepsy was triggered by bewitchment, fear, upset or evil spirits (Eastman, 2005: 10). This is further supported by a study conducted in 253 black second year South African university students who believed in different causes of epilepsy. They associated epilepsy with witchcraft or evil spirits, contagious disease (Peltzer, 2001: 64). The findings of this study concur with the results of the study that was conducted in Tanzania in which the participants associated epilepsy with non-medical causes such as demonic power, witchcraft and sickness from the ‘gods’ (Mushi et al. 2011: 340). The findings further revealed that these participants believed that someone can become epileptic if a chameleon breathes into his or her nose or it can be family misdeeds and failure to observe traditional practices or ancestral laws such as rituals.

The factors that determine the quality of life of PWE is the duration of time since being diagnosed with epilepsy and whether their seizures are fully controlled (Schachter 2005: 1). Stigma has been shown to have a negative effect on seizure control and the quality of life of PWE, with people often choosing to withdraw socially to cope with discrimination and stigma (Paschala et al. 2007: 2). PWE often encounter stigma, as well as societal restrictions and discrimination in the course of everyday activities, such as going to school, driving, working, and obtaining insurance (Paschala et al. 2007: 2). Social effects may vary from country to country. The discrimination and social stigma that surround epilepsy worldwide are often more difficult to overcome than the seizures themselves and PWE could be targets of prejudice. The stigma of the disorder could discourage people from seeking treatment for symptoms and being identified with disorder (Epilepsy: Social and Economic Impact 2009: 999). Epilepsy is generally poorly recognized and treated by general health services because of the social stigma it holds. Studies indicate that neither PWE nor the general public are very knowledgeable about epilepsy (Paschala et al. 2007: 2). Paschala et al. further state that limited public understanding of epilepsy has been found to contribute to stigma by breeding negative attitudes toward epilepsy itself and to PWE. Oswald (2007: 1) found that in Zambia, PWE are less likely to get employment marry or receive a proper education due to the stigma related to the disease. Stigma resulting from the public’s low expectations of PWE in the workplace has been reported frequently. Hollaway (2006: 22) suggests that lack of knowledge is one of the aspects of stigma. People with a higher education and are of a higher socio-economic class would have more opportunities to get information about epilepsy. The first aspect observed in these results was the negative correlation between education, social class and stigma in that as people become more knowledgeable about epilepsy, the stigma concerning epilepsy decreases. Mushi et al. (2011) found that PWE in Tanzania described their experiences as that of being stigmatised could not fulfil social functioning, discrimination and marriage and relying on family support. Mushi et al. further state that due to attached stigma, beliefs and inadequate health care delivery systems, relatively few PWE in developing countries use anti-epileptic treatment. Despite availability of effective and relatively cheap anti-epileptic drug treatment, relatively few people in Sub-Saharan countries make use of AEDs. This may be due to inadequate health care delivery systems; such as diagnostic facilities and reliable drug supply to primary health care (PHC) facilities, beliefs about causes and treatment of epilepsy and pervasive stigma which may prevent PWE and their carers from actively or openly seeking treatment (Mushi et al. 2011: 340).

2.6 EPILEPSY IN SOUTH AFRICA

A survey conducted by Foyaca et al. (2005:30) in Ngqwala Location in South Africa found that only 7,6% of PWE were under regular anti-epileptic treatment for three consecutive months. Most of them were under traditional treatment taking herbal remedies with “anti-seizure failure usually when wrong mixtures of plants, wrong selection, preparation and storage are made” (Foyaca et al. 2005: 30). PWE experience withholding of the opportunity to obtain a driving license, barriers to occupy certain occupations (WHO 2012:3). The National Road Act of South Africa makes reference to a person with epilepsy should be disqualified from obtaining a driver licence (Republic of South Africa 1996). The majority of African people seek care from traditional healers. Keikelame et al. (2012:108) thought that collaboration between western and informal traditional health care services is also needed. One of the studies done in South Africa found that some PWE combined western and traditional treatments for the treatment of epilepsy (Keikelame and Swartz 2007: 310), even in countries like China (Bartolini et al. 2011:430). It was found that epilepsy was poorly managed in primary care settings in Cape Town (Keikelame and Swartz 2007: 310).

The WHO has partners that look at the interests of PWE. These partners are; International League Against Epilepsy (ILAE) and Bureau for Epilepsy (IBE) which are carrying out a global campaign to provide better information and raise awareness about epilepsy (WHO 2012: 3). In South Africa there is Epilepsy South Africa which provides information about epilepsy (Epilepsy South Africa 2012).

2.7 CONCLUSION

This chapter presented the literature review on the extent of epilepsy globally, including Sub-Saharan Africa and in South Africa. Although the literature highlights that epilepsy affects people around the world, there are those countries with people that still do not understand epilepsy and treat PWE differently.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter will address methods used in the research design, research setting, sampling process, data collection, data analysis and ethical considerations.

3.2 RESEARCH DESIGN

According to Creswell (2013: 49), a design is a plan for conducting a study. Burns and Grove (2009: 220) state that the purpose of the research design is to achieve a greater control of the variables, thus improving the validity of the study in its examination of the research problem. For this study, a qualitative, descriptive study guided by a phenomenological approach was conducted to describe the experiences of PWE.

3.2.1 Qualitative design

Bowling (2002: 435) defines qualitative research as social research carried out in the field or natural setting and analysed largely in non-statistical ways. Qualitative researchers often collect data in the field at the site where participants experience the problem under study (Creswell 2013: 45).Hennink, Hutter and Bailey (2011: 9) argue that qualitative researchers study people in their natural settings, to identify how their experiences and behaviour are shaped by the context of their lives, such as the social, economic, cultural or physical context in which they live.

The strength of qualitative research lies in the people being studied in their natural setting, with in-depth data about the phenomenon under study gathered. It enables the researcher to gain better insight into the subjective feelings of the participants. This means that qualitative researchers study phenomena in their natural settings, attempting to make sense of phenomena in terms of the meanings people bring to them.

3.2.2 Descriptive design

Descriptive design focuses on portrayal of the characteristics of persons, situations or groups (Polit and Beck, 2008: 725). The purpose of qualitative research is to provide a detailed account of the phenomenon under study in order to understand the meaning of an experience (Burns and Grove 2007: 201). Descriptive research provides an in-depth description of participants' experiences in a narrative type description. This design was chosen because new meaning might be discovered which would describe that which already existed and would form the basis for the future research. The researcher was thus able to describe the experiences of PWE.

3.2.3 Phenomenological approach

Phenomenology is an approach that explores the understanding of people's everyday life experiences (Polit and Beck 2012: 267). The purpose of the phenomenological approach is to describe what people experience with regard to some phenomena and how they interpret those experiences; or what meaning the experiences hold for them. Phenomenologists focus on describing what all participants have in common as they experience a phenomenon (Creswell 2013: 76). It should help readers "see" something in a different way that enhances their understanding of experiences (Polit and Beck 2012: 495).

3.3 PHILOSOPHICAL UNDERPINNING OF A PHENOMENOLOGICAL STUDY

Phenomenology is rooted in the philosophical traditions of Edmund Husserland he is considered as a father of modern phenomenology (Phillips-Pula et al. 2011:67). His work was further explored by other three phenomenological philosophers namely Heidegger, Sartre and Merleau-Ponty (Maccan 1993: 1). Husserl thought the act of being present in a situation, contains both perception and meaning and that establishing inter-subjectivity with participants prepared a researcher to step into their experiential shoes (Phillips-Pula et al. 2011: 68). Intentionality refers to the inseparable connectedness of human beings to the world. Phenomenology tries to discover meanings that people attach to their everyday world (Polit and Beck (2006: 464). Phenomenological approach is inductive and descriptive and it aims to understand the cognitive subjective perspective of the person who has the experience and the effect that perspective has on the lived experiences (Flood 2010:7).

There are two main types of phenomenological frameworks namely, the descriptive type which is also known as the Husserlian type of phenomenology and the interpretive type, which is also known as the Heideggerian type of phenomenology (Creswell, 2013: 80). Heidegger and Husserl are the two most commonly adhered to phenomenological philosophers in qualitative research although there other philosophers such as Langeveld and Gadamer (Burns and Grove 2009: 54; Creswell 2013: 80). Heidegger and Husserl are acknowledged as the founders of phenomenological approach. The views of the Heidegger and Husserl differ in that Heidegger believes that the person is a self within a body i.e. is embodied. The body provides the possibility for the concrete actions of self in the world. The Hedeggernians believe that the person is situated as a consequence of being shaped by his or her world and thus is constrained in the ability to establish meanings (Burns and Grove 2009: 55).

Descriptive phenomenology describes ordinary conscious experience of everyday life, which includes hearing, seeing, believing, feeling, remembering, deciding, evaluating and acting. Interpretive phenomenology seeks to find out how individuals personal history, such as their education, social class, past events and their psychological make-up influences the ways in which they experience phenomena (Creswell 2013: 80). In other words, interpretive phenomenology is not only a description, but it is also an interpretive process in which the researcher makes an interpretation.

A descriptive phenomenological approach was used for this study which involved a search for the meaning of the experience of the participants and thus provided a foundation from which to build an understanding of what it is like to live with epilepsy. The researcher also contends that using a descriptive approach of phenomenological methodology has the potential to augment and expand what is known about living with epilepsy.

Gibson and Hanes (2003: 186) state that the interviewees and the descriptions of their experiences should be instantly recognizable, expanding and enriching the store of knowledge about the life world. It must be noted, however, that researchers can never totally step out of their own implicit pre-understandings and interpretations of the phenomenon. Therefore, pure description and knowledge, free of the researcher’s own perspective and involvement in the life world, are impossible. Polit and Beck (2006: 220) asserted that humans have intentionality and will see something as something when it presents itself. However, the researcher should acknowledge and consciously set aside or bracket their own pre-understandings and focus on description of the experience from the perspective of the participants in their own voices rather than via interpretation. In this study, this was done by ensuring that the four steps of a descriptive phenomenological study were maintained as follows:

3.3.1 Bracketing

Bracketing is the process of identifying and holding pre-conceived beliefs and opinions about the phenomenon under study (Polit and Beck 2006: 220). The researchers set aside their experiences as much as possible to take a fresh perspective towards the phenomenon under study (Creswell 2013: 78). Creswell further explains that bracketing does not take the researcher completely out of the study, but serves to identify personal experiences with the phenomenon and to partly set them aside so that the researcher can focus on the experiences of the participants in the study. Speziale and Carpenter (2003) describe bracketing as a fundamental methodological principle in phenomenological research and the authors state that researchers must first identify any pre-conceived motions or ideas about the phenomenon under investigation. Speziale and Carpenter (2003) further argue that identification of these ideas will assist the researcher to bracket or separate out of consciousness what the researcher know or believes about the topic under investigation. In this study, the researcher bracketed the knowledge about epilepsy and collected data from eight people who had experienced epilepsy.

3.3.2 Intuiting

Intuiting occurs when the researcher remains open to the meanings attributed to the phenomenon by those who have experienced it (Polit and Beck 2006: 220). In this study, the researcher took into consideration all data provided by the participants, and therefore, the researcher's views were not added.

3.3.3 Analysing

Analysing involves organizing, providing structure and to elicit meaning from data (Polit and Beck 2006: 397). In this study, the researcher analysed the data by reducing the information to significant statements or quotes and combines the statements into themes.

3.3.4 Describing

At this stage, the researcher develops a textural description of the experiences of the persons (what participants experienced), a structural description of their experiences (how they experienced it in terms of the conditions, situations or context), and a combination of the textural and structural descriptions to convey an overall essence of the experience. In this study, the researcher used the literature from other studies to form a foundation from which to describe the experiences of PWE.

3.4 RATIONALE FOR USING PHENOMENOLOGICAL METHOD FOR ENQUIRY AND ANALYSIS

The flexibility of phenomenological research and the adaptability of its methods of inquiry is one of its greatest strengths. A phenomenological analysis does not aim to explain or discover causes. Instead, its goal is to clarify the meanings of phenomena from lived experiences. Phenomenology, when practiced within a human science perspective, can thus result in valuable knowledge about individuals' experiences (Penner and McClemment, 2008: 2). Phenomenology differs from other approaches due to its emphasis on the participants' experienced meaning rather than just on a description of their observed behaviours or actions. This highlights the subjective aspect of human activity by focusing on the meaning rather than the measurement of the social phenomena. The descriptive phenomenological research method used in this study, therefore, attempted to uncover the underlying essences and meanings of experience to arrive at a deeper understanding.

3.5 STUDY SETTING

Descriptive qualitative studies are often conducted in natural settings (Burns and Grove 2007: 352). The study was conducted at Umlazi in eThekwini District. EThekwini District is a metropolitan area. According to the District Health Plan 2007-2008, the total area of this district is only 1, 4% of the total area of the KwaZulu-Natal (KZN) province and it contains over a third of the population of KZN and 60% of its economy activity (KwaZulu-Natal Department of Health 2006). This district has a population of 3 388835 million, which is 33, 9% of the total population of the province's 9 700 000. Only 35% of the municipal area is predominantly urban and the remainder is rural to semi-rural. Primary Health Care (PHC) services in this district are jointly provided by the Provincial Department of Health and the Local Government Authority, with the former contributing 60% and the latter 40%. Provincial facilities within the eThekwini District are distributed as follows: eight Community Health Centres (CHCs) and 47 PHC clinics. On the other hand, the Municipality has 77 PHC clinics and 15 mobile units, with one CHC shared by both authorities. The catchment population ratio per clinic is 1: 22 570 which is above the national norm of 1: 150000.

The participants were the patients who attend Umlazi U21 PHC clinic. This is a public clinic situated at U section at Umlazi. It serves the community from U, Z, Y sections and informal settlements of Malukazi and Tropica. Community members mostly communicate in isiZulu. Most people who attend this clinic are not on a medical scheme. This public clinic provides the following 24-hour free services to patients: chronic illness management, minor ailment treatment, maternity and child health, tuberculosis treatment, voluntary counselling and HIV treatment.

3.6 STUDY POPULATION

According to Polit and Beck (2012: 273), a population is the entire aggregation of cases in which a researcher is interested. In this study the population consisted of PWE who were receiving treatment at Umlazi U21 PHC clinic at eThekwini District in KZN.

3.7 SAMPLING PROCESS

Sampling is a process of selecting cases to represent the entire population so that inferences about the population can be made (Polit and Beck 2012: 275). In this study, a non-probability, convenience sampling was used to select the sample. Patients who come to the clinic on monthly basis to collect their treatment for epilepsy were informed about the study and those who wished to participate identified themselves by leaving details with the nurse attending them. An estimated number of +-120 PWE collect treatment from this clinic. Two participants were selected for the pilot study and six for actual study.

Inclusion criterion

- Patients who have been diagnosed with epilepsy and have been on treatment for epilepsy for a period of two years.
- Patients who collect their monthly anti-epileptic treatment at Umlazi U21 PHC clinic.
- Patients must be 21 years of age and above.

Exclusion criterion

- Patients that have been on treatment for less than two years.
- Patients with any form of physical disability, mental illnesses or mental retardation, as these can make a person experience the phenomena in a different way due to these other conditions.

3.7.1 Sample Size

The number of participants in a qualitative study is adequate only when saturation of information is achieved in the study area (Burns and Grove 2007: 348).Data saturation is when themes and categories in the data become repetitive and redundant, such that no new information can be gleaned by further data collection (Polit and Beck 2012: 62). When additional sampling provides no new information, only repetition of the previous information, the researcher will know that data saturation has been achieved. In this study data collection continued until data saturation was reached. Kumar (2005: 165) describes the sample size as the number of students, families or electors from whom the researcher obtains the required information. In this study the actual size of participants was eight participants.

3.8 DATA COLLECTION

To gain a full understanding of the lived experiences of PWE, several qualitative data gathering methods were employed. They included in-depth interviews, field notes and a self-reflexive journal. Parahoo (2006: 65) states that a primary tool for collecting data in phenomenological studies is the interview, during which the researcher seeks to gain insight into how respondents make sense of their experiences. In-depth interviews were conducted so to enable the researcher to have full access to the PWE experiences as they live their lives. The in-depth interviews were conducted with the use of an interview guide containing a demographic section as well as a central question to focus on the discussion. Kumar (2005: 124) defines in-depth interviewing as repeated face to face encounters between the researcher and participants which are directed towards their understanding of their experiences, or situations which are expressed in their own words.

In qualitative research, the researcher usually conducts face-to-face interviews with participants (Polit and Beck 2012: 537). Data was collected by the researcher using semi-structured interviews where a list of questions to ask each participant had previously been prepared (Appendix 5a and 5b). All participants did not fully understand English, so all interviews were conducted in IsiZulu. Participants were encouraged to talk freely about their feelings and experiences in relation to the questions and to tell their stories (Polit and Beck 2012: 537). Follow-ups probes were used to get more information. Probing is eliciting more detailed information from a participant in subsequent interviews to what was volunteered in the first interview (Polit and Beck 2012: 762). The researcher took notes during each interview and an audiotape was also used so that all information was collected. Length of interview was approximately 45 minutes and limited to one interview per day. An appointment was made with one of the participant's, as per her request, to be interviewed her at their home. For all other interviews, a consultation room at the clinic was used for conducting interviews.

The main question that was asked: 'What are your experiences in living with epilepsy?' In order to probe the participants for further discussion, the following questions were used as a guide:

- Does epilepsy limit you in doing anything?
- Does epilepsy change the way people treat you?
- How do you feel that you have epilepsy?
- Any other question will be asked based on the responses of the participant to the above questions

In order to detect personal bias due to my own beliefs and values, possible role conflict, a reflexive journal was used to document my observations during the interviews. Literature sourced was checked in order to support the findings of the study. Transcripts were reanalysed for the second time to get to unbiased results (Polit and Beck, 2012:496). This was done to achieve reflexivity, which is the process of reflecting critically on the self and of analysing and making note of personal values that could affect data collection and interpretation (Polit and Beck, 2012: 179). Before the interviews were conducted, the participants were given information about the study (Appendices 4a and 4b). The participants were free to express their views regarding their experiences of living with epilepsy. The use of an interview guide enabled the researcher to focus on the necessary issues but did not require the questions to be asked in the same sequence for each of the interviews. Participants' permission was obtained to audio-tape interviews. Interview sessions varied according to participants. The majority of participants were interviewed up to 30 minutes. Only one participant took more than 45 minutes. Except for the one participant, interviews were conducted after the participants had seen a doctor or received their treatment. Questions and thoughts that occurred while the interviewee was speaking were written by the researcher so as not to interrupt the flow of the interview.

3.9 CONCEPTUAL FRAMEWORK THAT GUIDED THIS STUDY

Meleis (2012: 28) describes theoretical framework as a basic structure developed to organize a number of concepts that are focused on a particular set of questions. Frameworks are developed to provide direction for research projects. A framework is a conceptual underpinning of a study (Polit and Beck, 2012: 728).

This study was guided by a conceptual framework by Parse, called Theory of Human Becoming in Nursing Practice. This theory focuses on the unity of lived experiences of unitary humans and the meanings and patterns of relating that create a person's unique processes of human becoming (Alligood and Tomey, 2006: 432). Phenomenologists usually ask this broad question 'What is the meaning of one's lived experience?' It is then described using Parse’s method which is described as follows: Being a person is self-interpreting; therefore, the only reliable source of information to answer that question is the person (Burns and Grove 1999: 341). This theory focuses on lived experiences of people, their meanings, and their participation in promoting their health. .

Three theoretical structures of Parse’s Theory of Human Becoming was implemented as described by Parse (1981: 71):

1. Powering is a way of revealing and concealing imaging. Nurse family situation in which members share their thoughts and feelings about a situation. This can include revealing and concealing of struggles that PWE go through to meet personal goals. Disclosing can change meaning of life in the person and family members. PWE will be able to reveal what their experiences are in living with epilepsy, which can further assist them to change their meaning of life or how they look at things. Some will hide other truths, but the researcher will not force them to reveal it. Alligood and Tomey (2006: 445) mentions that a person will discover something new, something explicitly not known before. This can facilitate decision making.

2. Originating is about human uniqueness and the ways persons create their own becoming as they choose from all the possible that could be. It is the unique choices people make when facing alternatives, and the consequences of those choices (Alligood and Tomey, 2006:441).
3. Transforming is a process of deliberately shifting one’s pattern of health. The shift may be a choice to change one’s attitude about a certain situation or the shift may be the change in how one live day-to-day routines or habits (Alligood and Tomey2006: 441).

3.10 PILOT STUDY

Polit and Beck (2012: 195) define a pilot study as a small scale version or trial run designed to test the methods to be used in larger, more rigorous study. A pilot study was conducted with two PWE and these participants did not form part of the main study. It was done so as to assess whether the research question was realistic and workable, to identify logistical problems which might occur using proposed methods and to develop a research question and research plan. The results of the pilot study showed that the interviewing skills of the researcher and the data analysis approach were acceptable. No changes were made after the pilot study. The pilot turned out to be a reassuring experience for the researcher.

3.11 DATA ANALYSIS

Giorgi's model of data analysis was used as a guideline to identify themes regarding experiences of PWE (Polit and Beck 2012: 566). Giorgi's four steps for data analysis were used. The aim of data analysis in this study was to identify commonalities and differences in the individual experiences of all participants. The goal was to keep the richness of the experience that each participant had as they live with epilepsy, whilst exploring the descriptive meanings of such experiences, through identification of essential themes (Polit and Beck 2012: 566).

The first step in using Giorgi's method in this research was to read and re-read the entire set of participants 'experiences in order to familiarize oneself and get a sense of the whole picture of the phenomena under discussion. This method helped the researcher to understand the meaning of the experience from the participants' viewpoints and not in terms of the researcher's theory about the topic under study. Notes of similar information were themed to achieve a sense of each person's experiences.

The second step involved reading each successive transcript thoroughly and breaking each down into distinct meaning units. Meaning units consisted of words, phrases, sentences or passages and were then coded by the researcher to ensure accuracy and completeness. After the whole description of the phenomena that was being studied had been broken down and divided into meaningful units, the researcher then reflected on these units in the context of the whole experience or phenomena under study. This was done so that the true essence and meaning of the experiences of PWE would not be lost during the data analysis process.

The third step using Giorgi's analytical method was to transform participants' words into scientific terms (Polit and Beck 2012: 566). This was done by re-describing the meaning units into psychological language and this was accomplished by searching for essential or dominating meanings in each unit. The researcher then related each meaning unit to the topic under study. This again was done so that the meaning of the participants' experience was not changed, but at the same time unimportant meanings in the participants' experience or situation were discarded.

The final step was to involve the synthesis of the transformed meaning units into an overall description of living with epilepsy. This the researcher did by consistently describing this phenomena and adding a psycho-analytical to the obtained data. The researcher then attempted a general analysis by focusing on the essential aspects and characteristics of the phenomena under study. By proving descriptions and then analyzing these meaning units, the researcher was able to draw individual and subjective meanings of all participants, relating to their experiences of living with epilepsy.

3.12 TRUSTWORTHINESS

As qualitative research has an element of subjectivity, and is open to criticism (Polit and Beck 2012: 174), it is important that the study and the findings provide evidence of validity and reliability. Lincoln and Guba (1985: 289) argue that there is an alternative to validity and reliability that would provide the evidence for a decision trail and suggested the term trustworthiness. Trustworthiness refers to the extent to which a research study is worth paying attention to, worth taking note of and the extent to which others are convinced that the findings are to be trusted (Babbie and Mouton, 2001: 276). Lincoln and Guba (1985: 289) suggested four criteria for developing the trustworthiness of a qualitative inquiry namely credibility, dependability, confirmability and transferability. To ensure trustworthiness in this study, the following criteria were used.

3.12.1 Credibility

Credibility refers to confidence in the truth of data and interpretations of them (Polit and Beck 2012: 175).To ensure credibility in this study, notes were written during the interview. Information was probed during interviews until data was saturated and detailed notes were written immediately after the interview. Voice recordings were also done. To establish confidence in the truth of the findings, during report writing voice recordings were replayed repeatedly to ensure that all the information was transcribed. The researcher bracketed existing knowledge, pre-conceived ideas and personal views regarding the existing problems in the clinical area.

3.12.2 Dependability

Dependability refers to the stability or reliability of data over time and conditions (Polit and Beck 2012: 585).Dependability is reliant on credibility (Polit and Beck 2012: 585). The audit involves a close scrutiny of the data collected by an external reviewer, in this case the supervisor. Although the researcher coded the interviews herself, the data and analysis were checked for discrepancies and scrutinised by the research supervisor who acted as an independent coder.

3.12.3 Confirmability

According to Lincoln and Guba (1985: 320-321), confirmability refers to the degree to which the researcher can demonstrate neutrality of the research interpretations. In qualitative research, confirmability focuses on the characteristics of the data gathered in the study and by utilising an audit trail. The themes and sub-themes identified by the researcher were contrasted with those identified by the supervisor. No major discrepancies were identified between the analyses of data.

3.12.4 Transferability

Transferability is the extent to which findings can be transferred to or have applicability in other settings or groups (Lincoln and Guba 1985: 321). To ensure transferability, there was a rich and thorough description of the research setting, study participants and of the research processes.

3.13 ETHICAL CONSIDERATIONS

Any qualitative study, like all the forms of research, is subject to Codes of Ethics and good practice for the protection of the participants (Polit and Beck 2012: 152). Ethical codes are based upon a few generally accepted moral values of respect for individual beneficence, respect for human dignity and justice. To ensure ethical consideration, these three broad principles on which standards of ethical conduct research are based were used (Polit and Beck 2012: 152).

3.13.1 Beneficence

Beneficence imposes a duty on a researcher to minimise harm and maximise benefits. It is the researcher's duty to avoid, prevent, or minimize unnecessary harm in studies with humans (Polit and Beck (2012:152). These authors further states that participants have a right to be protected from exploitation and should be assured that their participation or information they might provide will not be used against them.

The right to freedom from harm and discomfort was maintained as participants were not subjected to any risk of harm or injury. Before the study was conducted, it was first approved by the Institutional Research Ethics Committee of the Durban University of Technology (Appendix 1) and permission was sought and received from the KZN Department of Health (Appendices 2a and 2b) and eThekwini District (Appendices 3a and 3b). The information letter explaining what the study was about was provided to the participants before commencement of the study and the participants signed a consent form (Appendix 4a and 4b). The information was given in a language which participants understood. Where participants had questions, answers were provided. During the interview, the researcher ensured privacy by conducting the interview in a closed consultation room where other patients could not overhear the participants' narratives.

3.13.2 Respect for human dignity

Respect for human dignity includes the right to self-determination and to full disclosure (Polit and Beck, 2012: 154). The nature of the study was fully described; right to refuse participation and researcher's responsibilities to the participants were articulated to the participants (Appendices 4a and 4b). Prospective participants were informed that participation was voluntary, that they had the right to decide to participate in the study as well as to withdraw from it at any time without risking any prejudicial judgement.

Following the full disclosure of information regarding the study, participants were asked to voluntarily sign a written consent form to participate in the study. The researcher witnessed the signing and countersigned as witness.

3.13.3 Justice

Polit and Beck (2012: 155) states that justice involves participant's right to fair treatment and their right to privacy where participant selection has to be based on study requirements and not on a group's vulnerability. Selection of potential participants was open and fair without any discrimination. PWE who declined to participate in the study were not treated in a prejudicial manner. To ensure the right to privacy, participants' details were not written in the reports. All data provided by the participants were kept in strictest confidence.

3.14 CONCLUSION

This chapter described how the study was carried out and how data was collected. The sample chosen was appropriate for the data to be collected as it targeted people who live with epilepsy. A qualitative research methodology was implemented.

CHAPTER 4

PRESENTATION OF THE RESULTS

4.1 INTRODUCTION

The findings of the study will be presented in this chapter. The study was done through in-depth interviews with the participants. The sample was comprised of eight people with epilepsy, five females and three males. This study was guided by Parse's Human Becoming Theory which states that the quality of life from a person's perspective cannot be determined by those not living the life. It further states that the person is the only one who can describe his/her quality of life. Results presented in this section are from the interviews of PWE describing their own experiences. The main research question was "What are the experiences of people with epilepsy?

The researcher spent one week listening to tapes to familiarise herself with the data recorded before data transcription began. The researcher used different colours of highlighters to indicate codes and highlighted concepts and attributes that were similar. The researcher coded every script in order to develop a comprehensive framework for analysis. The comprehensive framework was then used for more detailed coding and thematic content analysis using manual methods. The researcher analysed all the transcripts. Five themes were identified.

4.2 DEMOGRAPHIC DATA OF THE PARTICIPANTS

The sample in the study comprised of eight participants. The participants' demographic information is illustrated in Table 4.1:

Table 4.1: Demographic data of the study participants

Criterion	Characteristics	Frequency	Percentage
Gender	Female	5	62,5%
	Male	3	37.5%
Age	21-25	1	12,5%
	26-30	0	0%
	31 and above	7	87,5%
Marital status	Never married	4	50%
	Married	2	25%
	Widowed	1	0%
	Separated	1	12,5%
Occupation	Student	0	0%
	Employed (part-time)	1	12,5%
	Unemployed	7	87,5%
Living with	Alone	0	0%
	Parents	0	0%
	Guardian	0	0%
	Siblings	1	12,5%
	Family	7	87,5%

A total of eight participants were interviewed. Each participant was asked questions as outlined in the interview schedule (See Appendix A) and also using probes in between the questions. Of the eight participants interviewed, five were females and three were males. Each participant was asked the following demographic data before the interview: age, home language, and when they were diagnosed with epilepsy. Of the eight participants, two were married, one separated, one widowed and four single. Most of them were living with their family members, who are children or siblings. Amongst the single ones, two were living with partners. The majority of the participants (87,5%) were unemployed, only one participant was employed because the employer is a medical doctor and therefore has a greater understanding of epilepsy. One participant received a grant which had been stopped. He reported that he was experiencing difficulty with the processing of the grant. Only one had a high school education, others only did lower primary and left school because of epilepsy or other family problems. The majority of the participants became unemployed after an episode of seizures was witnessed by the employer.

4.3 IDENTIFIED THEMES

After analysing data the following five themes were identified:

Theme 1: Experience of being diagnosed with epilepsy

Theme 2: Psychological experiences

Theme 3: Physical burden

Theme 4: Relationship burden

Theme 5: Support

These five themes and their sub-themes are presented in Table 4.1.

Table 4.2: Overview of the themes and the sub-themes

THEMES AND SUB-THEMES	
Theme 1	**Experiences of being diagnosed with epilepsy**
Sub-theme 1.1	Denial versus acceptance
Sub-theme 1.2	Barriers to disclosure
Sub-theme 1.3	Perceptions and misconception about epilepsy
Theme 2	**Psychological experiences**
Sub-theme 2.1	Fear of epilepsy
Sub-theme 2.2	Stigma
Sub-theme 2.3	Memory decline
Sub-theme 2.4	Low self-esteem
Sub-theme 2.5	Suicidal ideas
Theme 3	**Physical burden**
Sub-theme 3.1	Unemployment
Sub-theme 3.2	Self-care deficit
Sub-theme 3.3	Compliance with treatment
Theme 4	**Relationship burden**
Sub-theme 4.1	Relationship with a partner
Sub-theme 4.2	Rejection by the community
Sub-theme 4.3	No sense of belonging
Sub-theme 4.4	Work related experiences
Theme 5	**Support**
Sub-theme 5.1	Family support
Sub-theme 5.2	Support by medical professionals

The results of this study are presented along the themes and sub-themes that were derived from the analysis of interviews. Five themes that emerged out of this study are presented in Table 4.1. Applicable direct quotes are provided to substantiate relevant results.

4.3.1 Experiences of being diagnosed with epilepsy

4.3.1.1 Denial versus acceptance

The participants that had been diagnosed with epilepsy for many years reported that they had accepted epilepsy as part of their lives. Participants commented that they do not have a choice but to accept epilepsy. This was expressed as follows:

….“I would say I have accepted it as part of my life. I take it as permanent part of my life to live with epilepsy” **(Participant 7).**

…“It is really sad. There is nothing I can do, because as much as I take these tablets, epilepsy still starts. These tablets do not make epilepsy go away. Looking at the years I have been using this treatment but it does not get finished. Now it has become permanent part of my life”
(Participant 3).

However, it was worth noting that one participant that was diagnosed with epilepsy two years ago was still at the denial stage. The excerpt below confirms this:

…“It will take long for me to accept the fact that I now live with epilepsy. There are always changes because I have realised that I will never have good things as I have epilepsy. I can’t even travel long distances because I can fall at any time and anyhow. If I could fall on the way, who can help me? If I could go to town and fall who can help me there? I am not feeling well about this sickness. It will take long for me to understand this sickness. It is difficult to accept that this sickness has become permanent part of my life” **(Participant 6).**

4.3.1.2 Barriers to disclosure

The majority of the participants reported that they found it difficult to disclose that they had epilepsy due to the fear of stigma that is associated with epilepsy. One of the participants did not see the importance of neighbours knowing about her having epilepsy. During the interview, she reported that people who know about her epilepsy are the ones who may have seen her in the clinic where she collects treatment and this is reflected on the excerpt below:

> *…"In other words it is good that people do not know that I have epilepsy because they would think I am mentally ill. Only few people are aware of my condition…..and they discovered accidentally when we meet here at the clinic"* **(Participant 8)**.

However, one of the participants reported that it was important for him to disclose his illness because the community members would be able to assist him during a seizure and this is noted in the excerpt below:

> *..."I told myself that I had to disclose my sickness, then, it will depend on them as to how they will treat me. I did that so that when this sickness starts during the day when there is no one at home, then the community will be able to help me"* **(Participant 2)**.

4.3.1.3 Perceptions and misconceptions about epilepsy

The participants expressed different views on their understanding of epilepsy hence different perceptions of the condition. Their different perceptions influence their decision in the manner in which they managed episodes of epilepsy. One participant reported that she believed that epilepsy is caused by witchcraft; hence she was consulting with a traditional healer occasionally for traditional medicine. One participant reported that she believed that if she did the rituals for ancestors she would stay seizure free. This is how they describe their feelings:

> *....“The other traditional healer gave me the key to use, which I think helps me. I did not put it today as I was rushing, I forgot it. But if it wants to start, nothing will prevent it, it starts. Even on the road it would start. It would feel like there are people, who are calling me, it would start”* **(Participant 4)**.

> *......“When it was exam time, I would have a headache, eye problem. They were saying it was because of witchcraft. My family was very ignorant as they thought it was witchcraft. It is only now that I have discovered that I have epilepsy”* **(Participant 4)**.

> *......“My family did their rituals for ancestors. I noticed that after they did what diviners told them to do it became better as a result it does not attack me regularly”* **(Participant 7)**.

4.3.2 Psychological experiences

4.3.2.1 Fear of epilepsy

The majority of participants reported that they experience anxiety. They fear that seizure might come at any time because one cannot know the time when the seizure will occur. Sometimes there is fear that there might be no one who understands the condition or who can help them during a seizure. Participants also reported that they feel ashamed that sometimes they wet or soil their clothes during a seizure and fear that they might injure themselves. This was expressed as follows:

......"This sickness does not announce when it comes. Especially when you are annoyed it won't announce" **(Participant 8)**.

....."This thing affects me a lot psychologically. May be this is one of the reasons why this sickness attacks me regularly because I am stressed" **(Participant *2*)**.

4.3.2.2 Stigma

All the participants reported that they felt stigmatised due to epilepsy. They reported that they were called names by the community members. Their views are considered invalid as they have epilepsy. This is how they explain that:

....."At times when I try to speak to them they would say 'I don't speak to a person who has such a thing', you see such a thing? Hey! What can I do about you? What can I do with a person who faints? They say we are fainting. Others would say, 'You as you have fits'. They say all those sad things" **(Participant 2)**.

...."When you have epilepsy people will take you as if you are small-minded. Even if you could have a good suggestion you would not say it because they ignore you. They won't take your good ideas" **(Participant 8)**.

4.3.2.3 Memory decline

The majority of the participants also reported that sometimes their memory declined after a seizure. People who witnessed the episode when they had seizures thought that they had mental illness. This is how they described that situation:

*...“It is not that we choose tablets; when this sickness starts you even lose your mind” (***Participant 3)**.

…“When my mind returns, I will have to explain to them as to what is going on. I will have to explain that it is not happening for the first time” **(Participant 3)**.

....“When you speak to me, it will be like you talking afar, and I will forget that I am talking to someone. When I remember I will answer you. What I have noticed is that sometimes I lose my mind. They tell me that I give wrong answers. When we are having fun, they will say “Hey sister you are really sick because when you are asked something else you will give the irrelevant one”. When I ask, ‘what did I say?’ The person would say I asked that and you answered the other” **(Participant 4)**.

4.3.2.4 Low self-esteem

During a seizure it was a common experience among the participants of this study to pass urine and stools. When a person wets or soils him or herself, it is considered a shame and therefore, participants ended up with low self-esteem especially when it happened in front of other people. This is supported by the following statements:

...“They were always laughing because when you fall you also pee unconsciously. That thing saddens me. I stopped working because I realised that I could not carry on with that problem. But now my life is no longer the same as before” **(Participant 6)**.

...“There are always changes because I have realised that I will never have good things as I have epilepsy” **(Participant 6)**.

....“You will pee maybe do number two when you sick. You will feel ashamed because you know that people saw something. Maybe others felt like puking. That affects me” **(Participant 8)**.

4.3.2.5 Suicidal ideas

One of the participants reported that non-acceptance made her contemplate committing suicide. She further reported that her family members were not supportive. Her mother had a problem with her epilepsy. This is how she describes her experience:

…“I feel bad. I tried to commit suicide by drinking paraffin, but I did not die as they took me to the doctor. I also took the rope to hang myself, I was caught and they gave me hiding. I have tried so many things because even my mother by the time she was still alive she was irritated by the fact that I am always sick” **(Participant 4)**.

4.3.3 Physical burden

4.3.3.1 Unemployment

The findings of this study revealed that the majority of the participants were unemployed. Only one participant was employed on a part-time basis as her seizures occurred without warning. This participant’s employer is a medical doctor who understands epilepsy and it is this knowledge that PWE are still capable employees may be the reason she is in employment. The participants reported that they were unable to find jobs due to the fact that they were living with epilepsy:

....“I have noticed one difference. It is that epilepsy made me lose my job. As I am now jobless, I applied for social grant and obtained it. As time went by it was stopped. Now I have children that need to be fed and they are still schooling. At school I haven’t paid the school fees and there isn’t anyone who is working at home. Their mother does washings at other people’s homes. I can never be able to raise my kids properly with the money she gets from washing. It was much better by the time I was still employed. It was better by the time I left my job because I got my pension. Although that pension was not enough but it was not the same as the situation I am in now. This thing affects me a lot psychologically. May be this is one of the reasons why this sickness attacks me regularly because I am stressed” **(Participant 3)**.

....“I do piece jobs like painting for people. Sometimes I go with the boys who do plastering and I will mix concrete for them. When we mix cement they consider my condition they will ask me to step aside especially when the sun gets too hot. Maybe I will force issues and continue to work. That is how I earn some money to take care of myself” **(Participant 6)**.

4.3.3.2 Self-care deficit

The results of this study revealed that participants have to rely on other people to assist them. They are able to take care of themselves like bathing but there is always a need for someone to look after them as a seizure may occur anytime during activities of daily living like bathing or cooking. This study revealed that PWE will always be dependent on others. This is how they describe it:

.... “They prefer to do things for me. When I go to fetch water from the tap, this woman who is my landlady is always watching over me. Other tenants will pretend as if they are playing with kids, yet they are checking on me, if I don’t fall in the tub when I do washing” **(Participant 4)**.

....“They do allow me and then they will monitor my movements as it starts at any time. They don’t want me to come near fireplace or making fire, things like those. I am not allowed to boil water. I am always thinking that it may start at any given time, then, I avoid dangerous things. I avoid touching such things” **(Participant 1)**.

4.3.3.3 Compliance with treatment

The majority of participants were taking the treatment as it was explained at the clinic. One participant was taking treatment immediately after a seizure which she thinks makes her feel better. A few of the participants believe one should use more than the treatment they get in the clinic to control seizures. Treatment had side effects like feeling sleepy after taking it, which was one of the reasons they could not work. These are some of their views:

.....“I like working. First of all, when I am at work I drink the tablets in the morning. After I have taken them they make me feel tired. As I came here I did not take them, because I wanted to get the strength of being able to go back home. I was walking as I came here, you see? So tablets make me tired after drinking them it feels like I need to rest for some time, thereafter, I will start working. Let us say I took the tablets at 7am, I need about 30 minutes to relax before I could continue working. When it is time for me to take them I can’t work anymore. I will have to take them. Now at work I had a problem as I needed time to take them, and relax” **(Participant 2)**.

....“I started taking this treatment at the age of eight as today I am 51. These tablets are of great help there is no problem” **(Participant 8)**.

....“When I started taking western tablets and my family began to find out what is it that is wrong? They did their rituals for ancestors. I noticed that after they did what diviners told them to do it became better as a result it does not attack me regularly” **(Participant 7)**.

....“At times I work without any problem. When I get home it will start. When they give me tablets it will get better” **(Participant 5)**.

4.3.4 Relationship burden

4.3.4.1 Relationship with a partner

This study revealed that some partners will support each other irrespective of the one having epilepsy. Divorce was the result of one partner not disclosing that she had epilepsy. This is how they describe their relationship:

....“No, not yet married, but seemingly it could be a problem. It can be a problem because when I get married I will have to stay with my husband, you see. As I will have to stay with my husband that could be a serious problem as this things starts at any given time. My husband can never be able to look after me. I explained and told my lover.” “I told him early. He said he will be able to take care of me. I told him that I will have to get a person who can take care of me and do my washing, someone who will do things for me. He said he can pay for that person because he loves me” **(Participant 1)**.

....“In fact I stay with the mother of my children. Oh shame she really understands, because even if it starts at night she will try by all means to make sure that I don’t get injured. She is the person whom I spend most of

my time with because I only go home when there are special occasions" **(Participant 2)**.

...."If I don't work what would my children eat as their father left us after he saw that I have epilepsy. I ended up divorcing my husband. Then, I decided to stay with my children" (**Participant 8)**.

4.3.4.2 Rejection by the community

The participants reported that community members react differently towards a person living with epilepsy. They further stated that even though the community members are scared of a person who has an epileptic attack, some are helpful. They even call for help from those who are knowledgeable about the condition. The participants reported that community members assist them as other family members do not offer any support. One of the participants reported that the taxi fare to the hospital was paid for by a community member. Some community members would accompany them to hospital or clinic to collect treatment. Community members can have both positive and negative attitudes towards PWE as reflected below:

...."Hey! You know the community members will look at you as if they are looking at something not known. But they just get shocked as to what is happening. Others will move away being frightened as they see me fall. They wouldn't know what is happening. The other one would say "catch her, there she falls!" They just get confused not knowing what is it that is attacking me" **(Participant 1)**.

...."They treat me like a normal person, although there are "those". But those who are closer to me, especially my neighbours treat me well. At times when I try to speak to them they would say "I don't speak to a person

who has such a thing", you see such a thing? Hey! What can I do about you? What can I do with a person who faints? They say we are fainting. Others would say, "You as you have fits". They say all those sad things" **(Participant 2)**.

...."When you have epilepsy the community sees you as a mad person they don't take you serious. No matter how good your idea could be they won't take you serious" **(Participant 8)**.

....."They are okay they like me a lot. Community members understand my condition I wouldn't speak for all of them. When I am around the community members I feel good. The problem is at home. The community does not have a problem. I have never heard anyone making fun of it. They would say, "How are you now because yesterday you were sick". "Yesterday we had to take you home how is you now?" Then, I would say I am fine. The way they are good they even give me money to go to hospital for my consultation" **(Participant 6)**.

4.3.4.3 No sense of belonging

The findings of this study revealed that there is a feeling of not belonging anywhere. Family members and community were not supportive to a person with epilepsy. These participants felt that they do not belong to their families.

...."I have tried so many things because even my mother by the time she was still alive she was irritated by the fact that I am always sick. She would say, "Since this child was born she is always sick". My mother was a drunkard, she would say I am a nuisance as I am always sick, why don't I die. That is how my siblings started to despise me. She would say this thing "since her childhood she is sick, she does not die nor get healed".

Can you imagine your own mother saying that? I felt discriminated against" **(Participant 4)**.

...."Let us say you are meeting as a family because there is a family gathering then, they will treat you in a bad manner. It makes you stay away from your family always. You have to stay away from them because they are fine they don't have a problem. No matter you can come with a good thing they would say it came with you so it should be put aside as if it is also sick" **(Participant 8)**.

4.3.4.4 Work-related experience

The findings revealed that at work participants were discriminated. They ended up losing their jobs because they could not perform under certain conditions, like using machinery which may have been dangerous to them. If they are given special consideration by the employer, the other employees will complain. They were even teased at work by their colleagues. They ended applying for social grant which was not enough to support their families. This is how they described their experiences:

...."It affects me because at work I don't get the salary, which is equal to other people. When this sickness has started I will stay at home for the whole week. My salary will be cut. But I appreciate that there is something that I am getting because I am a mother with children. I am begging that I should get something to take care of my family. What they give me I am thankful of but sometimes I stay at home for the whole month without going to work" **(Participant 8)**.

…"They treat me well because the boss called them and explained to them that I have this sickness. I asked him to explain to them everything. He asked them to treat me like a family member. He told them

that I have epilepsy I take treatment so they should not shout at me. When they want me to do something they should tell me properly. If I failed to do that thing the way I was expected they should tell me how it was supposed to be done without screaming" **(Participant 8)**.

...."They were treating me well. The boss was good and other males. The problem was with females. They used to laugh and they can talk. You will hear from grapevine that somebody said this yesterday. When I heard that I will try to recall whom did I speak to about this? I once spoke to the boss about the way they ill-treat me at work. He said there is nothing they can do about it. Once you have this sickness you just have it. As you are temporary it is difficult because if you were permanent we were going to give the medical border. But it is up to you. I told him that I have to stop working because of the treatment I get from other employees. He used to call them trying to resolve the problem. He also feared that he was going to cause conflict between employees. I decided to avoid noise by choosing to go and stay at home" **(Participant 6)**.

4.3.5 Support

4.3.5.1 Family support

This study revealed that family members react differently towards PWE. Participants reported that some of the families will have positive attitudes and support whilst other will be negative. They were treated differently to other family members and feel isolated from the family. Family members that are educated on epilepsy provided support to participants. Others were assisted by relatives like aunts because close family members are not supportive. These are quotes from participants with family members that are supportive:

…"No shame, I don't want to lie they treat me like one of the family members. They give me good treatment, they see me as a family member they help me if necessary they don't have a problem. Even if I am not at home maybe I am with my relatives, my relatives don't treat me badly or discriminate against me. My relatives treat me like their own family member, not just a relative. Neighbours do have a problem and my family would say we can't abandon our child" **(Participant 1)**.

…"Hey! They are the ones who treat me exactly like my own family. I remember there was a time where I got sick for the whole month my mother-in-law had to come and stay with us to see what is it that is really happening. I must say they don't have a problem" **(Participant 2)**.

...."At home, they accepted that I now live with this sickness" **(Participant 3)**.

...."At home they treat me very well because where I stay, I stay with my children" **(Participant 5)**.

...."*My children are always by my side. Since they heard that I have this sickness they are always watchful of me"* **(Participant 7)**.

Other family members were not supportive to participants. This is how they described their experiences:

...."At times, I get to be assisted by unrelated people when I am away from home, can you imagine" (**Participant 1).**

...."My family is not supportive. They don't even come. Even when I go to the hospital they don't visit me. A week before last, I was in hospital because of asthma, they did not come. They phoned them, they were

even phoned by the other tenant I live with, till today they did not come. They will only hear when I phone them, may be they will phone back. That will be it. They will be told that I am have recovered, they will never come to confirm" **(Participant 4)**.

...."At home they don't treat me well. They are the main cause of this sickness to attack me regularly. For example, when speak to a child the child would say you are going to fall. When I speak to another person, they would say don't make him angry his fits will start. When I am at home I am always tense. I only feel relaxed when I am away from home with other people. It is not right that they will always say I am falling. It is me who has a right of telling people that I have epilepsy I am not ashamed of it. If they go around telling people about my condition it is not good" **(Participant 6)**.

..."Can you imagine these things happening because you are persecuted by your own family? Let me put aside the extended family. Your child would do anyhow knowing very well that you are sick when you tell that child he would care less" **(Participant 8)**.

4.3.5.2 Support by health professionals

In this study it was revealed that health professionals do support PWE. One of the participants was referred by the clinic to attend a health education session about epilepsy at the hospital. The following statements made by participants confirm this:

..."The clinic is my home [showing joy]. They give excellent treatment. The Sister- in-charge takes good care of me" **(Participant 6)**.

....“At times the doctor takes me to the hospital. He also assists me with money for transport fare” **(Participant 6)**.

...“I can’t remember the year they called us at the hospital to teach us about this sickness, they explained well” **(Participant 3)**.

4.4 CONCLUSION

In this chapter, the researcher analysed the information derived from the interviews with the selected participants so that certain themes could be identified. Table 4.1 provides a summary of themes and sub-themes. The five themes that emerged from the interviews were: experience of being diagnosed with epilepsy, psychological experiences, physical burden, relationship burden and support. Chapter 5 will elaborate further by discussing these findings.

CHAPTER 5

DISCUSSION OF THE RESULTS

5.1 INTRODUTION

The discussion of the results is guided by the research question described in the first chapter and Parse's Theory of Human Becoming as well as by the themes that emerged from the analysis of the interviews.

5.2 OVERVIEW OF THE RESEARCH DISCUSSIONS

The aim of this study was to describe experiences of PWE. In this study, five major themes were identified, namely:

Theme 1: Experience of being diagnosed

Theme 2: Psychological experiences

Theme 3: Physical burden

Theme 4: Relationship burden

Theme 5: Support

These themes and their sub-themes are interpreted below and validated using relevant literature and the Parse Theory of Human Becoming to support the interpretation of the findings.

5.2.1 Experience of being diagnosed with epilepsy

Parse's Theory of Human Becoming describes health as follows: "Health cannot be given or taken, controlled or manipulated, judged, or diagnosed. Health is the way persons live their values in ways consistent with their desires, hopes, and dreams. Patterns of health are paradoxical and include times of disappointment as well as times of success, and times of joy as well as times of sorrow" (Alligood and Tomey 2006: 437). Having epilepsy changes one's health but as they live with it, they are at the forefront for narrating their experiences. Disappointments are common in PWE as a seizure may come anytime and destruct whatever has been planned. After being diagnosed there is a series of stages PWE experience after diagnosis, which family members have to understand and accept that it can take up to two to three years for the person to come to terms with their illness. These are fear, denial, frustration, anger, devastation, grief and inability to cope (Gilliland 2001:87). Participants in this study have clearly shown these stages especially those who had epilepsy for less than three years. They have not accepted it although some of participants had accepted it as part of their lives. Epilepsy has a great psychological effect on PWE. All but one participant stated that they would freely disclose the condition to others hoping that they will be assisted during a seizure. Aydemir et al. (2009: 518) states that the motivating factor that they gave for nondisclosure or selective disclosure was the view of telling others was pointless, as there was nothing they could do to help. PWE also feared discrimination.

Cultural aspects deeply influence health-seeking strategies and supernatural beliefs may encourage people with epilepsy and their families to seek help from traditional healers (Bartolini et al. 2011: 433). It was different with the participants of this study who were taking treatment from the clinic and also using traditional healers and spiritual healers. There are misconceptions about epilepsy in that it is a mental health condition

(Njamnshi et al. 2009: 257) as PWE will experience memory loss immediately after a seizure as it was revealed in this study. People associate epilepsy with mental problems, losses, difficulties, and feelings of personal devaluation (Souza and Salgado 2006: 234). There was a feeling of shame, fear, low self-esteem, and insecurity that was observed amongst the participants. The community members believed that it is appropriate to put a metal object like a spoon in the mouth of a person experiencing seizure as that would prevent injuries, whereas current understanding suggest that an object placed in the mouth is likely to damage the oral mucosa as well as interfere with inhalation (Sunmonu et al. 2011: 558). Some PWE believed in traditional healers who gave them a key to hang around their neck to prevent a re-occurrence of a seizure. Results of this study show that the seizures occurred even if the person had a key around the neck. If people see someone with a key around the neck they will know that he has epilepsy that will lead to low self-esteem on a person. Even some traditional healers will not give any sort of treatment because if that person has sustained burns before because it is believed that epilepsy cannot be cured if a person has sustained any kind of burns. PWE loose hope of being cured if they had been burnt whereas epilepsy is incurable.

5.2.2 Psychological experiences

This study revealed that PWE experience anxiety, depression and low self-esteem (Collings.1990: 41) because of epilepsy. When a person is diagnosed with epilepsy there are many thoughts and feelings that will flash through his or her mind. PWE may react in different ways such as being worried and depressed and even angry (Chapell 2001: 87). Although some PWE accept epilepsy as part of their lives, it still affects them psychologically due to the fact that a seizure may occur unexpectedly. Stress is one of the factors PWE say will aggravate a seizure leading to repeated episodes of seizures. Some PWE will not cope with stress and depression and they tend to develop suicidal ideas and others will actually attempt suicide (Aydemir et al. 2009: 517). Some members of the community concluded that PWE have mental conditions as they sometimes lose their memory immediately after a seizure. Other PWE live with anger as this condition is not curable. There are conditions that are not curable like diabetes and hypertension but are considered as normal diseases whereas some community members consider epilepsy as an unacceptable condition.

PWE experience a lack of privacy because they have to be supervised; they cannot even lock the doors because seizure might occur at any time. PWE may not report other stressful situations or problems that might have been caused by factors other than epilepsy. This seems to indicate that feelings or lack of control in epilepsy can be generalized to other situations in life or that the condition of being sick might be the strongest source of stress (Souza and Salgado. 2006: 232). PWE have developed adaptive strategies, such as searching for social support, medical treatment, and spiritual help. Non-acceptance and difficulty in speaking about the disease decreases a person’s chances of being successful and reduces the possibility of academic, professional and interpersonal development. Emotional development is also affected, predisposing to the occurrence of affective disorders (Souza and Salgado 2006: 235).

A seizure can occur at any time with little or no warning (Baker 2002:26). Some PWE will experience aura e.g. a certain smell, which is the sign that a fit is about to occur. If a person experiences aura it does not mean that it will prevent a seizure from occurring. They will have that short period of time to lie down or find a place where injury may be prevented. Baker (2002: 26) states that constant threat of sudden unpredictable loss of control of seizures has been thought to compromise a fundamental facet of this condition. It becomes difficult for PWE to plan their daily activities if they have recurrent seizures as it can happen at any time. People with controlled seizures report to have normal lifestyles although there is always fear that a seizure may occur unexpectedly. After a seizure, some PWE believe that they have to take more medication, which shows lack of knowledge about the treatment of epilepsy.

According to Gibert and Walker (2009: 140) conditions that are associated with the highest degree of stigma share common attributes which are: it will be progressive and incurable, not well understood among the public and its symptoms cannot be concealed. Often there is fear and stigma attached to epilepsy, with widely held beliefs that it is caused by supernatural forces (Eastman 2005; 13). Attitudes shown by others toward PWE have more of an impact than epilepsy itself. The way people in the community treat PWE will cause stress and frustration as they should be the ones supporting PWE. Some PWE as well as their families had accepted the epilepsy and learnt to cope with it, although some feel stigmatized by the epilepsy and try to conceal it from outsiders (Yang et al 2011:5). The stigma of epilepsy still exists in all cultures and societies in the world. PWE have internalized stigma arising from their knowledge and beliefs about epilepsy (Guo et al. 2012: 287). The attitude and ability to deal with seizures constitute an important part of the stigma that PWE feel against them. People who know the causes of epilepsy feel less stigmatized than those who do not know the pathogenesis of epilepsy (Guo et al. 2012:287). PWE will either actually experience or have an imagined negative experience of being stigmatized (Collins 2011:52). Low self-esteem, social isolation, peer rejection and avoidance of activities have all been linked to fear of being treated differently or singled out (Baker et al. 2008: 399).

Most PWE will complain of poor memory or concentration, which can be a result of the seizure or side effect of medication (Baker et al. 2005: 559). Memory decline is mostly experienced immediately after a seizure which is accompanied by headache (Aydemir et al. 2009:517). Most people do not understand this stage and will label PWE as having mental conditions. Memory problems, learning difficulties and cognitive impairment are frequent, especially when they were still attending school (Aydemir et al. 2009: 517).

School and academic underachievement is common amongst PWE (Rodenburg et al. 2011: 48). Epilepsy has a negative effect on a child's education (Collins 2011: 49). This depends on the type of epilepsy they have, and treatment can affect academic performance and place individuals under pressure to keep up with their workload which can lead to anxiety and depression (Collins 2011: 49). Participants reported disruption to their education, failing to attend classes on regular basis, with the majority of participants having incomplete primary school education. Regular absenteeism can occur in children with epilepsy, either because of their seizures or because of attending hospital appointments (Baker, Spector and Soteriou, 2005: 559). Potential causes for underachievement are multiple, and academic problems are probably caused by the interactions of variety of factors which include neurological dysfunctional seizures, medications used to suppress seizures, and psychological factors (Rodenburg et al. 2011: 48). A study by Fong and Hung (2002:314) revealed that misunderstandings, myths, negative attitudes or misbehaviour are less amongst people with better education and younger ages.

5.2.3 Physical burden

This study revealed that PWE had problems with performing daily activities. PWE need someone to be around them during a seizure as they need assistance. Epilepsy is usually associated with mental problems, losses, difficulties, and feelings of personal devaluation. It was also associated with feelings of shame, fear, concern, low self-esteem, and insecurity, which reinforce the self-concept of abnormality, of being different, and of being sick (Souza and Salgado 2006: 232). PWE have fear of being injured during a seizure which limits them in their domestic responsibilities such as cooking, farming, and fetching water. In a study done by Aydemir et al. (2009:516) participants had other daily living activities that they could not do or were not allowed to do. This included washing clothes, cooking, taking a bath, playing outside, going near rivers or lakes and playing sports. PWE also complain about being unable to go out or travel alone as some family members do not allow PWE to drive as they are concerned about their safety. People who live with them have an impression that PWE are unable to carry out tasks of daily living or to contribute meaningfully to the family economy (Mushi et al. 2011: 340). It is believed that PWE should stay away from lakes, rivers, or ponds to avoid the risk of drowning during a seizure. Some will complain of post- seizure effects such as headaches, tiredness, exhaustion and weakness for a couple of days after the seizure (Aydemir et al. 2009: 517).

Unemployment levels have been found to be high among adults with epilepsy. Stigma and misunderstanding of epilepsy may influence the decision to employ someone with the condition (Baker et al. 2008: 398). There are jobs that are forbidden for PWE including physically heavy work, work at high altitudes or in water and work involving driving or climbing. Some people could work without a problem and others experience difficulties in attendance because of the occurrence of seizures and an inability to do certain types of work for fear of triggering a seizure (Aydemir et al. 2009: 516). Although PWE are willing to work many have a problem finding employment, as no one will hire them because they have been refused employment because of their condition (Aydemir et al. 2009:515).

Normal activities that PWE have to avoid could lead to serious injuries (Mateen et al. 2012: 292). Injuries sustained by PWE can lead to death for example, a seizure may cause PWE to fall, and if that area happens to be dangerous such as an open fire, the seizure may not kill the person but burns may do so (Mateen et al 2012: 292). For elderly PWE, they are vulnerable to the side effects of anti-epileptic drugs (AEDs) and also their frailty and medical comorbidities put them at risk of physical injury. Many older people cope relatively well with epilepsy and other chronic illnesses. This may be because they have already begun coping and adapting to other illnesses (Johnston and Smith 2010: 1908).

5.2.4 Relationship burden

The findings from this study showed that the participants' relationships were compromised by epilepsy. One of the participants mentioned that she did not tell her husband about her having epilepsy for fear of being rejected. After disclosing to her husband they were divorced. A study done by Aydemir et al. (2009: 512) supports that PWE are abandoned by their partners because of the seizures. The majority of the participants' partners were supportive whereas one partner was not supportive. One participant had a partner who was willing to marry her and get someone to look after her. Epilepsy was not a problem with this partner. People generally are reluctant to marry a person with epilepsy because of the fear of a seizure occurring happen at any time and could affect the person psychologically. Some partners will conceal epilepsy, but the condition will cause problems when the other partner finds out about the condition, leaves home and finally divorce pursues (Aydemir et al. 2009: 515).

PWE report a significant impact of the condition and its management in terms of family dysfunction, reduced social and leisure opportunities, increased levels of anxiety and depression and poor self-esteem when compared with people without the condition (Baker 2002: 26). Most PWE reported a sense of being a burden, financially and psychologically others, particularly their families (Aydemir et al. 2009: 517).

The findings of this study revealed that community members react in different ways to PWE. Some people were afraid because of the lack of knowledge regarding the condition; others believe it is a mental condition. One of the participants pointed out that negative reactions from people were common after publicly witnessing a seizure. The sight of seeing someone having a seizure was distressing and because witnesses did not know how to help, they thought that person was dying (Wilde and Haslam 1996: 66). The community in which they live show little or no knowledge about epilepsy.

For PWE it is difficult to find and keep employment although they feel the importance of working and supporting themselves (Sample et al. 2006:657). Aydemir et al. (2009: 517) states that very few PWE could work without experiencing difficulties such as impaired attendance because of the occurrence of the seizures and inability to do certain types of work for fear of triggering a seizure. Some employers will terminate the employment of persons with epilepsy if a seizure occurred during work because of unreported epilepsy (Fong and Hung 2002:313). n South Africa most of the PWE receive a disability grant which preclude them from the possibility of full time employment in the open labour market (McQueen and Swartz 1995: 862). The majority of employers will not employ a person with epilepsy because of concerns that they may cause accidents and upset other employers (Guo et al. 2012: 287)

5.2.5 Support

The study findings revealed that PWE relied on support from their family members and their belief in God as they are Christians. Evidence is provided in a study done by Mushi et al. (2011: 340) that PWE relied on support from their parents, grandparents, or siblings with females (mothers and sisters) being mostly frequently mentioned. There is also a problem of family members having to care for the person with epilepsy when all hands are needed to manage the demands of making a living (Baker 2002: 26). This person with epilepsy will end up with lack of support as there will be no one to look after him/her. Seeking support from the family is a common coping strategy, but it is difficult when the family feels shame for having a relative with epilepsy. Non-supportive family members may be due to a feeling of shame for having a relative with epilepsy (Bartolini et al. 2011: 432). Females who live with epilepsy receive more familial social support as compared to their male counterpart. This could be because females are more emotional inclined compared to males in as far as they share their feelings more freely and readily (Khalid and Aslam 2011: 46). Females perceive having someone to talk to as having adequate social support. Males will not share their feelings because they feel this is a sign of weakness. Hence, males tend to perceive they have lower social support system because they feel that they have no one to express their feelings to (Khalid and Aslam 2011: 46).

The greatest impact of epilepsy for family members appeared to be the psychological health of the person with epilepsy. Families expressed feelings of fears and hopelessness about their future, anger, sorrow, and fearful of their affected family member experiencing sudden death or injury as a result of a seizure. In addition family members also stated concerns and worries about the current health status of their family member with epilepsy (Aydemir et al. 2009:516). Family members also expressed concern over the burden of caring; having to care for a person with epilepsy constantly, facing difficulties because a family member had epilepsy, or shouldering all responsibilities for management of treatment of the person with epilepsy (Aydemir et al. 2009: 516). In other communities, an attitude such as a stigma towards PWE restricts a person with epilepsy from sharing meals with them or from marrying someone from their household (Tran et al. 2007: 567).

A few of the participants mentioned that they were treated well at the clinic and given advice. Mostly medical staff will provide treatment and emphasize the importance of taking it rather than education and emotional support (Bartolini et al. 2011: 432) which is mostly needed by PWE as they have to cope with psychological experiences.

5.3 LIMITATION OF THE STUDY

This study was conducted in a specific public PHC clinic in eThekwini District and, as such, is not be transferable to other districts. The issue of the participants opening up to the researcher was difficult at first, but after they had engaged with the researcher after few minutes, all participants opened up and described their experiences freely.

5.4 CONCLUSION

Experiences of PWE were explored in this study. The participants described their challenges or difficulties that they experienced in different contexts. The psycho-socio-economic needs are complex. Failure to address these needs has enhanced the negative labeling of PWE. The results of this study revealed that PWE have needs that should be met. PWE need psychological, physical, financial and other types of support as recommended below.

5.5 RECOMMENDATIONS

- Information and psychological support to be provided to PWE and their families.
- Hospitals to have a multidisciplinary team which deals with epilepsy, where the medical practitioner can refer to hospitals. This team should include doctors, nurses, psychologists and social workers.
- Nurses to be trained to specialize in epilepsy, as they are the medical personnel that are always next to the patient, they will be able to provide complete nursing care to the person with epilepsy.
- Community health workers to be trained on epilepsy and be able to give education to the community.
- Associations like Epilepsy South Africa to be available to all people and visit clinics and hospitals to give information on what is their role. They should be easily accessible to the community.
- The Department of Health to develop posters which explains about epilepsy and its causes.
- Epilepsy day to be known to all people living in South Africa. It should also be subsidized so that information could reach everyone.
- Similar studies to be conducted in other geographic areas.

5.6 FURTHER RESEARCH

This study focused only on the experiences of PWE. Since these people belong to families and communities, it would be ideal to conduct a further research study to explore the families' and communities knowledge, perceptions and attitudes towards PWE.

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DURBAN
UNIVERSITY of
TECHNOLOGY

INSTITUTIONAL RESEARCH ETHICS COMMITTEE (IREC)

14 February 2012

IREC Reference Number: REC 14/11

Mrs N Y T Shabangu
Y 623, Mpilonde Place
Umlazi
4066

Dear Mrs Shabangu

Experiences of people living with epilepsy presenting for treatment at Umlazi Clinic

I am pleased to inform you that Full Approval has been granted to your proposal REC 14/11.

The Proposal has been allocated the following Ethical Clearance number IREC 0[illegible]/2012. Please use this number in all communication with this office.

Approval has been granted for a period of one year, before the expiry of which you are required to apply for safety monitoring and annual recertification. Please use the Safety Monitoring and Annual Recertification Report form which can be found in the Standard Operating Procedures [SOP's] of the IREC. This form must be submitted to the IREC at least 3 months before the ethics approval for the study expires.

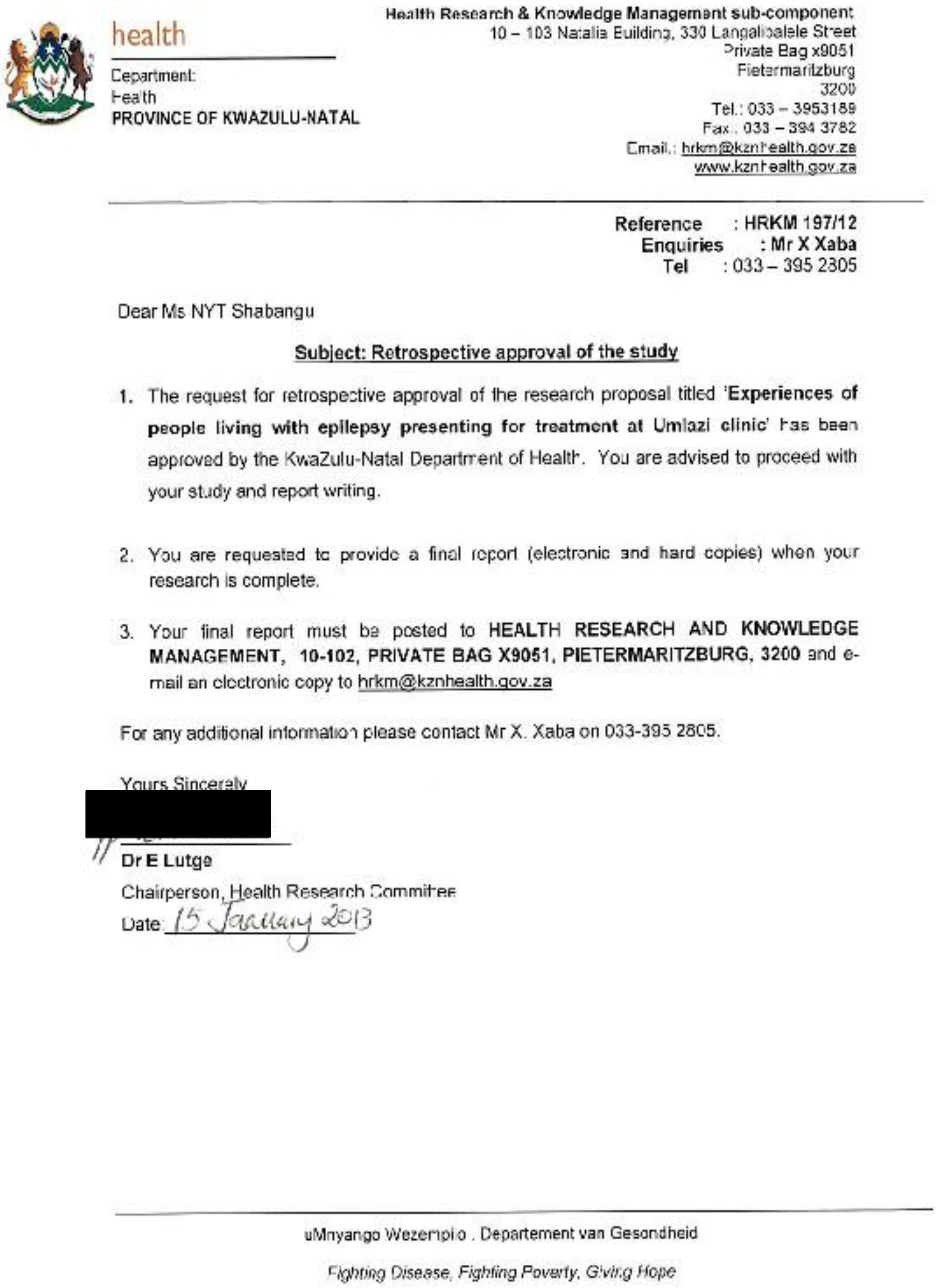
Any adverse events [serious or minor] which occur in connection with this study and/or which may alter its ethical consideration must be reported to the IREC according to the IREC SOP's. In addition, you will be responsible to ensure gatekeeper permission.

Please note that ANY amendments in the approved proposal require the approval of the IREC as outlined in the IREC SOP's.

Yours Sincerely

[redacted]

Prof T Puckree
Chairperson: IREC



health

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Reference : **HRKM 197/12**
Enquiries : **Mr X Xaba**
Tel : 033 – 395 2305

Dear Ms NYT Shabangu

Subject: Retrospective approval of the study

1. The request for retrospective approval of the research proposal titled '**Experiences of people living with epilepsy presenting for treatment at Umlazi clinic**' has been approved by the KwaZulu-Natal Department of Health. You are advised to proceed with your study and report writing.

2. You are requested to provide a final report (electronic and hard copies) when your research is complete.

3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

[redacted]

Dr E Lutge
Chairperson, Health Research Committee
Date: 15 January 2013

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uMnyango Wezempilo . Departement van Gesondheid

Fighting Disease, Fighting Poverty, Giving Hope

Appendix 3a: Permission letter to the DM of eThekwini District

Y623 Mpilonhle Place
Umlazi
4031

The District Manager
EThekwini Health District
Mayville
4000

Dear Madam

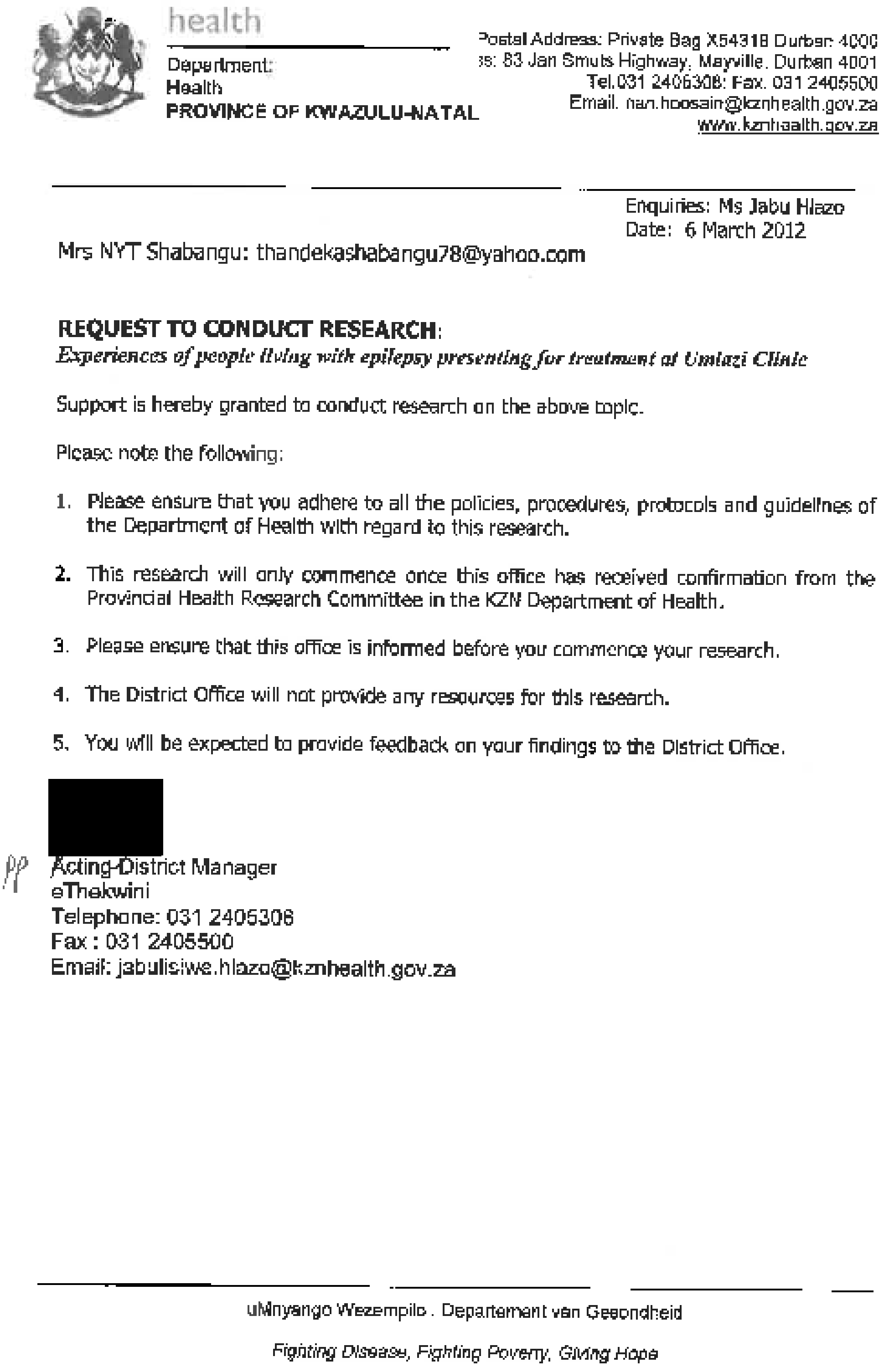
RE: REQUEST FOR PERMISSION TO CONDUCT A STUDY

I am presently registered as a student at the Durban University of Technology in the Department of Nursing doing Masters in Nursing. The proposed title of my research project is: '*Experiences of people living with epilepsy presenting for treatment at Umlazi Clinic*'. The aim of the study is to describe the lived experiences of people with epilepsy. In-depth, semi-structured interviews will be conducted to collect data.

I hereby request your permission to conduct a research project at Umlazi U21 clinic. My research proposal has been attached. Your support and permission to conduct the study at your facility will be appreciated.

Yours sincerely

....	....
NYT Shabangu (Mrs)	MN Sibiya (Dr)
M Tech student	Supervisor
Contact number: 073 836 1337	Contact number: 031-373 2606
Email address:	Email address:
thandekashabangu78@yahoo.com	nokuthulas@dut.ac.za



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Enquiries: Ms Jabu Hlazo
Date: 6 March 2012

Mrs NYT Shabangu: thandekashabangu78@yahoo.com

REQUEST TO CONDUCT RESEARCH:
Experiences of people living with epilepsy presenting for treatment at Umlazi Clinic

Support is hereby granted to conduct research on the above topic.

Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regard to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Please ensure that this office is informed before you commence your research.
4. The District Office will not provide any resources for this research.
5. You will be expected to provide feedback on your findings to the District Office.

[redacted]

pp Acting District Manager
eThekwini
Telephone: 031 2405308
Fax : 031 2405500
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uMnyango Wezempilo . Departement van Gesondheid

Fighting Disease, Fighting Poverty, Giving Hope

Appendix 4a: Letter of Information and Consent

Title of the Research Study: **Experiences of people living with epilepsy at Umlazi Clinic**

Principle Investigator: Mrs NYT Shabangu
Supervisor: Dr MN Sibiya

Dear Participant

Thank you for taking time to read this information letter. I am a Master's student and in order to qualify, I am required to complete a research dissertation. With your assistance and co-operation, I will be able to undertake this research study. The details are outlined below:

Brief Introduction and Purpose of the Study: Epilepsy is a condition that is experienced worldwide. People with epilepsy experience stigma within their families, friends and at the workplace there is alack of understanding among the public which might foster a sense of fear, misunderstanding and even discrimination in the community. Most patients conceal their epilepsy due to the fear of being stigmatized and discriminated. Due to these conditions, people with epilepsy can have different experiences. Therefore this study seeks to describe your experiences as a person living with epilepsy

Research Design: I hereby request that you allow me to interview you for approximately 45 minutes. I also request permission to record the interview and the recordings will be kept in a safe place and will be destroyed after a period of 5 years. Please note that the interviews will be recorded for the purposes of later transcription.

Risks or Discomforts to the Subject: You will not be subjected to any risk or discomfort. Please feel free to withdraw from the study at any time of the interview.

Benefits: This study seeks to increase the community's understanding of epilepsy.

Reason/s why the Subject May Be Withdrawn from the Study: Please feel free to withdraw from the study at any time of the interview.

Remuneration: There is no remuneration for participating in this study.

Appendix 4b: Incwadi yolwazi nemvume yocwaningo (IsiZulu)

Isihloko socwaningo: Izimo ababhekana nazo abantu abaphila nesifo sokuwa abelashwa emtholampilo waseMlazi.

Umcwaningi: Nkskz NYT Shabangu
Abeluleki: Dkt MN Sibiya

Sawubona

Isendlalelo nenhloso yalolu cwaningo: Isifo sokuwa siyisifo esikhona emhlabeni jikelele. Abantu abaphila nalesi sifo bathola ukucwaseka emindenini yabo, kubangane kanye nasemsebenzini. Imiphakathi isantula ulwazi mayelana nalesi sifo, okungaholela ekusabeni, ukungezwani kanye nokucwasana emphakathini. Abanye abantu abaphila nalesi sifo ngoba besabela ukucwaseka.

Indlela ucwaningo oluqhubeka ngayo: Ngicela ungivumele ukuba sibe nengxoxo engaba imizuzu engamashumi amane nanhlanu. Ngibuye ngicele nemvume yakho ukuthi ngiyiqophe ingxoxo yethu. Ingxoxo eqoshiwe kanye nayo yonke eminye imininingwane izogcinwa iminyaka eyisihlanu endaweni ephephile bese ilahlwa. Inhloso yokuqopha ukuthi uma sesiyiqedile ingxoxo yethu bese ngikwazi ukuyibhala phansi.

Ubungozi nokungaphatheki kahle: Abukho ubungozi noma isimo sokuhlukumezeka kulabo abazimbandakanya nalolu cwaningo noma ingasiphi isikhathi.

Inzuzo: Lolucwaningo luzama ukwandisa ulwazi lomphakathi mayelana nalesifo sokuwa.

Izizathu ezingenza abayingxenye yocwaningo bahoxiswe kulo: Ukhululekile futhi unelungelo lokuhoxa ocwaningweni noma ngabe kunini.

Ukuholelwa: Awukho umholo ozotholakala ngokuba yingxenye yocwaningo.

Izindleko zocwaningo: Azikho

APPENDIX 5a: Interview Guide

Age of participant : …………………………………

Gender : …………………………………

Language : …………………………………

Duration of epilepsy: …………………………………

Questions to include in the interview:

1. What are your experiences regarding living with epilepsy?
2. How do people relate to you as a person living with epilepsy?
3. How do you feel that you have epilepsy?
4. Any other question will be asked based on the responses of the participant to the above questions

APPENDIX 5b: Uhlelo lwemibuzo yenhlololuvo (IsiZulu)

Iminyaka yalowo obuzwayo : ………………………………….

Ubulili : ………………………………….

Ulimi : ………………………………….

Isikhathi unesifo sokuwa : ………………………………….

Imibuzo yenhlololuvo:

1. Iziphi izimo obhakana nazo njengoba uphila nesifo sokuwa?
2. Bakuphatha kanjani abantu njengoba uphila nesifo sokuwa?
3. Uphatheka kanjani njengoba uphila nesifo sokuwa?
4. Eminye imibuzo iyolandela izimpendulo zemibuzo engenhla