

AN EXPLORATORY STUDY INVESTIGATING THE EXPERIENCES OF
ADULTS LIVING WITH EPILEPSY IN THE KHOMAS REGION, NAMIBIA

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Abstract

This qualitative study explores the experiences of 10 adults with epilepsy (AWE) in the Khomas region of Namibia. The study focuses on the everyday of problems, needs and coping strategies of this population as described during semi-structured interviews.

An exploratory qualitative research design was used to investigate the experiences of AWE in the Khomas region of Namibia. Ten people with epilepsy were identified through purposive sampling. All participants were over the age of 18 years, no longer attended school and were not cognitively disabled. Semi-structured interviews were conducted using a self-designed interview guide. Fifteen broad open-ended questions focused on the everyday problems and needs that AWE encounter and the coping strategies that the participants have been using since they received a diagnosis of epilepsy. Thematic analysis was used to analyse the semi-structured interviews. George Engel's (2012) biopsychosocial model was used to identify themes and subthemes within the data and to conceptualize the discussion.

The main findings of the study revealed that AWE experience problems in the biological domain that relate to the provision of healthcare services to AWE, comorbid health conditions and challenges that arise as a result of medication. In the psychological domain problems centred on the impact of epilepsy on the psychological well-being of the AWE while the impact of seizures on daily functioning was most evident in the social domain. A need for specialized healthcare services, for the acceptance of the epilepsy diagnosis and for employment, financial resources, independence and public education emerged in the respective domains. It was found that coping strategies consisted of biological management through medication, various psychological coping strategies and the utilization of social support structures.

The study further shows that AWE in Namibia experience similar problems and needs as AWE in other sub-Saharan countries in Africa. It is clear from the findings that the impact of epilepsy extends beyond the biological factors of the condition and that psychosocial influences play a major role in the challenges encountered by AWE in the Khomas region of Namibia.

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List of Abbreviations

AEDs	Anti-epileptic drugs
AWE	Adults with Epilepsy
CBT	Cognitive behaviour therapy
CT	Computerized tomography
EEG	Electroencephalography
ES	Epileptic seizure
IBE	International Bureau for Epilepsy
ILAE	International League against Epilepsy
MRI	Magnetic resonance imaging
PWE	People/person with epilepsy
SSA	sub-Saharan Africa

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Declaration

I, Anina du Toit, hereby declare that this study is my own work, is a true reflection of my research, and that this work or any part thereof has not been submitted for a degree at any other institution.

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Name of Student

Signature

27 October 2017

Date

CHAPTER 1: INTRODUCTION

1.1 Orientation of the study

Epilepsy affects 65 million people worldwide, and approximately 80 per cent of those live in low- and middle-income countries (Moshé, Perucca, Ryvlin, & Tomson, 2015; World Health Organization, 2014). The epilepsy prevalence in sub-Saharan Africa (SSA) is estimated at almost double that of North America, Europe and Asia, with the median prevalence at 14.2 per 1 000 compared to 5.8 per 1 000 in more developed countries (Ba-Diop et al., 2014). However, there are currently no formal statistics on prevalence, incidence or diagnostic and treatment procedures available for epilepsy in Namibia (Angula, 2016). Causes and risk factors for epilepsy in SSA include a family history of seizures, traumatic brain injury, perinatal trauma, substance abuse and central nervous system infections such as neurocysticercosis (Ba-Diop et al., 2014).

Epilepsy is the most common chronic and serious neurological condition worldwide and involves a major burden in terms of costs, mortality, stigma, seizure-related disability and comorbidities (Moshé et al., 2015). Due to the serious nature of epilepsy, the International League against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) consider epilepsy to be a disease and not a disorder (Fisher et al., 2014).

Epilepsy is much more than just seizures. Sufferers and families often conceptualize the condition in terms of more everyday concerns, such as questions about independent living, uncertainties about social and employment situations, academic challenges and limitations on operating machinery and driving a car (Institute of Medicine, 2012). So, whereas freedom from seizures continues to be an important treatment goal in epilepsy, growing evidence suggests that the psychological and social domains have the greatest impact on the quality of life of persons with epilepsy (PWE) (Elliott &

Richardson, 2014).

1.2 Statement of the problem

There is a paucity of information regarding a link between psychosocial factors and epilepsy worldwide, and specifically in Namibia. Little has been published on epilepsy in the fields of either social work or psychology (Elliott & Richardson, 2014). Studies on epilepsy in Africa focus on the attitudes towards epilepsy of teachers in the Oshana region (Angula, 2016); epidemiology, causes and treatment of epilepsy in SSA (Ba-Diop et al., 2014; Preux & Druet-Cabanac, 2005); the social and economic impact of epilepsy in Zambia (Birbeck, Chomba, Atadzhanov, Mbewe, & Haworth, 2007); and the impact of epilepsy on the quality of life of PWE in Zimbabwe (Mielke, Sebit, & Adamolekun, 2000).

Experiential and qualitative reports indicate that PWE in Africa are frequently exposed to economic disadvantages and that this condition may have a profound impact on the social and psychological functioning of individuals (Birbeck & Kalichi, 2003; Mielke et al., 2000). Furthermore, PWE live with a chronic, unpredictable condition and are often exposed to discrimination, misunderstanding and social stigma (Ba-Diop et al., 2014; Moshé et al., 2015). The lack of information regarding epilepsy in Namibia combined with the possible detrimental psychosocial impact of this condition on AWE create an opportunity for research to explore the problems, needs and ways that adults cope with epilepsy in the Khomas region of Namibia.

1.3 Research questions

The study aims to answer the following research questions regarding the experiences of adults with epilepsy:

1. What everyday problems do adults with epilepsy in the Khomas region of Namibia experience?
2. Do adults with epilepsy in the Khomas region of Namibia have specific needs?
3. How do adults with epilepsy in the Khomas region of Namibia cope with their problems?

1.4 Significance of the study

The study provides an in-depth description of the daily challenges, needs and coping strategies of AWE in the Khomas region of Namibia. As such, it may provide a starting point for future clinical research to focus on the psychological and social domains of epilepsy in Namibia. Increased understanding of the impact of epilepsy on family, social, educational/vocational, healthcare and financial domains may assist in creating intervention programmes aimed at the specific needs and challenges of AWE. Furthermore, the findings of this study may create greater public awareness regarding this debilitating condition and may be a first step in the process of creating policies and procedures directed at the specific needs of AWE.

1.5 Limitations of the study

Participants in this study were not homogenous in terms of demographics and may therefore not be fully representative of the broader population of AWE in Namibia. Participants hailed from various age groups and socio-economic backgrounds. This implies that needs and challenges may differ between age groups as participants are at different developmental stages in their lives. The same applies to socio-economic

status, where needs and challenges may be influenced by factors related to income, education, social position and opportunity for employment.

1.6 Definition of key terms

1.6.1 Epileptic seizure

The ILAE and the IBE define an epileptic seizure as “a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain” (Fisher et al., 2005, p. 471).

1.6.2 Epilepsy

Epilepsy is characterized by an “enduring predisposition of the brain to generate epileptic seizures, with neurobiological, cognitive, psychological, and social consequences” (Fisher et al., 2005, p. 471).

1.6.3 International League against Epilepsy

The International League against Epilepsy (ILAE) is the world’s foremost association of physicians and other health professionals working towards a world where no person’s life is limited by epilepsy. It was founded in 1909 and is an organization of more than 100 national chapters (ILAE, n.d.). The goals and mission of the ILAE are:

- to advance and disseminate knowledge about epilepsy;
- to promote research, education and training;
- to improve services and care for patients, especially by prevention, diagnosis and treatment.

1.6.4 Epilepsy Namibia

Epilepsy Namibia is a non-governmental organization founded in 2007 by Harmiena Riphagen (Epilepsy Namibia, n.d.). It is the only support organization for PWE in Namibia and aims to raise awareness of epilepsy through training, advocacy and lifestyle management programmes.

1.6.5 Khomas region, Namibia

The Khomas region is the most central of Namibia's 14 administrative regions, with a surface area of 36 805 square kilometres (4.5% of the total area of the country). The capital of the Khomas region, Windhoek, is the judicial and administrative centre of the country. The region's population of 342 141 represents over 16 per cent of the total population of the country. The Khomas region, and specifically Windhoek, is home to most of Namibia's manufacturing industries and to business, educational and transport sectors (Khomash Regional Council, 2015).

1.6.6 Everyday problems

For purposes of this study, *everyday problems* refer to any life event that forms a basic or regular part of the person's daily interactions in a certain context and that causes some degree of discomfort.

1.6.7 Needs

The Oxford Dictionary of Psychology (Colman, 2006, p. 494) defines a *need* as "A lack of something that is required for survival" or "A motivational state resulting from the lack of something that an organism requires or desires". In this study, a *need* is something that an AWE requires to overcome everyday problems.

1.6.8 Coping strategies

Lazarus and Folkman (1984, p. 110) define coping as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person”. For purposes of this study, *coping strategies* refer to any attempts made by an AWE to manage everyday problems or to meet the needs necessary for survival.

1.7 Chapter overview

The document is structured to include a detailed explication of the relevant literature on epilepsy and a description of the biopsychosocial model that is used to understand the findings of the study in Chapter 2. Chapter 3 outlines the research methodology of this study. In Chapter 4, the results and key findings of the study are presented followed by a discussion of the findings of the study in Chapter 5. Chapter 6 concludes the study and provides a discussion of the limitations of the study and the recommendations for future research before it summarizes the conclusions.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter provides an overview of the literature by focusing on the historical background, classification and clinical picture of epilepsy. It provides a closer look at factors that contribute to the aetiology and the epidemiology of the condition. The section thereafter continues to review the various diagnostic techniques and treatment options for epilepsy. This is followed by an overview of the available literature pertaining to the psychiatric, psychosocial and medical comorbidities that feature in the lives of AWE. A discussion of how adults cope with a diagnosis of epilepsy is followed by a brief look at the role of stigmatization and marginalization of PWE and a brief overview of epilepsy in Namibia. The chapter concludes with a description of George Engel's (2012) biopsychosocial model that is used to interpret the experiences of AWE across the biological, psychological and social domains of the person's life and how these interact to form a coherent whole.

2.2 Historical background

The first recorded accounts of epilepsy appeared as early as 1000 BC in Babylon, formerly Mesopotamia (Angus-Leppan & Parsons, 2008; Chaudhary, Duncan, & Lemieux, 2011). These early writings suggest that seizures are caused by supernatural forces, astrological or magical influences, bad deeds or demons (Angus-Leppan & Parsons, 2008; Chaudhary et al., 2011). The condition was described a divine nature because of its symptoms and was treated using supernatural means (Chaudhary et al., 2011).

An anonymous monograph dated 400 BC (the Hippocratic era) titled *On the Sacred Disease*, argues that epilepsy originates in the brain and that the divine character of

epilepsy is “a shelter for ignorance and fraudulent practices” (as cited in de Boer, 2010, p. 631). The writer of *On the Sacred Disease* concludes that epilepsy “is no more divine than other diseases, it is a hereditary, its cause lies in the brain, the releasing factors of the seizures are cold, sun and wind which change the consistency of the brain. Therefore, epilepsy can and must be treated not by magic but by diet and drugs” (as cited in de Boer, 2010, p. 631).

It was only by the late 17th and 18th century that the Hippocratic concept of epilepsy as a brain disorder began to take root in the Western world (de Boer, 2010). The modern medical view of epilepsy developed under the leadership of three English neurologists, John Hughlings Jackson, Russell Reynolds and Sir William Richard Gowers (de Boer, 2010). Jackson recognized that seizures can cause alterations in consciousness, sensation and behaviour and defined it as extreme, infrequent and unsystematic discharge of nerve tissue on muscle (de Boer, 2010).

However, even in the 21st century, societal ideas about epilepsy lag behind medical understanding and the association of seizures with divine or demonic possession, witchcraft and mental health conditions still prevails (Chaudhary et al., 2011; de Boer, 2010; Institute of Medicine, 2012). Studies conducted across the world report that people continue to believe that the causes of epilepsy are related to evil spirits, witchcraft, punishment from dark forces, black magic and supernatural forces (de Boer, 2010; Ekeh & Ekrikpo, 2015; Jacoby et al., 2008; Mugumbate & Mushonga, 2013; Ogunrin, Adeyekun, & Adudu, 2013; Osungbade & Siyanbade, 2011). These misconceptions about epilepsy “have resulted in terminology with negative and sensationalized connotations and led to cultural and societal beliefs, perceptions, and stereotypes about epilepsy that can be difficult to modify” (Institute of Medicine, 2012,

p. 31). It is evident that many mistaken beliefs about the condition have prevailed throughout the centuries in particular parts of the world or in certain eras or cultures. In the developing world, these conceptions and the prevailing prejudice often lead to isolation, rejection and denial of education (de Boer, 2010).

The word *epilepsy* hails from the Greek term meaning “to seize” or “to attack,” as it was thought that the condition “was caused by an attack from a demon or god” (Chaudhary et al., 2011, p. 109). Even today, epilepsy-related terminology remains troublesome (Noble, Robinson, Snape, & Marson, 2017; Reuber, 2014). Epilepsy remains a highly stigmatized condition and the words used when referring to epilepsy may not just shape attitudes, but also reflect it (Noble et al., 2017). Whereas phrases such as “epileptic” or “epileptics” have been used traditionally, organizations around the world, including The Institute of Medicine (2012), now perceive the term to have judgmental and negative connotations (Noble et al., 2017). The epilepsy field, therefore, suggests that the term “people with epilepsy” be used instead of “epileptics” (Institute of Medicine, 2012).

2.3 Clinical definition and classification of epilepsy

In 2005, a task force of the IBE and the ILAE formulated conceptual definitions for “epileptic seizure” and “epilepsy.” The task force made a distinction between an epileptic seizure, which is defined as “a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain” and epilepsy, which is characterized by an “enduring predisposition of the brain to generate epileptic seizures, with neurobiological, cognitive, psychological, and social consequences” (Fisher et al., 2005, p. 471). Although the conceptual definitions of epileptic seizures and epilepsy delineate the disorder in broad terms, this is too difficult to apply in

everyday practice (Moshé et al., 2015). For this reason, an operational definition of epilepsy, more suited for clinical use, was formulated by an ILAE task force in 2013 (Fisher et al., 2014). The operational definition stipulates the following: “Epilepsy is a disease of the brain defined by any of the following conditions: (i) At least two unprovoked (or reflex) seizures occurring >24 h apart; (ii) One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years; and (iii) Diagnosis of an epilepsy syndrome. Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or those who have remained seizure-free for the last 10 years, with no seizure medicines for the last 5 years” (Fisher et al., 2014, p. 477).

Scientific advances necessitated changes in how “seizure types” are conceptualized and they now denote the primary site of onset of the seizure in the brain, as the epileptic focus or zone (Moshé et al., 2015). As a result, in 2010 the ILAE Commission on Classification and Terminology proposed that “partial” seizures be replaced by “focal” seizures and that “simple” versus “complex” be made redundant (Moshé et al., 2015). According to the new classification, seizures can be divided into three major categories namely, (i) focal seizures that are limited to one cerebral hemisphere; (ii) generalized seizures that originate in one hemisphere and rapidly spread to both hemispheres; and (iii) unknown onset (Berg et al., 2010; Institute of Medicine, 2012; Moshé et al., 2015).

For the sake of brevity, the latest ILAE classification of seizure types is included in graphical format (Figure 1). This operational and practical classification is based on the signs and symptoms of the various seizure types. Typical signs and symptoms of focal seizures may include automatisms such as lip-smacking, walking in circles or

undressing; sudden loss of strength in one limb such as an arm or a leg; spasms, jerks or stiffening in the limbs; vigorous thrashing or pedalling movement; changes in autonomic nervous system functions such as increases or decreases in skin colour, blood pressure and heart rate; a sudden freeze or pause in movement; impaired cognition that may affect language and maths ability; changes in emotional state, such as involuntary crying, laughing or spontaneous anxiety, fear or joy; and changes in sensory perception, such as tastes, hot-cold feelings, sounds and smells. Generalized seizures typically consist of a combination of signs and symptoms such as loss of awareness, incontinence, tongue biting, rhythmic jerking, loss of muscle tone and strength, spasms and stiffening of the limbs (Fisher, 2017). Although the ILAE 2017 seizure classification has not yet been finalized, it does allow for easier classification of types that did not previously fit into any category. It increases the clarity and transparency of terminology for both the medical and nonmedical fields (Fisher, 2017).

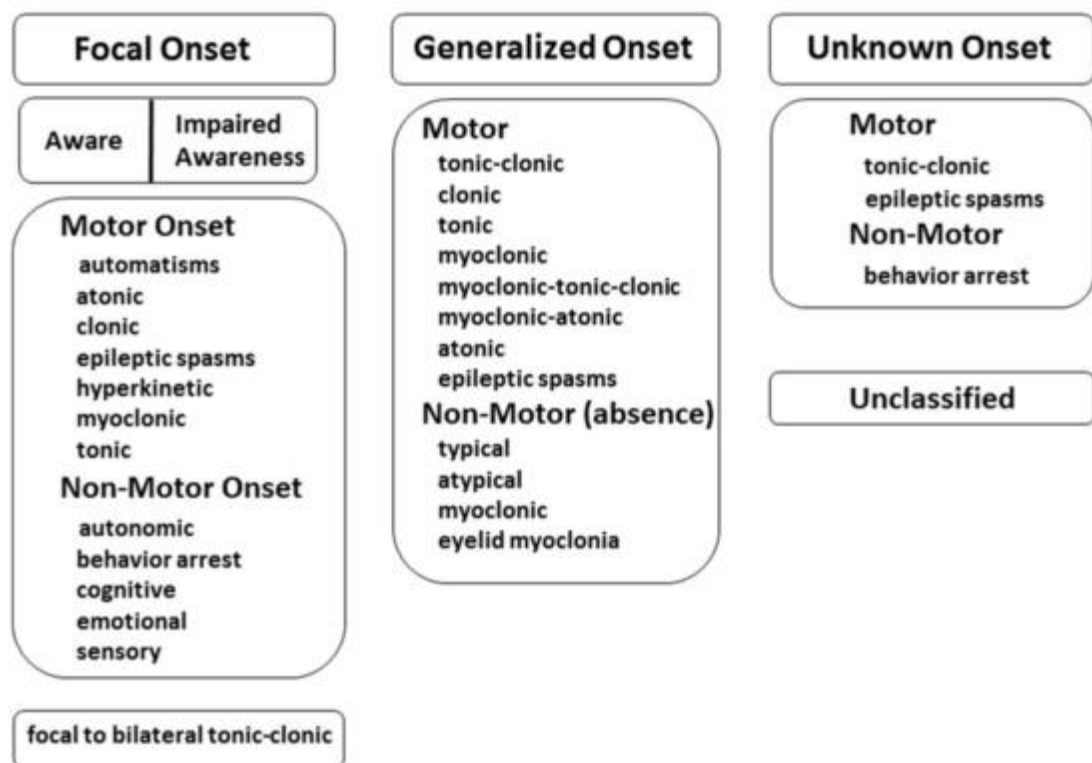


Figure 2.1 An overview of the ILAE 2017 classification of seizure types

Reprinted from *Epilepsy & Behavior*, Vol: n/a, Edition: n/a, R. Fisher, An overview of the 2017 ILAE operational classification of seizure types, p. 2., Copyright (2017), with permission from Elsevier (Appendix A).

2.4 Aetiology

In 2010, the ILAE decided to change the aetiological categories for epilepsy from idiopathic, symptomatic and cryptogenic to genetic, structural/metabolic and unknown cause (Berg et al., 2010; Scheffer et al., 2014). This decision was prompted by the development of new investigative technologies and the acquisition of new information regarding epilepsy (Berg et al., 2010). As a result, the term “idiopathic” is replaced by “genetic” where “the epilepsy is the direct result of a known or presumed genetic defect(s) in which seizures are the core symptom of the disorder” (Berg et al., 2010, p. 680). A “structural/metabolic” aetiology is conceptualized as the presence of “a distinct structural lesion that is associated with a substantially increased likelihood of developing epilepsy” (Scheffer et al., 2014, p. 8). Examples of possible causes for structural/metabolic epilepsy include cortical malformations, brain tumours, trauma and stroke (Moshé et al., 2015). Finally, an “unknown cause” is defined as “the nature of the underlying cause is as yet unknown” (Berg et al., 2010, p. 680). With an “unknown cause” it is, therefore, not possible to make a definitive diagnosis, although genetic defects or unrecognized disorders cannot be ruled out (Berg et al., 2010; Scheffer et al., 2014). The aetiological factors are discussed in more detail in the next section.

2.4.1 Genetic factors

A great proportion of the severe epilepsies is thought to be caused by genetic factors, even though the mechanism is often uncertain and may consist of more than one

genetic factor (Angus-Leppan & Parsons, 2008). Chromosomal abnormalities are seldom implicated in the causation of epilepsy, although Down's syndrome may cause epilepsy at all ages and especially later in life (Angus-Leppan & Parsons, 2008). Single gene and hereditary disorders with cerebral manifestations, such as tuberous sclerosis and Dravet syndrome are only evident in a small number of patients (Angus-Leppan & Parsons, 2008; Scheffer et al., 2014). In a study conducted in Uganda, 29 per cent of respondents cited genetic causes for their epilepsy (Kaddumukasa et al., 2016). However, genetic studies on epilepsy in adulthood, and especially in an African context, are rare, although it is estimated that about one third of all epilepsies have a genetic basis (Angus-Leppan & Parsons, 2008).

2.4.2 Structural/Metabolic factors

Structural factors refer to abnormalities in the brain that are visible during neuroimaging of the brain (Scheffer et al., 2014). Epilepsy due to structural causes is linked to higher mortality rates, persistent seizures and worse overall prognosis (Preux & Druet-Cabanac, 2005). In SSA, epilepsies related to structural factors are often caused by central nervous system infections, traumatic brain injury and childhood febrile convulsions (Ba-Diop et al., 2014; Ogunrin et al., 2013). A large cross-sectional study performed in five SSA countries between 2008 and 2011 reported that 11 per cent of epilepsy cases were due to adverse perinatal events, 10 per cent to acute encephalopathy and 3 per cent to traumatic brain injury (Kariuki et al., 2014). Infections caused by neurocysticercosis (pork tapeworm), malaria, HIV, bacterial meningitis and tuberculosis account for up to 26 per cent of epilepsy cases in SSA (Ogunrin et al., 2013; Preux & Druet-Cabanac, 2005). The most common cause of brain injury in Africa is road accidents, although work- and war-related injuries, acts

of violence and active sports all contribute to the estimated 17 per cent of epilepsy caused by traumatic brain injury in SSA (Ba-Diop et al., 2014; Ogunrin et al., 2013; Preux & Druet-Cabanac, 2005). Perinatal causes of epilepsy in SSA are implicated in 1 to 36 per cent of seizures (Ba-Diop et al., 2014; Preux & Druet-Cabanac, 2005). This may be ascribed to injuries suffered at birth as a result of a difficult pregnancy or childbirth and may lead to hypoxaemia and hypoglycaemia, which in turn may cause epilepsy (Ba-Diop et al., 2014).

2.4.3 Other contributing factors

A study performed in Benin established a link between epilepsy and malnutrition (Crepin et al., 2007), although few studies have been published in less developed countries about a possible link between epilepsy and malnutrition (Ba-Diop et al., 2014). However, in a study conducted by Kariuki et al. (2014) across five SSA countries, it was reported that malnutrition was present in 14.8 per cent of PWE. In another cross-sectional SSA study, malnutrition was positively associated with epilepsy in adults (Ngugi et al., 2013). Furthermore, under-nutrition was detected in up to 25 per cent of African children with epilepsy under the age of 10 years (Kariuki et al., 2014; Quet et al., 2011). Malnutrition may therefore be both a cause, due to insufficient micronutrients in the diet, and a consequence of epilepsy, for example, due to stigma (Crepin et al., 2007).

2.5 Epidemiology

To date, no epidemiologic studies have been performed to determine the prevalence and incidence of epilepsy in Namibia (Angula, 2016). However, according to recent studies, epilepsy affects between 65 and 70 million people across the world (Ba-Diop et al., 2014; Ngugi, Bottomley, Kleinschmidt, Sander, & Newton, 2010). Of these,

between 80 and 90 per cent are found in developing countries (Ba-Diop et al., 2014; Ngugi et al., 2010).

2.5.1 Prevalence

Epilepsy prevalence in SSA is estimated at almost double that of North America, Europe and Asia, with median prevalence set at 14.2 per 1 000 compared to 5.8 per 1 000 in more developed countries (Ba-Diop et al., 2014). Epilepsy prevalence in developing countries has even been reported as high as 5-74/1 000 (Preux & Druet-Cabanac, 2005). Increased access to healthcare services in urban areas may play a role in the lower prevalence of epilepsy in these areas (Ngugi et al., 2010). However, this variation may be also be attributed to regional differences in risk factors such as a higher degree of parasitic infections and poor antenatal care in SSA (Ba-Diop et al., 2014; Ngugi et al., 2013; A. Singh & Trevick, 2016). The impact of certain risk factors is evident when one compares the epilepsy prevalence of urban and rural populations in SAA. In Nigeria, an epilepsy prevalence of 20.8/1 000 was found in a rural community compared to 4.7/1 000 in a semi-urban community (Osakwe, Otte, & Alo, 2014). Similarly, a high prevalence of 49/1000 was found in a study conducted in rural Rwanda (Sebera et al., 2015).

2.5.2 Incidence

Few studies have been published on the incidence of epilepsy in SSA specifically (Ba-Diop et al., 2014). However, findings from a 2011 meta-analysis reported a median epilepsy incidence of 50.4/100 000/year with a high annual incidence of 81.7 per 100 000 for low- and middle-income countries, compared to 45.0 per 100 000 for high-income countries (Ngugi et al., 2011).

2.5.3 Gender

Most studies report no statistically significant difference in epilepsy prevalence between men and women (Ba-Diop et al., 2014; Institute of Medicine, 2012). A large population-based cross-sectional study conducted in SSA reported epilepsy prevalence as 30 per cent higher in Kenyan males compared to females, although differences in male/female prevalence across the remaining four centres in the study varied marginally or not at all (Ngugi et al., 2013). A systematic review of SSA studies on epilepsy reported no gender difference in the age group 0–39, although a higher prevalence was observed among women between the ages of 40 and 59 and among men between the ages of 20 and 39 (Paul et al., 2012).

2.5.4 Age

Even though epilepsy affects people of all ages, it most often starts in childhood or late adulthood (Institute of Medicine, 2012). In the same study mentioned above, epilepsy prevalence was found to be 60 per cent higher in adolescents and young adults in the age group 13 to 28 than in children aged 0 to 5 years (Ngugi et al., 2013). Similarly, in Nigeria, the age range of 7 to 24 presented the highest epilepsy prevalence (Osakwe et al., 2014). Likewise, a systematic review of 32 SSA studies on epilepsy revealed that epilepsy prevalence peaks between ages 20 and 29 and again between ages 40 and 59 (Paul et al., 2012).

2.6 Diagnostic techniques

Accurately diagnosing epilepsy can be difficult as clinicians seldom have the opportunity to witness a seizure first-hand and often have to rely on reports by patients and other witnesses (Institute of Medicine, 2012). Diagnosis is further complicated by

medical conditions that look like seizures, but which are in reality not epilepsy (Institute of Medicine, 2012). The gold standard for diagnosing epilepsy is an electroencephalography (EEG) or video-EEG recording of semiological activity in the brain (Dixit, Banerjee, Chandra, & Tripathi, 2017). EEG is used to track and record brainwaves to detect abnormalities in electrical activity, which registers as asynchronous patterns indicative of seizure activity (Holtz, 2011). Unfortunately, epilepsy is frequently misdiagnosed due to the over-interpretation of EEG results and its accuracy is, therefore, sometimes questioned (Benbadis & Lin, 2008).

The current recommendation is that people who present with a first seizure undergo a full neurodiagnostic evaluation. This includes an EEG recording, a computerized tomography of the head (CT) and magnetic resonance imaging (MRI) scan (Institute of Medicine, 2012; Krumholz et al., 2007). This is in addition to a full physical and neurologic examination and an investigation of the patient's medical history (Krumholz et al., 2007). Laboratory testing of blood glucose, blood counts and electrolyte panels may sometimes be helpful, although there is insufficient data to support its necessity in the diagnosis of epilepsy (Krumholz et al., 2007). Unfortunately, physical examination and clinical history are often the only diagnostic modalities available in developing countries due to the lack of specialized equipment such as EEG, CT and MRI scans (Kvalsund & Birbeck, 2012). According to the World Health Organization, Namibia is no exception, as they report that Namibia has 4.78 CT units, 0.87 MRI units and 0.77 EEG monitors per million people (World Health Organization, 2016). However, an interesting study conducted in India reported that mobile phone images can be successfully harnessed to accurately classify epilepsy (Dash et al., 2016). This finding may have benefits for a developing country such as Namibia where mobile phones are readily available.

2.7 Treatment

Moshé et al. (2015, p. 894) state that “epilepsy is a multifaceted disease that needs a comprehensive approach” and that barriers that prevent PWE from leading a productive life include gaps in knowledge, treatment, diagnosis, education, advocacy, legislation and research. The authors continue to explain that poor understanding of the numerous components of epilepsy and its implications contribute to the knowledge gap among healthcare professionals (Moshé et al., 2015). Similarly, Birbeck et al. (2007) state that the well-being of PWE can only be improved through multimodal strategies that address stigma, psychoeducation, advocacy of social and economic decision-makers and the promotion of empowerment among PWE.

It is evident from the above literature that epilepsy has severe and debilitating effects on all aspects of a person’s life beyond the immediate impact of the seizures itself. Treatment and intervention programmes for epilepsy should therefore be tailored to the specific needs and experiences of the individual PWE.

2.7.1 Pharmacology

Epilepsy is primarily treated with medication that aims to control seizure recurrence (Ba-Diop et al., 2014; Institute of Medicine, 2012). A multitude of anti-epileptic drugs (AEDs) are available for the treatment of seizures and they are often prescribed for people with epilepsy (Institute of Medicine, 2012). Although treatment with AEDs can control seizures in approximately 70 per cent of PWE, unwanted adverse and toxic effects often lead to treatment failure and eventual discontinuation (Perucca & Gilliam, 2012; S. P. Singh, Sankaraneni, & Antony, 2017). Common side effects of AEDs include for example headaches, fatigue, cognitive impairment, depression, irritability, double vision, agitation, aggressive behaviours, ataxia, fluctuations in weight and

decreased bone mineral density (Perucca & Gilliam, 2012). In order to minimize the adverse effects of AEDs, patients should be educated about the use of AEDs and regular clinical monitoring and preventative measures should be implemented (Perucca & Gilliam, 2012).

In developing countries, a large proportion of PWE do not receive AED treatment (Cameron et al., 2012; Mbuba, Ngugi, Newton, & Carter, 2008). The number of people who require treatment for epilepsy in Africa but who are not receiving it, known as the treatment gap, is estimated at approximately 75 per cent for low-income countries and 90 per cent for the poorest in Africa (Kvalsund & Birbeck, 2012). A combination of factors contributes to the treatment gap and they often relate to the healthcare infrastructure, such as inadequately skilled manpower, insufficient healthcare financing and unavailability of AEDs (Cameron et al., 2012; Mbuba et al., 2008). Treatment seeking among PWE is also influenced by long travel times to reach healthcare facilities and traditional and cultural beliefs regarding epilepsy (Mbuba et al., 2008).

2.7.2 Surgery

Some types of epilepsy are amenable to surgery, which can be a potential treatment option for people whose seizures do not respond to medication (Institute of Medicine, 2012). “Surgical treatment includes resection, destruction, or disconnection of epileptic brain tissue” and depends on the localization of the epileptic zone (Moshé et al., 2015, p. 892). The success rate of surgery for certain types of epilepsy ranges between 50 to 87 per cent (Chandra & Tripathi, 2010). However, more research is needed to assess the long-term results and effectiveness of surgery compared to other types of treatment (Institute of Medicine, 2012; Moshé et al., 2015; S. P. Singh et al.,

2017). Unfortunately, epilepsy surgery is rarely performed in resource-poor countries such as in SSA due to the high cost, the low number of neurosurgeons and the lack of sophisticated technology (Ba-Diop et al., 2014; Boling et al., 2009; A. Singh & Trevick, 2016).

2.7.3 Vagal nerve stimulation

Stimulation of the vagus nerve is reserved for people who suffer from severe epilepsies, who are not ideal candidates for surgery and who have failed multiple medications (Institute of Medicine, 2012; Moshé et al., 2015; S. P. Singh et al., 2017). This type of deep brain stimulation entails the implantation of a device that is designed to prevent seizures through the electrical stimulation of the vagus nerve when abnormal electric activity is detected in the cortex (Moshé et al., 2015). Due to its high cost, this type of treatment is not widely available in SSA (Caraballo & Fejerman, 2015).

2.7.4 Psychotherapy

Psychological therapies can be an integral part of the treatment of mental health disorders in PWE (Tang, Michaelis, & Kwan, 2014). Notwithstanding the fact that few studies have investigated the efficacy of combination therapy in PWE, it is suggested that psychotherapy can consolidate the efficacy of medication intervention (Kanner et al., 2012). In this context, a recent systematic review found that “psychotherapy can improve depression and anxiety in patients with epilepsy” (Mehndiratta & Sajatovic, 2013, p. 39). Although psycho-behavioural therapies aim to improve the individual’s ability to cope with epilepsy, it may also increase psychological well-being and seizure control (Tang et al., 2014). Two systematic reviews of cognitive behavioural therapy

(CBT) for PWE suggest that this type of treatment may be effective for the treatment of depressive symptoms in PWE (Gandy, Sharpe, & Perry, 2013; Leeman-Markowski & Schachter, 2017). Trigger management as part of behavioural therapy aims to teach PWE “how to recognize or identify possible seizure triggers by observing environmental, personal, or lifestyle factors (such as lack of sleep, flashing lights, fever, or excessive alcohol consumption) that appear to increase their susceptibility to seizures” (Institute of Medicine, 2012, p. 171). Some psychosocial treatment interventions show promise in addressing the treatment needs of PWE, such as programmes that focus on social adjustment, improving quality of life, medication education and adjustment to seizures (Mittan, 2009).

2.8 Psychiatric comorbidities

There seems to be an increased likelihood of psychiatric disorders in PWE, as is the case with many other chronic conditions (Angus-Leppan & Parsons, 2008). Findings of epidemiologic studies suggest a bidirectional relationship between psychiatric disorders and epilepsy, which implies “that not only are PWE at greater risk of developing psychiatric comorbidities, but also patients with primary psychiatric disorders are at greater risk of developing epilepsy” (Kanner, 2016, p. 307).

Depression and anxiety are particularly dominant in PWE and with levels higher than those found in the general population (Angus-Leppan & Parsons, 2008; Green, Norman, & Reuber, 2017). In a study conducted in Zambia, 60 per cent of PWE reported symptoms suggestive of underlying depressive and/or anxiety disorders (Mbewe, Uys, & Birbeck, 2013). It was also found that suicide risk is elevated in people with depression and comorbid anxiety (Kanner et al., 2012). Furthermore, stress may be a trigger for seizures in PWE and it is also regarded as a risk factor for

the development of anxiety and depression (Lee, Lee, & No, 2010). Interestingly, PWE mention that seizures are often precipitated by stressful situations (Lee et al., 2010; Nakken et al., 2005). Other psychiatric comorbidities include attention deficit hyperactivity disorder (ADHD), bipolar disorder, movement disorder, pain disorders and sleep disorders (Ottman et al., 2011). In a study conducted in the U.S., bipolar disorder, ADHD and movement disorder “were more than twice as prevalent in people with versus without epilepsy” (Ottman et al., 2011, p. 314).

2.9 Medical comorbidities

The most frequently stated medical comorbidities in PWE as reported in a study conducted in the UK include arthritis, diabetes, stroke, migraine, asthma, heart disease and fractures (Linehan, Tellez-Zenteno, Burneo, & Berg, 2011). Injuries sustained as a result of epilepsy vary according to geographic location, with falls into an open fire indicated as the most common cause of injury in Africa, while motor vehicle accidents and drowning are the most common in the UK (Angus-Leppan & Parsons, 2008). A study conducted in China reports that the risk of premature death in PWE is approximately five times higher than in the general population (Mu et al., 2011). Deaths were most often due to accidents (59%), drowning (45%), sudden unexpected death in epilepsy (14%) and status epilepticus (6.9%) (Mu et al., 2011).

2.10 Psychosocial factors

In addition to psychiatric and medical comorbidities, epilepsy can have a profound effect on day-to-day life, such as the perception of personal control, work and income, transportation and interpersonal relationships (Lin, Mula, & Hermann, 2012). The Commission for the Control of Epilepsy and its Consequences stated in 1975 that “[p]ossibly the least understood and most neglected aspects of epilepsy are the social,

psychological, and behavioural problems that are so common... [These] can be more handicapping than the actual seizures, yet these problems often are unrecognized and little skilled assistance is available” (as cited in Mittan, 2009, p. 371). In the past five years (2010–2014), advances in the understanding of the psychosocial and behavioural comorbidities of epilepsy resulted in a greater than 2.5-fold increase in the number of articles published in a prominent epilepsy journal that include the terms “psychosocial”, “behavioural” and “psycho-behavioural” (Wagner, 2014). This seems to be a reflection of the increased awareness that psychological and social factors play an important role in the lives of PWE. Unfortunately, a limited number of these studies focus on epilepsy in an African context.

The Global Burden of Disease Study 2015 found that only HIV infection had greater disability weight than uncontrolled, severe epilepsy (GBD 2015 DALYs and HALE Collaborators, 2016). Additionally, it is reported that PWE “have significant neuropsychological, psychiatric, and social impairments that limit their education, employment opportunities, and possibilities for marriage” (Zhao et al., 2012, p. 369). This was confirmed by the Global Burden of Disease Study 2015, which stated that life chances are reduced for adults with epilepsy in terms of marriage and employment and that they face devastating social consequences, such as premature mortality, stigma and discrimination (GBD 2015 DALYs and HALE Collaborators, 2016).

For example, PWE in Zambia reported higher mean perceived stigma scores, less education and poorer employment status (Birbeck et al., 2007). Furthermore, in a study conducted in Zimbabwe, one quarter of respondents experienced problems with interpersonal relationships, difficulties with public transport when required to travel long distances and sexual functioning (Mielke et al., 2000). Suicide among PWE is

common in Nigeria and is associated with emotional distress and poor seizure control (Nuhu, Lasisi, Yusuf, & Aremu, 2013). In a study conducted on epilepsy patients in rural Zambia, it was found that functional difficulties were reported in the domains of solving daily problems, the speed of thinking, relationships with co-workers, friends and family and using public transportation (Birbeck et al., 2007).

Studies conducted elsewhere in the world corroborated the above findings with PWE in both China and Vietnam. These studies described epilepsy as enormously disruptive and reported that it impacts significantly on other family members as well as employment and marriage prospects (Jacoby et al., 2008). This was also confirmed in a study performed by Kobau et al. (2014) in which adults with epilepsy reported significantly worse psychological health, more cognitive impairment, difficulty in participating in some social activities and reduced health-related quality of life. It is evident from the literature that living with epilepsy is challenging, not only because of the constant uncertainty associated with seizures, but mainly because of comorbid mental illness, social disadvantage, stigma, cognitive dysfunction and limitations on daily activities (Institute of Medicine, 2012).

2.11 Coping with epilepsy

Adapting to a diagnosis of epilepsy relates to four main spheres of psychosocial problems as outlined by Livneh, Wilson, Duchesneau and Antonak (2001). These include “the anxiety and concerns about the unpredictability of the disease, the stigma associated with the diagnostic label of epilepsy, the impact of epilepsy-specific life stressors, and the consequences related to denial of the condition” (Bautista, Rundle-Gonzalez, Awad, & Erwin, 2013, p. 286). The manner in which people cope with these psychosocial problems is determined by a combination of factors such as personality

type, cognitive abilities and environmental circumstances (Lazarus & Folkman, 1984). Coping strategies are traditionally classified as either problem-focused, for example when individuals attempt to actively manage their condition through information seeking, planning and positive reframing; or emotion-focused, where techniques such as avoidance and denial are used (Bautista et al., 2013; Livneh et al., 2001).

Results from a study conducted in the U.S. indicate that PWE favour problem-focused strategies such as religion, acceptance and emotional support over emotion-focused strategies such as humour, denial and substance abuse (Bautista et al., 2013). Problem-focused coping was also associated with increased psychosocial outcomes and decreased levels of depression and anxiety in PWE (Livneh et al., 2001). The type of coping strategy employed, whether problem- or emotion-focused, is mediated by a personality characteristic called locus of control (Quintas et al., 2012). An individual's views regarding the amount of control they have over events in their lives can be either internal (outcomes are due to their own efforts) or external (consequences are the result of chance, luck or fate and they have little personal control over events) (Colman, 2006). A more passive stance and depressive type thinking are associated with an external locus of control, which is reported to be more prevalent in PWE than in the general population (Hermann & Jacoby, 2009). It is then not surprising that older adults with epilepsy describe the condition as a balancing act between loss of control, stigma, reliance on others and a desire for "strategies to restore loss of control, acceptance, increased awareness of epilepsy and supportive relationships" (Yennadiou & Wolverson, 2017, p. 87).

Several studies highlight the importance of programmes and interventions aimed at improving the coping abilities of PWE. These include the importance of exercise and

diets, participation in sport, the self-management of epilepsy, psycho-education, the involvement of family in the management of epilepsy and programmes aimed at increasing epilepsy awareness and decreasing stigma (Bautista, 2017; Capovilla, Kaufman, Perucca, Moshé, & Arida, 2016; Elliott, Lu, Moore, McAuley, & Long, 2008; Mameniškienė, Guk, & Jatužis, 2017; Miller, Bakas, & Buelow, 2014; Njamnshi, Angwafor, Tabah, Jallon, & Muna, 2009; Ridsdale, Philpott, Krooupa, & Morgan, 2017).

2.12 Stigmatization, marginalization and exclusion

Knowledge about epilepsy is often crippled by misbeliefs that may lead to stigma and hamper access to appropriate health care services and treatments for epilepsy (Tran et al., 2007). Especially in Africa, epilepsy is often seen as a curse or the result of witchcraft or possession by evil spirits (Darghal, 2010; Mushi et al., 2011; Osungbade & Siyanbade, 2011). The resultant stigma from these erroneous beliefs leads to reduced opportunities for employment, marriage and education among PWE (Wilmshurst, Birbeck, & Newton, 2014). This may further lead to poverty, food insecurity, physical vulnerability and even physical and sexual abuse (Birbeck et al., 2007; Birbeck & Hesdorffer, 2011; Carter et al., 2012; Chomba, Haworth, Atadzhanov, Mbewe, & Birbeck, 2007).

It is then not surprising that a strong link between epilepsy and poverty was established in Ethiopia and that it is associated with subsistence farming and lower educational achievement (Vaid et al., 2012). Furthermore, in a study conducted in Rwanda, respondents indicated a high level of stigmatized beliefs, with 66 per cent indicating that PWE “should not be entitled to schooling, to work (72%), the use of public places (69%), or to marriage (66%)” (Sebera et al., 2015, p. 128). Fifty per cent of respondents

in the same study believed that epilepsy was untreatable and 40 per cent indicated that it was a contagious disease (Sebera et al., 2015). Similar attitudes were reflected in a study conducted in Laos with widely shared beliefs that epilepsy is contagious (57%), fatal (60%), incurable (>75%), and attitudes such as that respondents would not share a meal with a PWE (62.7%) or allow someone from the household to marry a PWE (61.4%) (Tran et al., 2007). In a study conducted in Cameroon, 35 per cent of respondents linked epilepsy to insanity and indicated that women with epilepsy are unable to fulfil community expectations of marriage such as raising children and doing household chores (Njamnshi et al., 2009). In the same study, 57.3 per cent of respondents discriminated against the employment of PWE (Njamnshi et al., 2009).

It is evident from the above literature that PWE in Africa face huge barriers and that interventions to decrease stigma and increase awareness are greatly needed.

2.13 Epilepsy in Namibia

There appears to be a lack of scholarly sources on epilepsy in Namibia, however, the founder of the only support organisation for PWE in Namibia state that the epilepsy prevalence in Namibia appears higher than the global average of 1 in 100 (H. Riphagen, Personal communication, Epilepsy Namibia, 27 June 2016). She continues to explain that the higher prevalence of epilepsy in Namibia can be ascribed to tropical illnesses, worm infections and substance abuse. According to Ms Riphagen, PWE in Namibia often face challenges such as stigma, discrimination and isolation by their communities. For this reason, Epilepsy Namibia renders assistance to PWE and their families by offering support, lifestyle management, training and advocacy (H. Riphagen, Personal communication, Epilepsy Namibia, 27 June 2016). In an attempt to raise awareness about epilepsy in Namibia, this organisation spearheads several

social education and awareness-raising programmes through the use of public and social media such as posters, pamphlets, web and Facebook pages, radio and television appearances, print media and training programmes (Gray, 2017). In addition to these efforts, social workers in Namibia are lobbying for more resources for PWE from the government (Gray, 2017). It appears from the above information that there is a definite need for more research on epilepsy in Namibia. The availability of more information on epilepsy in Namibia can strengthen appeals to government and other stakeholders for resources to assist and support PWE in Namibia.

2.14 Theoretical framework

Whether a qualitative or quantitative approach is used, theory greatly contributes to the framing and execution of every phase of a research study (Anfara Jr. & Mertz, 2006). A theoretical framework guides an investigation by integrating the purpose for conducting the specific study with fundamental beliefs and assumptions regarding the topic (Anfara Jr. & Mertz, 2006).

The medical community continues to focus primarily on freedom from seizures (the biomedical model) despite growing evidence that psychological and social factors have the greatest impact on the lives of PWE (Elliott & Richardson, 2014). In order to take into account the role of psychological and social factors in the maintenance of epilepsy, the researcher decided to use the biopsychosocial model of George Engel, first penned in 1977 (Engel, 2012), to interpret the everyday problems, needs and coping strategies of AWE.

This model emphasizes the bidirectional relationship between the “biological and social influences on people’s well-being and their mental and physical health” (Elliott & Richardson, 2014, p. 56). For purposes of this study, the biological domain of the

model was conceptualized as factors that describe the physical or medical aspects of the AWE. These include the age, gender, comorbid somatic conditions, age at onset of seizures and number of primary care visits in the past year (Elliott & Charyton, 2014; Elliott & Richardson, 2014). The psychological domain was defined to include active psychological/psychiatric conditions such as anxiety, depression, post-traumatic stress disorder, history of suicide ideation or attempts, self-perceived life stress and mental healthcare utilization in the past year (Elliott & Charyton, 2014; Elliott & Richardson, 2014). The social domain describes the sociocultural, socio-political and socioeconomic factors that play a role in the person's life (Elliott & Richardson, 2014). These factors are represented by marital or relationship status, employment, education, annual income, family structures and sense of belonging to the community (Elliott & Charyton, 2014; Elliott & Richardson, 2014).

The model as described above was therefore used to interpret and make sense of the experiences of AWE across the biological, psychological and social domains of the person's life and how these interact to form a coherent whole.

2.15 Chapter summary

An overview of the literature on epilepsy was provided in this chapter, with a specific focus on conditions in SSA. First, the historical background of epilepsy was discussed, followed by an outline of the classification and clinical definition of the condition. Next, a comprehensive account of the aetiology underlying epilepsy was provided, as well as the epidemiology, diagnostic techniques and treatment options. Thereafter, the available literature on the psychiatric and medical comorbidities was discussed, together with the psychosocial factors, coping strategies, and stigmatization and marginalization of PWE. Finally, a brief overview of epilepsy in Namibia was

provided. The chapter concluded with an outline of the biopsychosocial model that was used to interpret the findings of the present study. The next chapter focuses on the research methodology that was utilized in the study.

CHAPTER 3: METHODOLOGY

3.1 Introduction

This chapter discusses the research methodology employed in this study. First, the chapter outlines the research design. It then continues to focus on the description and selection of participants and the research instruments used in the study. Thereafter, the data collection procedures are described. This is followed by a discussion of the data analysis procedures and the processes used to ensure trustworthiness. Finally, the ethical considerations applied to the study are described.

3.2 Research design

The research study made use of an exploratory qualitative research design. Since PWE encounter unique challenges in their daily lives, it is essential to explore and understand these and the impact they have on the everyday functioning of the PWE (Pugh et al., 2005). Despite its ability to attain a deep understanding of individual experiences, qualitative methodologies remain underutilized due to the opinion that these approaches are too subjective (Resch et al., 2010). However, Merriam (2002) argues that qualitative studies are useful to understand the meaning that people construct about their world and their experiences. Furthermore, qualitative research methods enable the researcher to generate a deeper understanding of the complexity of human illness behaviours (Johnson, 2004). A qualitative research design was, therefore, deemed appropriate for this study, which aimed to understand and make sense of epilepsy from the participant's perspective and to provide a richly descriptive account of the information.

3.3 Participants

Purposeful sampling techniques were used to identify 10 potential participants from the available epilepsy population in the Khomas region. Purposeful sampling in qualitative research allows for the selection of information-rich cases that will provide data to satisfy the research aims (Patton, 1999). Furthermore, in qualitative research, the sample size is determined by the context and purpose of the study (Johnson, 2004). Consequently, qualitative studies aim to produce depth rather than breadth (Sandelowski, 1986). Sample sizes are therefore not intended to achieve statistical representativity, but instead to reflect the diversity of the study population (Popay, Rogers, & Williams, 1998). The total number of interviews ultimately depends on theoretical saturation and this is reached when various themes are repeatedly mentioned during the preceding interviews and no new information emerges (Lincoln & Guba, 1985). The ideal is to aim for a sample size of 12–15 participants so that the research can reach a point where no new information is forthcoming from the interviews (Morrow, 2005).

The participants had to be adults over the age of 18 years, not attending school and had to reside in the Khomas region. The eligibility criterion for each ES participant was a confirmed diagnosis of epilepsy by an experienced practitioner based on the results of EEG monitoring. Patients who are cognitively challenged were excluded from the study.

3.4 Research instruments

A self-developed questionnaire (Appendix B) was used to gather biographical information such as the participant's name, age, gender, home language, employment and relationship status, time since diagnosis, type of epilepsy, seizure frequency and

current treatment plan. This information was required for descriptive purposes and to establish the demographics of AWE in the Khomas region.

The research was further conducted using a self-designed interview guide to conduct semi-structured interviews (Appendix C). This questionnaire consisted of 15 broad open-ended questions that focused on the everyday problems and needs that the PWE encountered and the coping strategies used since the participant received a diagnosis of epilepsy.

The following questions were used to guide the interviews:

1. Do you experience everyday problems because of your seizures? If so, what type of problems?
2. Do you have any specific needs because you are a person with epilepsy? If so, what type of needs?
3. How do you cope with everyday problems and needs?
4. In your opinion, what are the main challenges that PWE encounter?
5. What are the general attitudes/reactions from people when they find out you have epilepsy?

3.5 Data collection procedures

Epilepsy Namibia is the only epilepsy support organization in Namibia. They keep an informal register of PWE. In order to select a sample of AWE, the researcher forwarded a letter of invitation (Appendix D) that explained the nature of the study to Epilepsy Namibia. This letter was circulated to members of Epilepsy Namibia who met the inclusion criteria. AWE who were prepared to participate in the study contacted the researcher directly to indicate their willingness to partake in the study.

Individuals who met the inclusion criteria were contacted via telephone and a meeting was arranged at a time and a place that suited the participant. Prior to conducting the interview, the relevance and purpose of the study were explained to the participant and questions regarding the study were answered. The participant was then asked to read and sign the informed consent form (Appendix E) and to complete the biographical questionnaire (Appendix B). Permission was requested from the participant to record the interview for the purposes of the transcription process. Once permission had been obtained from the participant, the researcher commenced with the interview (Appendix C). The semi-structured interview consisted of broad open-ended questions to prompt participants to elaborate on his or her experiences on living with epilepsy. Probing techniques were used in response to participants' comments during the interviews to obtain as much information as possible from each participant. The researcher assumed a flexible attitude to allow participants to lead the discussion and talk about the issues that were most important to them. Interviews lasted between 30 and 50 minutes. Each interview ended by thanking the participant for their time and willingness to participate in the study.

3.6 Data analysis

Thorne (2000) states that a qualitative researcher should take a critical and dynamic stance throughout the process of data analysis to make sure that raw data are successfully transformed into meaningful knowledge. Some analytic approaches describe various methods of analysing qualitative data such as content analysis, narrative analysis, thematic analysis, grounded theory, case survey and thematic networks (Attride-Sterling, 2001; Bazeley, 2009; Braun & Clarke, 2006; Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005; Thorne, 2000). However, these

approaches vary in their strengths, weaknesses and ability to manage different forms of evidence and the nature of the questions for which it is most suitable (Dixon-Woods et al., 2005; Thorne, 2000). For purposes of this study, thematic analysis was deemed most suitable to explore and describe the everyday problems, needs and coping strategies of AWE. Thematic analysis can be regarded as a foundational method that creates basic skills that can be applied to several other methods of qualitative analysis (Braun & Clarke, 2006).

Thematic analysis is a set of procedures that are used to identify, analyse and report themes or patterns across a dataset (Braun & Clarke, 2006). It is a flexible and convenient method that requires basic theoretical knowledge without being tied to a specific theoretical framework (Braun & Clarke, 2006). However, the researcher is expected to apply a rigorous and deliberate thematic approach to produce an insightful analysis that addresses the research questions (Braun & Clarke, 2006). Braun and Clarke (2006) provide a clear set of guidelines for performing thematic analysis that includes six distinct phases of analysis.

The first phase requires the researcher to become completely familiar with the data through a process of actively reading and rereading it (Braun & Clarke, 2006). The individual interviews with AWE were transcribed by a transcription service due to time constraints. Once the completed transcripts had been received, the original audio recordings were compared to the transcripts to ensure that they are an accurate reflection of the original interview. The transcripts were reread a second time to enable the researcher to start noting patterns in the data, which formed the basis for subsequent phases of analysis.

Phase 2 required the researcher to create preliminary codes based on the initial patterns

that had been identified during phase one (Braun & Clarke, 2006). A coding system was created based on features in the data that related to the research questions of the study. First, a hard copy of each transcript was printed and coloured pens were used to mark important features in each of the interviews. Microsoft OneNote was then used to group the marked portions electronically on different pages in one section. Those sections of the interviews that were relevant to a specific code were copied and pasted to the corresponding page. Each piece of data was referenced with a unique code that identified the original interviewee. Finally, some pages could be combined, while others were eliminated in order to arrive at a complete picture of the data.

The third phase of analysis required the researcher to start identifying overarching themes in the data (Braun & Clarke, 2006). Themes can be described as recurring patterns in the dataset that address and are relevant to the research questions (Braun & Clarke, 2006). Themes are created by combining the different coded sections and data extracts according to the various patterns identified in the data (Braun & Clarke, 2006). The selection of themes was based on the researcher's own judgement regarding the relevance of the coded extracts with respect to the various everyday problems, needs and coping strategies of AWE. This process was further facilitated by tabulating the different domains of the biopsychosocial model (Engel, 2012), namely the biological, psychological, and social domains. An illustrative mind-mapping tool called thematic networks (Attride-Sterling, 2001) was then used to organize themes according to the various domains. Finally, the various codes were added to the thematic network, which enabled the researcher to identify patterns of repetition within the dataset (Braun & Clarke, 2006). At the end of this phase, the various themes, subthemes and coded extracts, organized according to the various domains, provided an overall impression of the entire dataset.

Phase 4 required the researcher to refine the themes by critically evaluating the relevance of the coded extracts to each theme and the dataset in its entirety (Braun & Clarke, 2006). This evaluation process enabled the researcher to remove redundant themes, to combine some themes to form a coherent whole, while others were divided into separate themes (Braun & Clarke, 2006). By the end of this stage, the researcher had a clear understanding of the overall picture of the dataset and how the various themes interact to form a cohesive narrative (Braun & Clarke, 2006).

During Phase 5, the researcher was able to organize the themes into a coherent whole and continued to create subthemes that complemented each individual theme (Braun & Clarke, 2006). A detailed analysis of each theme was then created in a clear, concise and organized manner.

Phase 6 required the researcher to write a report that relates the complex story of the data in a convincing manner (Braun & Clarke, 2006). The researcher should attempt to convince the reader of the merit and strength of the data analysis by using vivid examples and extracts from the data (Braun & Clarke, 2006). The final report tells the story of the data in a continuous and logical way, using evidence in the form of direct quotations to support the themes. During this process, the researcher aimed to apply the analytic narrative not merely as a description of the data, but as an argument that answers the research questions. The results of the study are reported in Chapter 4 according to the various domains of the biopsychosocial model (Engel, 2012) and the main and subthemes that were identified as everyday problems, needs and coping strategies of AWE.

3.7 Maintaining trustworthiness

The value of quantitative research is evaluated using criteria such as reliability and

validity. However, the use of these methods has been questioned in qualitative research (Long & Johnson, 2000). Instead, the concept of trustworthiness is proposed as a method to test the worthiness of a qualitative research study (Guba, 1981). To this end, Guba (1981) proposes four criteria that are applicable to a trustworthy study, namely credibility, transferability, dependability and confirmability.

3.7.1 Credibility

Credibility can be defined as “the methodological procedures and sources used to establish a sound level of congruence between participants’ expressions and the researcher’s interpretations of their expressions” (Jensen, 2008b, p. 3). Peer debriefing and member checks were used to ensure that the data reflected a truthful, accurate and fair picture of the phenomenon being studied (Given & Saumure, 2008; Long & Johnson, 2000; Shenton, 2004).

Peer Debriefing. Peer debriefing can be described as a process during which the researcher and superiors discuss emerging findings in order to establish a sounding board for ideas, to identify biases in thinking and to generate different perspectives and explanations regarding the research project (Shenton, 2004). This measure was achieved by regularly engaging in discussions with the research supervisor to receive guidance and to explore emerging ideas and areas of concern regarding the study.

Member Checks. Member checking allows participants the opportunity to verify the findings of the collected data to establish that it is a true representation of their viewpoint (Krefting, 1991; Long & Johnson, 2000; Shenton, 2004). Checks were performed both during and after the interview process. During interviews, the researcher summarized the key points and participants were requested to confirm

whether their words were correctly interpreted. After the transcription process, some of the participants were asked to verify their transcripts to clarify and correct information that was unclear during the recording process.

3.7.2 Transferability

Transferability is the equivalent of external validity and describes the extent to which the research findings can be generalized to different situations or contexts (Jensen, 2008c; Merriam, 1995). In order to allow other researchers to decide whether the findings of a study can be transferred to other settings, the researcher has to provide detailed contextual information regarding the study to enable them to make an informed decision (Merriam, 1995). Consequently, the researcher provided comprehensive accounts of the research study, the topic and the participants to enable users to arrive at their own conclusions regarding the transferability of the findings (Morrow, 2005).

3.7.3 Dependability

Dependability reflects the concept of reliability in quantitative research and determines whether a qualitative study can be replicated, yielding the same results, without undue variation as a result of historical effects or maturation (Shenton, 2004). Future researchers should be able to arrive at similar results when provided with adequate methodological information on the study (Saumure & Given, 2008). In order to achieve dependability, in-depth descriptions of data collection methods, steps taken during analysis and reporting of the results are provided.

3.7.4 Confirmability

Confirmability is comparable to objectivity in quantitative research and is concerned with the degree to which the findings of a study excludes the beliefs and biases of the researcher and truly reflect the perceptions of the participants (Decrop, 1999; Jensen, 2008a). The researcher used reflexivity and triangulation to manage the influence of subjectivity.

Reflexivity. Researcher reflexivity allows the researcher the opportunity to reflect on how personal experiences, subjective values, feelings, attitudes and worldviews may affect the research process (Long & Johnson, 2000; Morrow, 2005). A possible factor that may have influenced the way in which the researcher approached this study is the fact that the researcher is still a novice and in the process of developing a workable knowledge of research processes. Furthermore, as a mature student, the researcher has been involved in the field of psychology for the past 12 years, which may have created some preconceived ideas about mental health, treatment options and general healthcare. In addition, the researcher is married to a person with epilepsy, which in some respects may have given her a better understanding of the challenges encountered by other AWE, but at the same time may also have coloured her own perception of the participants. In order to reduce the impact of researcher bias and subjectivity, a descriptive profile of each participant (Appendix F) was compiled in which the researcher reflected on the individual interviews.

Triangulation. Triangulation refers to the process of addressing the research questions from different perspectives through the use of multiple data sources, theories and researchers (Decrop, 1999; Long & Johnson, 2000). The purpose of triangulation is to reduce the potential impact of investigator bias on the findings and interpretation of

the study (Decrop, 1999; Long & Johnson, 2000). In this study, the researcher used triangulation of data sources, theory and researchers.

The selection of a diverse group of informants from different contextual backgrounds maximizes understanding of the topic and serves to achieve triangulation of data sources (Krefting, 1991). The researcher recruited participants from different socio-economic backgrounds who differed on variables such as seizure type, time of onset, age and gender to ensure triangulation of data sources.

Theoretical triangulation involves incorporating ideas from different theoretical perspectives to interpret the same data (Decrop, 1999; Guion, 2002; Patton, 1999). This type of triangulation is accomplished by involving individuals from different status positions or disciplines in the interpretation and evaluation of the dataset (Guion, 2002). In order to ensure the triangulation of theory, emerging patterns within the dataset were discussed with the researcher's supervisor to explore and compare various perspectives on the same topic.

Researcher triangulation requires that different investigators interpret and analyse the same dataset (Decrop, 1999; Patton, 1999). Through the comparison of multiple perspectives on the same dataset, the researcher can gain an important "check on selective perception and blind interpretive bias" (Patton, 1999, p. 1195). According to Guion (2002), the results of a study can be confirmed when evaluators from different disciplines or status positions arrive at similar conclusions regarding the findings of the study. Triangulation of researchers was achieved through the involvement of the researcher's supervisor during the process of data analysis. This facilitated the process of identifying and clarifying discrepancies in the final product.

3.8 Ethical considerations

Prior to the commencement of the proposed study, the proposal was reviewed by members of the Faculty of Humanities and Social Sciences' Research and Publications Committee of the University of Namibia after which ethical clearance was granted by the University of Namibia's Research Ethics Committee with Ethical Clearance Reference Number FHSS /238/2017 (Appendix G). Participants were informed about the purpose of the study and that participation in the study is voluntary and that no remuneration will be offered for partaking in the study. Written informed consent was obtained from each participant prior to the commencement of the study. Participants were assured that they could withdraw from the study at any point with no adverse consequences for themselves personally or professionally. Participant identity was not disclosed during the investigation and final results excluded any identifiable information. Participants were identified through a coded numbering system. Participants were informed of the goal of the research and any benefits that may arise because of it. Data collected during the study were stored in a safe and secure environment for the duration of the study and will be appropriately destroyed after a period of three years. The proposed study was classified as low risk as the research was conducted on a largely uncontroversial topic through semi-structured interviews. The participants were adults and not considered a vulnerable research population.

3.9 Chapter summary

This chapter provided a description of the research design and methodology that were employed in the present study. First, the rationale for using a qualitative research design was presented, followed by a description of the participants. The research instruments were discussed next. Thereafter, sampling and data collection were

discussed, as well as procedures that were applied in the thematic analysis. Finally, the steps to ensure trustworthiness and the ethical considerations were described. The next chapter presents the results of the study.

CHAPTER 4: RESULTS

4.1 Introduction

This chapter reports on the results of the study. First, the demographic information of the participants is described. Thereafter, the results of the thematic analysis are reported according to themes and subthemes identified during the analysis process.

4.2 Description of participants

The participants included five males and five females. One of the participants was Coloured, four were African and five were White. The average age of participants ranged from 19 to 54 years (mean = 34) and the average age at diagnosis ranged from birth to 47 (median = 19) (Table 4.1).

Table 4.1

Demographic description of participants

Participant Code	Age	Gender	Race	Age at diagnosis	Employment status
P1	40	Female	Coloured	12	Full-time
P2	19	Female	White	14	Unemployed
P3	24	Female	White	9	Unemployed
P4	38	Female	African	24	Full-time
P5	27	Male	White	6	Self-employed
P6	33	Male	African	27	Student
P7	36	Male	African	25	Temporary
P8	20	Male	African	Birth	Unemployed
P9	54	Male	White	47	Self-employed
P10	47	Female	White	31	Self-employed
Mean 34 M: 50% 4A;1C;5W Median 19					

P = Participant code; 1 to 10 = Sequence in which interviews were conducted

Two of the participants indicated that they are in full-time employment, three were unemployed at the time of the interviews, three are self-employed and one is in temporary employment, while the other is a full-time undergraduate student.

Seizure frequency varied among the participants, with two participants reporting that they experience more than one seizure per week, whereas four participants have as many as four seizures per month. Two participants indicated that they experience approximately four seizures per year, while the remaining two participants stated that they have not experienced any seizures over the past 18 months.

4.3 Results of the thematic analysis

During the data analysis of the semi-structured interviews, one overarching theme emerged in addition to three main themes that encapsulate the problems, needs and ways to cope as expressed by AWE. The overarching theme bridges all three domains and describes the frequent lack of knowledge and awareness about epilepsy. The first main theme, namely the biological and psychological triggers that may result in seizures, stretches across both the biological and psychological domains. The second main theme, which describes the need for employment and education, connects the biological and social domains. Finally, the importance of social support in coping with epilepsy links the psychological and social domains. Results are reported according to the four themes that centre on problems, needs or coping strategies. Thereafter, subthemes are categorized according to the biopsychosocial model (Engel, 2012) to interpret and make sense of the experiences of AWE across the biological, psychological and social domains of the person's life and how these interact to form a coherent whole. Results from the thematic analysis are briefly illustrated in Figure 4.1 and explained in more detail in Table 4.2.

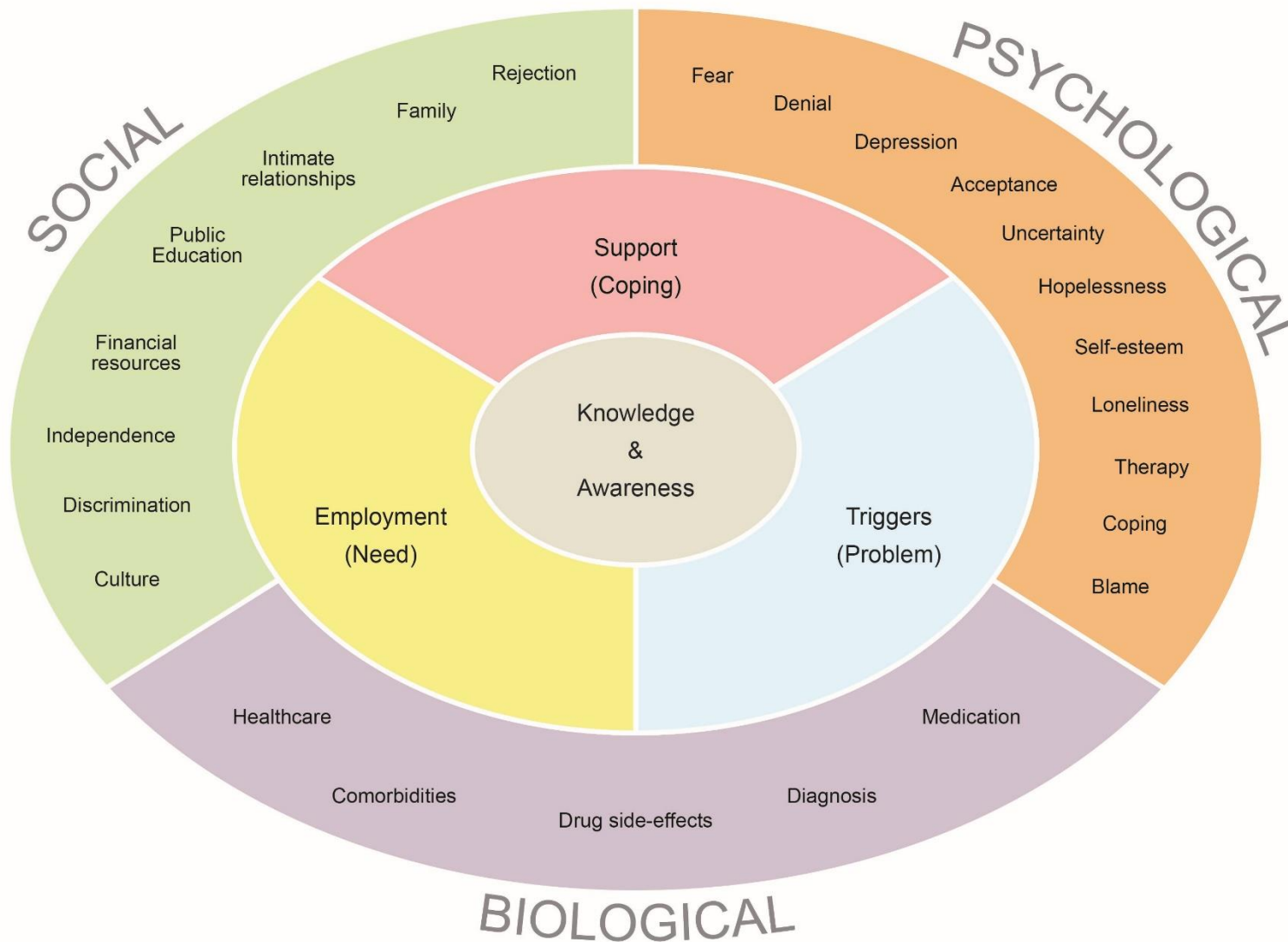


Figure 4.1 A graphical illustration of the main themes and subthemes that were identified as problems, needs and ways to cope according to the different domains of the biopsychosocial model

Table 4.2

Main themes and subthemes that were identified as problems, needs and ways to cope according to the different domains of the biopsychosocial model

	Biological	Psychological	Social
	K N O W L E D G E A N D A W A R E N E S S		
	S e i z u r e T r i g g e r s		
Problems	<ul style="list-style-type: none"> • Inadequate healthcare services • Comorbid health conditions • Challenges due to drug side effects 	<ul style="list-style-type: none"> • Impact of epilepsy on psychological functioning 	<ul style="list-style-type: none"> • The impact of seizures on everyday functioning • The role of cultural attribution
	Need for Employment		and Education
Needs	<ul style="list-style-type: none"> • Need for specialized diagnostic services 	<ul style="list-style-type: none"> • Need to accept epilepsy diagnosis 	<ul style="list-style-type: none"> • Need for employment • Need for independence • Need for financial resources • A need for public education
	The Importance of Social Support		
Coping Mechanisms	<ul style="list-style-type: none"> • Adherence to medication 	<ul style="list-style-type: none"> • The use of a variety of coping strategies • The importance of therapeutic support 	<ul style="list-style-type: none"> • The reliance on social support • The role of intimate relationships • Family as a source of support

4.3.1 Frequent lack of knowledge and awareness about epilepsy

Knowledge and awareness about epilepsy permeate all the themes, subthemes and domains. This theme and its related subthemes can therefore be applied to all the subthemes that emerged during the data analysis. In the biological domain, lack of knowledge is highlighted by the absence of definitive diagnostic results and an understanding of the impact of regular use of AEDs. Failure to recognize that psychological intervention may alleviate some of the effects of being diagnosed with epilepsy is highlighted in the psychological domain. Finally, lack of understanding about epilepsy is by far the most evident in the social domain, where respondents reflected on the reactions of others when faced with a person who experiences a seizure.

4.3.1.1 Biological domain

In the biological domain, the lack of knowledge about epilepsy is reflected in people's ignorance about the different types of epilepsy, the possible side effects that may arise as a result of AEDs and the importance of regular follow-ups to monitor liver functioning.

But they never told me you have this type of epilepsy (P2¹).

I don't know what kind of epilepsy it is because I've never really heard anyone tell me what type it is (P6).

I don't know if I have side effects. I have maybe. I don't know (P7).

¹ Participant code: P = Participant; 1 = Number of the interview

I was supposed to get tested at the government hospital for my liver and the medication, but it was not done. The doctor was telling me I had to go. I was supposed to go, but it was not done. It's about nine years now (P7).

Because every six months my medication has to be renewed, but they don't do any tests they just write the new prescription (P10).

4.3.1.2 Psychological domain

Five respondents commented that they were either never referred to a psychologist or that they did not consider it necessary to seek psychological support after receiving a diagnosis of epilepsy.

I can't remember if someone said that. You cope with it and adjust with it (P10).

I don't know, I never tried it. I just don't feel comfortable speaking out (P2).

4.3.1.3 Social domain

The impact of a lack of understanding and knowledge about epilepsy becomes the most visible in the social domain, where most of the participants described other people's reactions and levels of ignorance when faced with a PWE.

People don't understand it and they have this fear of what will happen when this person has a seizure (P4).

I have a feeling they don't quite know what it is. Many people think she's going to collapse and shiver. People think that people with epilepsy have a disability. They think they are retarded (P3).

Most people just run (P6).

People don't know what to do so they walk away because they are too scared to get involved (P10).

4.3.2 Problems: biopsychological triggers that may result in seizures

Participants explained that seizures can be triggered by biological processes and psychological factors. These processes and factors are influenced by problems in the various domains. The cumulative effect may impact on the overall well-being of AWE.

4.3.2.1 Biological domain

Problems reported in the biological domain centred on the biological triggers that may cause seizures, inadequate healthcare services, comorbid health conditions and challenges experienced due to AED side effects.

4.3.2.1.1 Biological triggers. Eight of the respondents highlighted the importance of proper eating habits, restrictions on alcohol intake, staying hydrated and getting enough sleep in an effort to avoid seizures. Poor habits and exposure to emotional stressors are described as possible triggers for seizures.

Food plays a very big role because if you don't get the right nutrients, then your brain will suffer. If I get hungry then I start feeling dizzy and then I know it is starting. Water is another problem because our water in Windhoek is not always clean (P1).

It was triggered by being exhausted and the extreme heat. If I'm either like really exhausted and had too many things going on in one day (P2).

I think stress makes the seizures worse. I had a very stressful job at the newspaper and the seizures got worse (P3).

As a young man back in the days I would have days when you have too much fun. And then I would go out drinking like on the weekend, maybe Friday, Saturday, with the boys. Then, during the week, I wouldn't have a good week. I would probably have one seizure after the next (P6).

It's more prone to happen when you drink and smoke cigarettes and stuff (P8).

Medication should ideally be supported by a lifestyle that does not aggravate the condition, such as adequate sleep, low-stress environment, lack of excessive alcohol intake (P9).

4.3.2.1.2 Inadequate healthcare services. Three of the participants indicated that they rely on state medical facilities for medication and support. However, these services are sometimes inadequate and frustrations arise when state facilities are unable to provide medication on a regular basis.

The state doesn't always have the right medication to control epilepsy. The state does not really have the facilities to handle epilepsy patients (P1).

I saw the state doctors and there was nothing really that they could say to help me go through what I was going through. Actually, I don't blame them. They didn't make an effort. Do they have the resources? (P6)

It was worse last year because we are on public hospitals and last year there were no medicines at all. It was frustrating because you now have no money because I used to buy with my money every month. But then you go to the pharmacy and they don't want to give you, you have to go to the doctor there in the public hospital and then he writes it only for one month and you have to

go back every time and you are supposed to be doing your things to make some money (P7).

4.3.2.1.3 Comorbid health conditions. Eight of the participants reported that they are plagued by other health concerns, some of which precipitated the epilepsy, while others play a perpetuating role. A further three participants indicated that they often suffer an injury during seizure manifestation.

I had Histiocytosis X, it is a very rare type of cancer and it comes with other rare conditions like diabetes insipidus, it is a chronic sickness, not with sugar but with water. I am also dyslexic (P3).

I had migraine when I was a child and maybe it's related to epilepsy because that migraine was always disturbing me at school and it was lifelong (P7).

I do have ADHD. I just don't concentrate (P8).

I used to hurt myself a lot when I have seizures because I fall and then I kick around. I am also very forgetful now and I didn't use to be like that. I fell on my face and broke my front teeth. But normally I'm not a person that gets sick (P4).

I once just went face flat and another time I fell straight on the ankle and I kept scratching it on the floor (P6).

I just fell forward and that caused me to get some scrapes on my face and once I also got punctured by some of the glass when I helped my father. I am also starting to get a stomach ulcer, the signs of it are now coming out. I also struggle to pick up weight (P5).

4.3.2.1.4 Challenges due to drug side effects. According to five of the participants, they have noticed some unwanted changes in their biological functioning. They describe this as possible side effects of AED usage.

I get insomnia from the epilepsy medication and I was like a walking zombie (P3).

They actually switched it three months ago because the other medication had a lot of side effects, I used Urbanol and Epilim. Now I sweat a lot whereas previously I never had that problem but none of the deodorants are working and sometimes I smell bad. I really struggle. And all my hair had fallen out, not just on my head, but all over my body. It fell out within the first year since I started using medication. My skin also becomes very dry (P4).

I have moods. Sometimes there are times I just want to be alone. But being weak, maybe sometimes. I also think slow because I was born a strong, very strong man, physically, I always think I'm not slow but maybe I am (P7).

I believe I have increased my weight, which is partially due to the medication. And maybe an element of erectile dysfunction which may also be ascribed to the medication (P9).

I am just more forgetful (P10).

4.3.2.2 Psychological domain

The impact of a diagnosis of epilepsy became evident in the psychological domain where respondents described their feelings, concerns and their everyday struggle to come to terms with their condition.

4.3.2.2.1 Impact of epilepsy on psychological functioning. All the respondents stated that they experienced a variety of negative reactions when diagnosed with epilepsy. Feelings such as depression, anxiety, loss of control, uncertainty, helplessness, worry and fear were mentioned by most of the participants.

It has influenced my life dramatically because of being so young, being sick at a young age and all that. I was bullied a lot, so I didn't really have a childhood. I was suicidal, depressive, everything. I had stress, anxiety and panic, everything (P3).

It happens when you least expect it. Basically, it is kind of terrifying. I can't control it really because it is very violent and sometimes I even vomit. It's very, very scary. It does really mess with me. Sometimes, to know that my brain is a ticking time bomb. One day I can be fine and the next day I can just have a seizure (P8).

I'm just scared of having a seizure next to people that don't know what's going on like, especially people that are totally clueless, so I'm kind of like scared when I do go in public (P3).

Sometimes I blame myself, you want things to go your way, but they don't always. I got trapped, like trapped, trapped, trapped. Like when the company threw me out because of the epilepsy I was 24 and look where I am now, I am 36. I am getting old. Nothing is going on. Like I can't go home. I can't go to school. I can't get a job. I just feel trapped actually (P7).

4.3.2.3 Social domain

In the social domain, participants described how seizures impact their everyday functioning and how the role of culture influences common beliefs regarding the causes and treatment of epilepsy.

4.3.2.3.1 The impact of seizures on everyday functioning. Seven of the participants stated that the occurrence of seizures has a significant impact on their everyday life.

I had the attack that morning at 4 o'clock and I couldn't go to work the next day. There was a time when I didn't work for about five years (P1).

And then for five days in a month, I would be out of school. I was also bullied and there was a lot of gossip. The coldness and ignorance from the teachers. I was victimized (P2).

I don't have much of a social life. Most of the time I'm just at home and I'd read and I'm trying to make a family book, but my laptop is broken at the moment. Sometimes when I have a seizure and it is in public, then people might take my cell phone and my money, but at least they didn't do anything to me (P4).

I fell like twice in the exams. I was a bit jittery. It affected me more in the first two years, especially the recovering part. It's always the irritating part. You can't eat properly, you don't trust in yourself (P6).

4.3.2.3.2 The role of cultural attribution in epilepsy. Six of the participants indicated that cultural beliefs may prevent PWE from seeking medical treatment and that the family often demands that a traditional healer should treat the condition.

Culture also plays a role because there are many cultures that believe epilepsy is caused by witchcraft. They also keep the child back to not become part of the school's activities, the child must just stay behind closed doors (P1).

Some of my family still have cultural beliefs but I would rather go to a church so that a pastor can pray for me before I go to a traditional doctor (P4).

Especially in our African culture, they believe that it is bewitchment. Because of the education part it makes you see the world differently but now and again, I'm also African, my identity is who I am, it comes to my mind, like why did I get it when it was so late? Because it happened after I visited my grandmother and aunt in the villages and when I came back to town, that's when I got sick. I did consider going to a traditional healer. Being African, we have to go through those things and I couldn't say no because these are my parents and emotionally they were in turmoil. So we went to all that stuff. It was more like out-of-town and some of them do have some success in treating people with epilepsy, some actually have cases where they actually took people out of that whole thing and if someone makes you believe you can do better, you actually could get better (P6).

4.3.3 Needs: the need for employment and education

In the second main theme, participants expressed the various needs of an AWE. These needs focus on the ability to secure employment, which is dependent on accurate diagnostic techniques in the biological domain and the need to accept a diagnosis of epilepsy in the psychological domain. In the social domain, needs revolve around independence, financial resources and public education about epilepsy

4.3.3.1 Biological domain

The steps necessary to arrive at a diagnosis of epilepsy often involves the services of specialists and specialized diagnostic tests in the biological domain as described by participants.

4.3.3.1.1 Need for specialized diagnostic services. All the participants in this study were subjected to investigations by specialists and underwent various tests such as CT scans, EEGs and in some cases, MRI scans. Three of the respondents were referred to Cape Town for further testing. In most cases, the results were inconclusive.

They did brain scanning and brain fluids. The specialist referred me to South Africa now to go and see Doctor Butler because the seizures are too many and maybe they can do surgery. But until now they couldn't find anything wrong with me. They also did an EEG (P4).

I did a CAT scan and an EEG scan on my brain and they showed that either the left or the right side of my brain had a fracture in it. But they never told me you have this type of epilepsy. I saw to specialists in Namibia (P2).

I did go for tests and scans, but they couldn't find anything but my mother also has epilepsy, so I got it through her because it's passed over (P5).

I went down to James Butler in Cape Town for tests and then they just put it down to stress (P10).

4.3.3.2 Psychological domain

In the psychological domain, participants voiced their inability to come to terms with being diagnosed with epilepsy.

4.3.3.2.1 Need to accept epilepsy diagnosis. Five of the respondents stated that they have not yet accepted their condition and often prefer not to talk about it.

I have not made peace. You can never make peace with something that's bad (P6).

Sometimes I just want to be normal. Like I wish I was normal. I wish I didn't have this sickness in my brain (P8).

I find it difficult to accept that I have epilepsy and tend to downplay it or ignore it because it is not visible and evident on a regular, recurring basis. I do not promote or advertise my condition and have made a reasonable effort not to make it public knowledge (P9).

When you are epileptic you don't want to talk about it (P7).

4.3.3.3 Social domain

The needs of AWE became markedly visible in the social domain where questions about the ability to function independently are influenced by a lack of financial resources, the ability to secure gainful employment and where the perceptions that others have about epilepsy influence life chances.

4.3.3.3.1 Need for employment. Only two of the participants in this study expressed satisfaction with their current employment situation. The remaining respondents narrated the challenges, their dreams and future goals where employment is concerned.

I used to be a journalist when the seizures started but then I had to leave the job. Many people started distancing themselves. Even the companies that called me in for an interview and even when I was one of the best candidates.

The minute I mentioned that I have epilepsy, I never hear from them again. Even the government had that problem, but they felt sorry for me because I was unemployed for such a long time, five or six years. But at least they were prepared to give me a chance. I still want to do something else but people still have that fear, and I cannot push them. I would like to travel but I am scared that I will go and get sick on the other side (P4).

I was afraid to lose my job so I didn't go to the hospital to continue my medicine. And then I had a seizure and when they found out that I was epileptic they immediately sent me home and then eventually they retrenched me. Then I went back to one company I worked for an engineering company, but there were issues because I told them that I was epileptic. Then I cut hair in 2012, 2013, 2014, and 2015 and then I wrote the estate agents exam and I tried to do real estates, but I could not pay the licence fees and I gave it up. There were issues because I didn't have a driving licence and it was difficult to take clients around. I am not applying at other companies because they will not even take me because of the epilepsy, but I need the money. I like technical stuff like electrical testing. I like working with my hands but it's hard because of the falling. I don't like an office job. I always wanted to go to school and stuff but I can't I'm just through with it. I don't know why (P7).

4.3.3.3.2 Need for independence. For most of the participants, independence related not only to employment, but also to the ability to live by themselves and to drive a motor vehicle. Six of the respondents explained that they still live with their parents and are often dependent on public transport to get around.

No, I am not allowed to drive a car, I depend on public transport to get around. We are also still living with my parents (P1).

I live with one of my brothers. I am a private person and I enjoy being on my own although it is nice to spend time with the family, but I am looking for a place of my own, but my siblings don't want me to live alone (P4).

I am currently staying with my mother, I don't drive a car but I would like to learn to but I wouldn't want to drive a car with someone in the car because I don't want to put someone else's life in jeopardy (P5).

4.3.3.3 Need for financial resources. Possibly the biggest concern for most of the respondents was the financial implications of living with epilepsy. Participants explained that apart from daily living expenses, the cost of medical services to manage their condition is often very high.

I had to start working again, money is a factor and standard of living. It costs a lot of money to have epilepsy. The doctors cost money. Sometimes people don't have money to pay for transport to go to the doctor. There are some people that don't have enough to eat (P1).

I have a medical aid, but they will only pay for some of the expenses in Cape Town. And we had to pay for all my treatments ourselves. My sister works for a private doctor and they allow me to pay off my medical debt when I can afford it. The family wants somebody to go with me, but it is too expensive even though the medical aid is paying. I still need to pay about 50,000 myself. We have a family fund, but we wanted to use the money for tombstones for the parents. But I will have to take everything that there is and then I will go to

these cash loan places. Or maybe the bank where the interest is not so high (P4).

4.3.3.3.4 A need for public education. There was a cry from seven of the participants for increased public awareness and knowledge about epilepsy. Respondents made it clear that epilepsy is surrounded by ignorance and misunderstandings that have an effect on how AWE are perceived and treated in the social domain.

People have this misconception about what a seizure is. Just because the TV show that when you have a seizure you have to foam out of your mouth and drop to the floor and faint but it's not like that, every seizure is different. There is a lack of education and understanding. There is a lot of ignorance about epilepsy (P2).

Epilepsy is really something that's not spoken about at all. I think people really need to be educated about epilepsy in this country, especially in the poor side or shall I say the rural areas. Even have TV programmes where they teach people when someone is falling like that, it's not scary, just put them on their side. Just basic things to help you and not to run away. I once had a seizure where they braai the Kapana and everybody just split (ran away) (P6).

The government will only help if people get up and talk about it. Otherwise they will not realize that there are people that need help. One can start making a difference by raising awareness amongst the young people that are still in school (P1).

I think that it's important that people educate themselves more about epilepsy. They start panicking and if more people know what to do, it will make everyone safer (P3).

4.3.4 Coping mechanisms: the importance of social support

In the final main theme, the importance of support for AWE is highlighted in subthemes that focus on the importance of adhering to medication, the use of coping strategies and therapeutic support, and the reliance on significant others, family and friends to counter the effects of epilepsy.

4.3.3.4 Biological domain

In the biological domain, participants described a strong reliance on medication and how others remind and encourage them to take AEDs regularly.

4.3.3.4.1 Adherence to medication. All of the participants stated that taking medication on a regular basis has become a way of life and that when they fail to take their medication they experience feelings of guilt and worry that they might have a seizure.

I set my alarm for each day. Every morning, 7 o'clock. Then I get up. Then I take it and I keep an eye on my watch that makes the sound for each hour that passes and the closer it comes to 7 at evening time. I then make sure that I get my holder with the tablets in closer to me (P5).

I can't sleep when I don't have my medicines. The doctor says just take your medicine and you will be fine. That's what I do. I like this medicine because it's my life (P7).

But I take my medication every day. Epitec. It works fine and the days that I don't take it, like if I'm not very stressed, I don't take it. If I go on holiday, I don't take it, to see if I can't wean myself off it. But I'm too scared. I feel guilty if I don't take it. What if it happens? If I'm driving, and something happens? (P10).

4.3.3.5 Psychological domain

In the psychological domain, it was evident that respondents often struggle to cope with epilepsy. The use of emotion-focused strategies was evident from some of the comments made by participants.

4.3.3.5.1 The use of a variety of coping strategies. Most of the participants admitted that they failed to cope with the diagnosis of epilepsy during the early stages of the condition. However, as time moved on, they managed to find a variety of ways to adapt to their circumstances.

In the beginning it was really difficult and I couldn't handle it. But with time I got used to it (P4).

It's all mental you have to convince yourself that there is nothing wrong with you that you are just like everyone else, the only difference is you have this epilepsy, but it's nothing (P5).

I've always been a person who is confident about everything even if it's the worst thing in the world I would make myself and everyone else feel like it is the best. I could fall today right now in front of everyone and I'm in front of the whole class tomorrow, making jokes about what happened (P6).

I try not to think too far ahead I try to take it one step at a time. It's not a disability. It's just something that you are given. I've come to terms with it. I'm happy with myself. I don't try to think that it's a weakness. It's just something that I was born with. I can't change that (P8).

4.3.3.5.2 The importance of therapeutic support. Although only one of the respondents sought help from a professional, the remaining respondents indicated that they often received therapeutic support from family and others close to them.

I saw a therapist in Cape Town. Although my sister was there I needed someone else to talk to and it worked really well for me. It changed my life (P3).

I got counselling from my own family and that makes it a lot easier (P6).

I'm so used to speaking to my mom that if I speak to other people I'm worried that they might judge me. My mom is my psychologist (P2).

My father and I spoke about things that worry me, things that aren't nice, so that I didn't have to carry these issues with me. My father played a big role in my acceptance and how I cope with it (P1).

4.3.3.6 Social domain

It was evident from responses in the social domain that AWE rely on the support and understanding of people close to them, without whom they would not be able to cope with the profound impact of epilepsy on their everyday lives.

4.3.3.6.1 The reliance on social support. Questions regarding availability of social support elicited mixed responses from the participants. Some respondents indicated

that they are surrounded by people who understand their condition, while others felt that they were rejected and misunderstood and that they crave protection and comfort.

My friends knew what they had to do, they handled it very well and it didn't give them a fright anymore (P1).

UNAM had always been understanding since the first year because even when I missed exams or the assignments that come in late, the lecturers understood (P6).

I approached the school with a request to help and expected people to be more compassionate. It was nothing like this. Unfortunately, it was a huge disappointment. There was no support from the school principal (P2).

It used to happen when I was sitting in class at the Politech. I don't have a friend anymore. I don't have people that are close to me, except my family. Because people got scared of me (P4).

Being with friends. I don't care, that's one thing I had to push out of my life completely. If they are drinking they want you also to drink. But then I can't because of my medication. But then they would start making funny jokes and making fun of me (P2).

Not even your good friends understand in detail what you are going through, so talking about it is a big problem. One feels isolated because people don't really understand what you are going through (P1).

4.3.3.6.2 *The role of intimate relationships.* Four of the participants indicated that they were married, two were in a relationship and four were single. From the responses, it was evident that people rely on their partners and value these supportive relationships.

I am married now and my wife is a strong person because I had a seizure on our first date. She has really been there for me and she's helped me to go through a lot of stuff and achieve a lot more (P6).

I have a boyfriend and he does understand and he always reminds me to tell him what to do (P3).

My husband looks after me everywhere where I go. He is a bit scared and it is very difficult for him to handle (P1).

I date very good girls. They are always supportive of me and they try and take care of me (P8).

4.3.3.6.3 *Family as a source of support.* Most of the respondents indicated that they receive invaluable support from their families. Responses further indicated that family members experience their own sense of trauma and worry as a result of the AWE.

My parents are really supportive and me and my mom are best friends. We are really close. My brothers are really overprotective. It was an extra strain that whacked us all and it was tough (P2).

The doctor saw how sick and tired my mom was with me having to go through seven different types of epilepsy medication. There is a lot of support from my family but it sometimes can get frustrating because just every little thing would

make them nervous, it stuck with them. My parents have always been overprotective (P3).

There is a lot of support from my family. My mother was overprotective because she didn't just let me go play with the other students or the other children by the street (P5).

My father also has epilepsy. He tries to set an example for me. He makes me realize that I'm not the only one with it. It's not just my problem. But my family members, like my cousins, they've seen it happen and they worry about me, but they are supportive about it (P8).

4.4 Chapter summary

This chapter reported the results of the thematic analysis of the data. First, the demographic results of the participants were reported and thereafter the results of the semi-structured interviews. During the analysis of the 10 semi-structured interviews, one overarching theme and three main themes emerged as the most common problems, needs and ways that AWE cope. The overarching theme of a lack of knowledge and awareness about epilepsy permeated all the other themes and subthemes. The various subthemes were reported according to the four main themes that centre on problems, needs and coping strategies and were categorized according to the biological, psychological and social domains of the biopsychosocial model (Engel, 2012). In the next chapter, the results of the study are discussed at the hand of the biopsychosocial model and in relation to existing literature on the topic.

CHAPTER 5: DISCUSSION

5.1 Introduction

This chapter discusses and interprets the most significant findings from the thematic analysis. The biopsychosocial model (Engel, 2012) is used to integrate the results from the study with existing literature on the topic in order to answer the research questions of the study.

5.2 Discussion of literature, theoretical framework, findings and objectives

Experiential and qualitative reports indicate that PWE in Africa are often exposed to economic challenges and that this condition may have a profound impact on the social and psychological functioning of individuals (Birbeck & Kalichi, 2003; Mielke et al., 2000). Furthermore, PWE live with a chronic, unpredictable condition and are often exposed to discrimination, misunderstanding and social stigma (Ba-Diop et al., 2014; Moshé et al., 2015).

Little information is available on the psychosocial factors and epilepsy, not only in Namibia but all over the world. Fields such as social work or psychology do not boast studies on epilepsy (Elliott & Richardson, 2014). The lack of knowledge regarding the problems, needs and coping strategies of AWE in the Khomas region of Namibia necessitates research on this topic. The findings of this study can be compared to previous studies on epilepsy in Africa. The available studies include work on the attitudes of teachers in the Oshana region towards epilepsy (Angula, 2016); epidemiology, causes and treatment of epilepsy in sub-Saharan Africa (Ba-Diop et al., 2014; Preux & Druet-Cabanac, 2005); social and economic impact of epilepsy in Zambia (Birbeck et al., 2007); and the impact of epilepsy on the quality of life of PWE in Zimbabwe (Mielke et al., 2000).

The three domains of the biopsychosocial model (Engel, 2012) are used to contextualize this discussion. As noted in Chapter 2, a theoretical framework guides an investigation by integrating the goal of the specific study with fundamental beliefs and assumptions regarding the topic (Anfara Jr. & Mertz, 2006). Through the use of the biopsychosocial model, the following discussion highlights the bidirectional relationships between the AWE's biological, social and psychological well-being and how these interact to form a coherent whole. In addition, the subthemes that emerged as problems, needs and ways to cope in each of these domains are discussed at the hand of previous findings to provide a holistic view of the experiences of AWE in the Khomas region of Namibia.

5.2.1 The biological domain

The biological domain of the biopsychosocial model includes factors that describe the physical or medical aspects that affect AWE (Elliott & Richardson, 2014). Examples in this study include problems such as biological stressors that may lead to seizures, inadequate healthcare services, comorbid health conditions and challenges due to drug side effects. Participants identified a need for specialized diagnostic services that include appropriate information and guidance on their condition. In the face of these problems and needs, medication is often seen as a way to cope with seizures and provides some relief for AWE.

Most of the participants in this study stated that the diagnosis of epilepsy was communicated by a specialist and that some form of neurodiagnostic evaluation was performed to confirm the diagnosis. Notwithstanding the recommendation that people who present with a first seizure undergo a full neurodiagnostic evaluation that includes an EEG recording, a CT and an MRI scan, diagnostic modalities available in

developing countries often rely on physical examination and clinical history alone (Institute of Medicine, 2012; Krumholz et al., 2007; Kvalsund & Birbeck, 2012). Given the fact that Namibia has 4.78 CT units, 0.87 MRI units and 0.77 EEG monitors per million people (World Health Organization, 2016), it is heartening to know that these participants were able to undergo some specialized diagnostic investigation prior to the confirmation of their diagnosis. However, one of the problems is that none of the participants was able to name their type of epilepsy or specific instructions that they received as to the management of their condition. This raises the question whether patients are adequately educated about epilepsy and its implications at the time of diagnosis. Receiving a diagnosis of epilepsy can be a life-changing event and the impact reverberates throughout various aspects of a person's life (Collard & Ellis-Hill, 2017; Hosseini, Sharif, Ahmadi, & Zare, 2013; Jacoby et al., 2008; Wo, Lim, Choo, & Tan, 2015).

AWE and their families require basic education about seizure types and causes, treatment and management options such as medication, surgery and dietary modifications, safety risks, possible comorbidities, social concerns, emotional responses and community resources for epilepsy (Institute of Medicine, 2012). However, based on the findings of this study, another problem is that participants received very little guidance and support on epilepsy-related matters when they were diagnosed. This is reflected in comments about the lack of support and information received from healthcare providers, especially in state healthcare facilities. This leads to the need for specialized diagnostic services that can inform AWE about their condition and that can provide the necessary support and education that AWE require to manage their condition. Furthermore, problems arise with the regular occurrence of injuries and the failure to recognize that migraines and ADHD often co-occur with

epilepsy, is a reflection of the lack of knowledge about epilepsy as these conditions are frequently associated with the disorder (Ottman et al., 2011).

Based on the findings of this study, AWE derive a sense of comfort and security from the knowledge that by taking their medication, the seizures can be controlled. It was further evident from the responses that medication is often seen as a way to cope with the seizures and participants go to great lengths to ensure that they take their AEDs as prescribed. However, some participants indicated that they are unaware of any side effects caused by AEDs which raised another problem. Through continued probing, it became evident that respondents experience signs of cognitive impairment, depression, irritability and weight increase. In addition, participants were unaware that they have to undergo regular clinical monitoring to establish the effect of medication on liver functioning and bone density. This highlights the lack of knowledge about AED usage as common side effects include headaches, fatigue, cognitive impairment, depression, irritability, double vision, agitation, aggressive behaviours, ataxia, fluctuations in weight and decreased bone mineral density (Perucca & Gilliam, 2012). The literature suggests that patients should be educated about the use of AEDs and that regular clinical monitoring and preventative measures should be implemented to minimize the adverse effects of AEDs (Perucca & Gilliam, 2012). This, however, seems lacking in AWE in the Khomas region.

The final problem that was raised by participants was that seizures may be precipitated by certain events or stressors. Participants explained that lack of sleep and poor nutrition, excessive alcohol intake, spending too much time in the sun and stressful events often contribute to an increase in seizures. "Trigger management involves teaching people how to recognize or identify possible seizure triggers by observing

environmental, personal, or lifestyle factors (such as lack of sleep, flashing lights, fever, or excessive alcohol consumption) that appear to increase their susceptibility to seizures” (Institute of Medicine, 2012, p. 171). Judging by the responses, participants in this study are able to avoid or manage these triggers to a certain extent, which allows them some degree of control over their seizures.

The discussion returns to the overarching theme of lack of knowledge and awareness in the biological domain as it becomes clear from the above discussion that many of the problems and needs identified by AWE can be mediated by the provision of adequate information and education about epilepsy. However, healthcare providers often fail to inform patients about the implications of their condition, which may be ascribed to time constraints and resource limitations. Furthermore, patients themselves neglect to educate themselves about epilepsy, which has serious implications for the self-management of this condition.

5.2.2 The psychological domain

In the psychological domain, psychological/psychiatric conditions and mental healthcare are considered to play a vital role in the overall well-being of PWE (Elliott & Richardson, 2014). Examples pertaining to this study include problems such as feelings of depression, anxiety, fear, hopelessness and lack of acceptance. In addition, there is a need for the AWE to accept the diagnosis of epilepsy while the use of both problem- and emotion-focused coping strategies and the importance of therapeutic support was mentioned as ways to cope.

Despite evidence that there is an increased likelihood of psychiatric disorders in PWE and that patients experience feelings of anger, confusion, shame, stigma and fear when

faced with a diagnosis of epilepsy (Angus-Leppan & Parsons, 2008; Pembroke, Higgins, Pender, & Elliott, 2017), none of the participants in this study sought professional psychological help when they were diagnosed with epilepsy. Some participants stated that it never occurred to them to seek help and that their healthcare provider did not advise them accordingly, yet many of the respondents indicated that they experienced problems with feelings such as depression, anxiety, loss of control, uncertainty, helplessness, worry and fear since being diagnosed with epilepsy.

This failure to seek professional therapeutic assistance indicates that the psychological impact of epilepsy is gravely underestimated by respondents in this study. According to the literature, depression and anxiety are particularly dominant in PWE with 60 per cent of PWE in Zambia reporting symptoms suggestive of underlying depressive and/or anxiety disorders (Angus-Leppan & Parsons, 2008; Green et al., 2017; Mbewe et al., 2013). The failure to seek professional psychological assistance can also be ascribed to people's ignorance about the benefits of professional therapy. Some of the respondents in this study indicated that they rely on significant others to provide therapeutic support and utilize this as a way to cope. However, it was proven that psychotherapy in the form of CBT and psycho-behavioural therapies can play an integral part in the treatment of depressive symptoms and anxiety in PWE, as well as in the individual's ability to cope with epilepsy (Gandy et al., 2013; Leeman-Markowski & Schachter, 2017; Mehndiratta & Sajatovic, 2013; Tang et al., 2014).

Coping strategies are traditionally classified as either problem-focused, where individuals attempt to actively manage their condition through information seeking, planning and positive reframing; or emotion-focused, where techniques such as avoidance and denial are used (Bautista et al., 2013; Livneh et al., 2001). Based on the

findings, participants use a combination of problem- and emotion-focused strategies to cope with their condition. Problem-focused techniques were evident in responses that indicate the reliance on religion, positive reframing and emotional support to cope with epilepsy. Notwithstanding the finding that participants fail to seek information about epilepsy actively, they do perform planning in terms of adherence to medication and managing seizure triggers. This is a positive sign as the use of problem-focused coping is associated with increased psychosocial outcomes and decreased levels of depression and anxiety in PWE (Livneh et al., 2001). Furthermore, results from a study conducted in the U.S. indicate that PWE favour problem-focused strategies such as religion, acceptance and emotional support over emotion-focused strategies such as humour, denial and substance abuse (Bautista et al., 2013).

However, it was clear from the responses that some respondents use emotion-focused strategies to cope with epilepsy such as humour, alcohol abuse, avoidance and denial. The use of these strategies points to a lack of illness acceptance, as well as to efforts to distance themselves from the consequences of their condition (Bautista et al., 2013). Failure to come to terms with epilepsy may have adverse effects for PWE as lower levels of illness acceptance relates to decreased physical and psychological functioning (Staniszewska, Religioni, & Dąbrowska-Bender, 2017). Participants acknowledged the need to come to terms with their seizures and seemed to realize that failure to do so may have detrimental effects on their well-being.

From the above discussion, it is apparent that a diagnosis of epilepsy has serious implications for the psychological well-being of AWE. Although the psychological impact of this condition can be addressed through psychotherapy, few participants made use of professional services to assist them in coming to terms with their

diagnosis. This situation can again be ascribed to the overarching theme of a lack of knowledge and awareness with specific reference to the availability of psychological services and the possible role it can play in alleviating psychological distress. Psychotherapy can also assist AWE in developing more constructive coping strategies in an attempt to reach a higher level of illness acceptance which was identified as the main need in the psychological domain.

5.2.3 The social domain

The social domain of the biopsychosocial model describes the sociocultural, socio-political and socioeconomic factors that play a role in the person's life (Elliott & Richardson, 2014). Examples of influences in this study include problems with how the cultural attribution of seizures impact on the AWE's life and the effect of seizures on everyday functioning. Needs related to employment and financial resources, the need for independence and the need for public education. Intimate and family relationships and the reliance on social support contribute to the AWE's ability to cope with epilepsy. In the social domain, the problems, needs and ways that AWE cope are strongly intertwined and are affected by factors in the biological and psychological domains.

Illness intrusiveness is a term used to describe the degree to which an illness disrupts valued activities and interests in a person's life (Walker et al., 2015). The degree to which epilepsy intrudes upon a person's everyday functioning is not only influenced by factors in the social domain but also depends on psychological well-being, level of illness acceptance and seizure control. In this study, the subthemes of impact of seizures on everyday functioning and need for employment, independence and financial resources constitute the level of intrusiveness experienced by participants.

According to the literature, epilepsy has a profound effect on day-to-day life, such as the perception of personal control, work and income, transportation and interpersonal relationships (Lin et al., 2012). The problem findings of this study corroborate the previous statement with respondents stating that seizures often cause absenteeism from work, school and studies which in turn defies the need for employment. Although some of the participants are in full-time employment, others alluded to feelings of discrimination, rejection and pity when their epilepsy status is revealed during job applications. This is in line with responses from PWE in Zambia where higher mean perceived stigma scores, less education and poorer employment status were reported (Birbeck et al., 2007).

Failure to secure employment intrudes on the need for independence, with participants stating that they rely on others for transport, housing and financial support. Participants experience the inability to drive and to live on their own as restrictive and severely limiting their independence, a finding that is reflected in other studies involving PWE (Choi et al., 2011; Staniszewska et al., 2017). The resultant effect may influence an individual's views regarding the extent of the control they have over events in their lives and can be either internal (outcomes are due to their own efforts) or external (they have little personal control over events) (Colman, 2006). A more passive stance and depressive type thinking are associated with an external locus of control, which is more prevalent in PWE than in the general population (Hermann & Jacoby, 2009). This passive stance and depressive type thinking, associated with an external locus of control, were evident in responses that described that seizures severely hamper social involvement with other people. Failure to engage socially was ascribed to the poor reactions received from people when a person has a seizure. These reactions included panic and running away, which were attributed to misunderstanding and ignorance

regarding epilepsy. It is, however, interesting to note that AWE voiced the need that the public requires more knowledge and education regarding epilepsy, while their own knowledge regarding epilepsy is lacking. Notwithstanding this observation, it is evident that the general lack of knowledge and awareness about epilepsy should be addressed in order to foster acceptance and to reduce stigma (Ba-Diop et al., 2014).

Despite the challenges discussed above, some participants rely heavily on social support from family and friends to cope and to overcome some of the burdens associated with epilepsy. The value of social support in coping with epilepsy has been extensively documented with higher levels of social support associated with increased health and well-being of PWE (Institute of Medicine, 2012; Sallis, Owen, & Fisher, 2008; Walker et al., 2015). In addition, “Social support from marriage may influence a positive adjustment to epilepsy” (Elliott, Charyton, McAuley, & Shneker, 2011, p. 202). This was evident from responses that highlighted the amount of support from marriage partners and the strong reliance on these relationships to cope with epilepsy.

However, the opposite was also evident, with participants reporting that they are often rejected by others and that there is a lack of understanding from friends and peers. This lack of understanding extended to some family members who expect the AWE to seek help from a traditional healer. Especially in Africa, epilepsy is often seen as a curse or the result of witchcraft or possession by evil spirits (Darghal, 2010; Mushi et al., 2011; Osungbade & Siyanbade, 2011). This expectation from family members to conform to cultural concepts of epilepsy places pressure on the AWE and influences the way in which they experience support from their family.

The above discussion highlights some of the experiences of participants in the social domain. The most salient problems relate to how epilepsy intrudes on everyday

functioning and adversely affects the ability to secure employment. This, in turn, hampers the need for independence and financial freedom. Participants rely heavily on social support from family and marriage partners to overcome these burdens. However, the overarching theme of lack of knowledge about epilepsy again colours the perceptions of others which results in rejection and the tendency among AWE to isolate themselves.

5.3 Chapter summary

This chapter discussed and interpreted the most significant findings from the thematic analysis. The three domains of the biopsychosocial model (Engel, 2012) were used to integrate the results from the study with existing literature on the topic in order to answer the research questions of the study. It was evident that a lack of knowledge and awareness about epilepsy permeate all the problems, needs and ways that AWE cope with this condition. In the biological domain the provision of adequate information and education about AED side effects, comorbidities, healthcare needs and seizure precipitants can address many of the challenges experienced by participants in this domain. In the psychological domain, there was evidence that epilepsy impacts negatively on psychological functioning and that participants often struggle to cope successfully. However, failure to engage in psychotherapy prompted the conclusion that participants have to be informed of the role of this treatment modality and its potential benefits for AWE. Finally, in the social domain, it became clear that epilepsy intrudes heavily on everyday functioning and the ability to gain independence. Furthermore, while participants receive varying degrees of social support, lack of understanding and knowledge about epilepsy causes some participants to feel excluded and misunderstood.

The next chapter provides concluding remarks, followed by a discussion of the limitations of the study and recommendations for future research.

CHAPTER 6: CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

6.1 Introduction

This chapter provides concluding remarks on this study. This is followed by a discussion of the limitations of the study and recommendations for future research.

6.2 Conclusions

The main objective of this study was to investigate the experiences of AWE in the Khomas region of Namibia given that existing literature indicates that PWE in Africa are frequently exposed to economic challenges and that this condition may have a profound impact on the social and psychological functioning of individuals (Birbeck & Kalichi, 2003; Mielke et al., 2000). In addition, PWE live with a chronic, unpredictable condition and may often be exposed to discrimination, misunderstanding and social stigma (Ba-Diop et al., 2014; Moshé et al., 2015).

The first research question aimed to explore the everyday problems experienced by AWE. The findings of this study confirmed that AWE encounter daily problems in all three domains of the biopsychosocial model. In the biological domain, AWE are faced with problems such as inadequate healthcare services, comorbid health conditions and challenges due to drug side effects. In the psychological domain, participants described that they are often confronted by feelings of fear, insecurity, hopelessness, depression and isolation as a result of ES. Problems in the social domain revealed that AWE experience debilitating effects on their everyday functioning such as the inability to drive, to secure employment and to functioning independently. These problems are further exacerbated by cultural expectations and misconceptions about epilepsy.

The second research question aimed to explore the specific needs of AWE. Findings again indicated that the needs of AWE span across all three domains of the biopsychosocial model. In the biological domain, participants expressed the need for affordable and accessible healthcare services that specialize in the diagnosis and treatment of epilepsy. This is followed by the psychological need to come to terms with the diagnosis of ES and to accept the condition in order to achieve a sense of control and freedom in their everyday lives. Needs in the social domain centred on securing employment, financial resources and the need for independence in their daily lives. Needs in the social domain also highlighted the importance of educating the public on epilepsy-related matters in order to foster acceptance.

The third research question explored how AWE cope with their problems and needs. Findings in the biological domain pointed to a strong reliance on AEDs to achieve a sense of control over ES. In the psychological domain, it became evident that AWE employ a variety of coping mechanisms and often rely on therapeutic support from significant others in their lives. In order to cope with the effects of ES and to mediate the impact of the disorder on their lives, AWE cited the reliance on social support, intimate partner relationships and family ties as coping structures in the social domain.

The aim of this study was not to draw specific conclusions about the problems, needs and coping strategies of AWE, but rather to expose them to allow for further research on how to address the challenges experienced by AWE in the Khomas region of Namibia. This study achieved its objective in answering the above questions and provided in-depth descriptions of the daily problems, needs and coping strategies of AWE in the Khomas region of Namibia. The study shows that AWE in Namibia experience many of the same problems and needs as AWE in other SSA countries. It

is also clear from the findings that the impact of epilepsy extends beyond the biological factors of the condition and that psychosocial influences play a major role in the challenges encountered by AWE.

6.3 Significance and implications of the findings

Based on the findings of this study it became evident that there is a major gap in knowledge where epilepsy and its implications are concerned. First, AWE have to be educated about the consequences of epilepsy to enable them to cope with the repercussions of this disorder. Second, it is important to inform the family and immediate support systems how to react appropriately when faced with ES and how to render constructive support and understanding to AWE. Finally, greater public awareness of epilepsy is needed as societal attitudes determine how AWE experience epilepsy and its consequences (Mlinar, Petek, Cotič, Mencin Čeplak, & Zaletel, 2016).

It remains to be seen how educational content can be structured, delivered and made available to not only AWE, their families and immediate support systems, but also to healthcare providers and broader society. As such, the findings of this study may provide a starting point for future clinical research on the biological, psychological and social domains of epilepsy in Namibia. In addition, results may increase understanding of the impact of epilepsy on family, social, educational/vocational, healthcare and financial domains and may serve as a departure point for the creation of intervention programmes aimed at the specific needs and challenges of AWE in Namibia. Furthermore, the findings of this study may create greater awareness regarding this debilitating condition and may be a first step in the process of creating policies and procedures directed at the specific needs of AWE in Namibia.

6.4 Limitations of the study

This study yielded data that reflect the existence of various problems and needs that AWE experience on a daily basis. This research creates awareness of the challenges encountered across the biological, psychological and social domains of the AWE's life. However, there are limitations to this study. Participants in this study were not homogenous in terms of demographics and may therefore not be fully representative of the broader population of AWE in Namibia. As a result, the findings of this study may not be generalizable to the wider Namibian population. Similar studies on various populations in Namibia may very well yield different results. The aim of the study was not to generalize the results of the study, but rather to examine the unique experiences encountered by a small sample of adult AWE in the Khomas region of Namibia. A further limitation of this study is that participants hailed from various age groups and socio-economic backgrounds. This implies that needs and challenges may differ between age groups as participants are at different developmental stages in their lives. The same applies to socio-economic status, where needs and challenges may be influenced by factors related to income, education, social position and opportunity for employment. These limitations should be viewed as incentives for future studies in this research area and not merely as shortcomings.

6.5 Recommendations for future research

The following recommendations are based on the limitations of the study and questions raised during the research process. First, the sample of this study included participants from various socio-economic backgrounds and a wide age range. It is recommended that future research should be refined to differentiate between age groups, socio-

economic status and time since receiving a diagnosis of epilepsy. Further research into the effect of these variables on the experiences of AWE would certainly be insightful.

Second, based on the major findings in each domain of the biopsychosocial model, the following recommendations can be made. Future research that focuses on the problems and needs experienced by AWE in the biological domain may focus on how healthcare provision to AWE can be improved. This includes exploring how training programmes can be structured to increase the epilepsy knowledge of healthcare personnel and to create an awareness of the psychosocial factors that play a role in this condition. This may enable healthcare providers to better serve and prepare AWE for the demands of living with ES such as the importance of adhering to medication, possible drug side effects and comorbid health conditions.

Third, based on findings in the psychological domain, future research may explore how mental healthcare services and providers can assist AWE. In addition, it is important to investigate how these services can be promoted to AWE and their families. It was evident from the findings that few of the participants utilized the services of psychologists after being diagnosed with ES despite experiencing problems such as depression, anxiety and isolation. This could be ascribed to the perception that ES is a physiological condition and that the psychological effects are often underestimated. It also became apparent that many respondents did not consider using professional psychological services due to a lack of awareness regarding the benefits of such interventions even though the need for acceptance and therapeutic support featured strongly as a means to cope. It may therefore be important to investigate how mental healthcare can be brought to the attention of AWE in order to facilitate more frequent use of these services.

Finally, in the social domain future research aimed at increasing public awareness regarding ES may alleviate some of the problems experienced by AWE. Discrimination by future employers based on preconceived ideas of AWE and the resultant failure by AWE to satisfy their need for employment and financial freedom may be ameliorated through continued programmes aimed at educating the public about epilepsy. In addition, epilepsy support groups may provide valuable resources to family members and significant others who are often relied upon by AWE as a means to cope. It may therefore be important to explore the impact of living with an AWE and to identify the problems and needs of this population in future studies.

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Appendix A: Publisher Copyright Clearance for Figure 2.1

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Appendix B: Biographical Questionnaire

Instructions: Please fill in your biographical information. Indicate your choices by circling the correct option.

Name and Surname:

.....

Age:

Gender: Male/ Female

Ethnicity: African/Coloured/White/Other*

If other, please specify:

.....

Marital Status:

.....

Home language:

.....

Email address:

.....

Contact number:

.....

Employment details (employer, job title, duration):

.....

Type of epilepsy, when diagnosed?

.....

How often do you get seizures?

.....

Current treatment plan (medication, other treatments):

.....

Appendix C: Semi-Structured Interview Questions

Questions for Participants

1. How did you feel when you were diagnosed with epilepsy?
 - How was the diagnosis made?
2. Do you experience everyday problems because of your seizures?
3. What type of everyday problems do you experience?
 - How do you cope with these?
4. Do you have any specific needs because you are living with epilepsy?
 - Can you satisfy those needs?
 - How do you satisfy your specific needs?
5. Does your epilepsy have an effect on your personal relationships with people?
 - How does it affect your relationships?
 - What do you do about it?
6. Does your epilepsy have an effect on your job or employment?
 - How does it affect your job?
 - What do you do about it?
7. Are there financial implications when diagnosed with epilepsy?
 - If so, what are the implications?
8. Is your general health being affected by your epilepsy?
 - If so, how is your health affected?
 - How do you cope with these?
9. Do you think there is a stigma attached to being diagnosed with epilepsy?
10. What are the general attitudes/reactions from people when they find out you have epilepsy?
11. Are there any misconceptions from people regarding epilepsy?
 - How do you cope with these?
12. Does Namibia currently have any policies, procedures or support specifically for people with epilepsy?
 - If so what are these?
 - Is it effective?
13. What would you consider to be the most effective treatment for epilepsy?
 - Availability of this in Namibia?
14. What are in your opinion the main challenges encountered by people with epilepsy?
15. What things make it easier (or will make it easier) for you as a PWE? Any final thoughts on the matter?

Appendix D: Letter of Invitation to Participant

Epilepsy Interview

AN EXPLORATORY STUDY INVESTIGATING THE EXPERIENCES OF ADULTS
LIVING WITH EPILEPSY IN KHOMAS REGION, NAMIBIA

Dear Person with Epilepsy,

Epilepsy affects 65 million people worldwide and approximately 80% of those live in low- and middle-income countries (Moshé, Perucca, Ryvlin, & Tomson, 2015). However, there are currently no formal statistics on prevalence, incidence or diagnostic and treatment procedures available for epilepsy in Namibia (Angula, 2016). Epilepsy is the most common, chronic and serious neurological condition worldwide and involves a major burden in terms of costs, mortality, stigma, seizure-related disability and comorbidities (Moshé et al., 2015).

As part of my Master's study titled: An exploratory study investigating the experiences of adults living with epilepsy in Khomas region, Namibia, I am investigating the everyday challenges, needs and ways that people cope with epilepsy. In order to address this question, I devised a simple list of questions which should only take 30 to 45 minutes to conduct. You are invited to partake because you have been identified as a person with epilepsy. Your participation is greatly valued, as this study will be a first for Namibia and may form the basis for more research to be conducted on epilepsy. Increased understanding of the impact of epilepsy on family, social, educational/vocational, healthcare and financial domains may assist in creating intervention programs aimed at the specific needs and challenges identified by epilepsy with epilepsy. Furthermore, the findings of this study may create greater public awareness regarding this debilitating condition and may be a first step in the process of creating policies and procedures directed at the specific needs of epilepsy with epilepsy.

Participation in the study is voluntary and anonymous and you will be free to withdraw at any time. All responses will be kept confidential. If you decide to participate, you are free to stop at any time and to choose not to answer specific questions.

If you have any questions about this study or are willing to participate, please contact Anina du Toit, (081 149 0010) or via e-mail (anina@letstalkpsych.biz).

Thank you in advance for your consideration to participate.

Sincerely,

Anina du Toit (Hons)

Master's student, University of Namibia

Appendix E: Informed Consent Form

UNIVERSITY OF NAMIBIA

CONSENT TO PARTICIPATE IN RESEARCH

AN EXPLORATORY STUDY INVESTIGATING THE EXPERIENCES OF ADULTS
LIVING WITH EPILEPSY IN KHOMAS REGION, NAMIBIA

REFERENCE NUMBER: FHSS /238/2017

PRINCIPAL INVESTIGATOR: Anina du Toit (BA Hons Psychology)

ADDRESS: 10 Barella Street, Klein Windhoek, Windhoek, Namibia, 9000

CONTACT NUMBER: 081 149 0010

You are asked to participate in a research study conducted by Anina du Toit, from the Psychology Department at the University of Namibia. Results from this study will be contributed to thesis research. You were selected as a possible participant in this study because you have been identified as a person with epilepsy.

Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **UNAM Research Ethics Committee** and will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki (2008), The Belmont Report (1974) and the International Ethical Guidelines for Biomedical Research involving Human Subjects (2002). The proposed study underwent ethical review by the University of Namibia Department and Faculty Postgraduate Studies Committees and the UNAM Research Ethics Committee.

PURPOSE OF THE STUDY

The proposed study will provide an in-depth description of the daily challenges, needs, coping strategies and future uncertainties of people living with epilepsy in Namibia. As such, it may provide a starting point for future clinical research to focus on the psychological and social domains of epilepsy in Namibia. People with epilepsy live with a chronic, unpredictable

condition and are often exposed to discrimination, misunderstanding and social stigma. The purpose of this study is, therefore, to explore and describe the experiences of people with epilepsy in Namibia.

Increased understanding of the impact of epilepsy on family, social, educational/vocational, healthcare and financial domains may assist in creating intervention programs aimed at the specific needs and challenges identified by PWE. Furthermore, the findings of this study may create greater public awareness regarding this debilitating condition and may be a first step in the process of creating policies and procedures directed at the specific needs of PWE.

For the purpose of this study, a PWE is defined as any person, whether male or female, over the age of 18, who had been diagnosed with epilepsy of any type and who is not cognitively challenged.

PROCEDURES

If you volunteer to participate in this study, you would be asked to do the following things:

- You will be invited to partake in a once-off semi-structured interview that will last approximately 20-45 minutes, during which time you will talk about your experiences as a PWE. Questions will focus on the everyday problems you experience, your specific needs and how you cope as a PWE.

The study will be conducted at a time and place that suits you. Approximately 15 individuals will participate in this study. Interviews will commence with the completion of a biographical questionnaire. This will be followed by a semi-structured interview, consisting of questions that relate to your experiences as a PWE. The interviews will be conducted one-on-one and I (a Psychology Master's student) will be conducting the interviews. Each interview will be approximately 20-45 minutes long. With your permission, the interview will be audio-recorded so that it can be transcribed verbatim for the data analysis. You, the participant, retain the right to review/edit all recordings.

POTENTIAL RISKS AND DISCOMFORTS

The proposed study can be classified as low risk as the research will be conducted on a largely uncontroversial topic through semi-structured interviews. The participants are adults and not considered to be a vulnerable research population. The research will compose of information that can be regarded as non-sensitive, such as everyday experiences and will be collected anonymously through semi-structured interviews.

POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Most of the studies that have been conducted on epilepsy have taken place in developed countries, while developing countries such as Namibia have received less focus. A study of this nature has not been conducted in Namibia, and it is possible that the knowledge obtained from this study may assist in creating intervention programs aimed at the specific needs and challenges identified by people with epilepsy. Furthermore, the findings of this study may create greater public awareness regarding this debilitating condition and may be a first step in the process of creating policies and procedures directed at the specific needs of PWE.

There will be no direct benefit for taking part in this study. However, this study is one of the first of its kind in Namibia, and it is thus possible that the findings of this study could be published as a scholarly article in a peer-reviewed journal. This could lead to a greater understanding of the challenges and needs experienced by people with epilepsy in the Khomas region of Namibia.

PAYMENT FOR PARTICIPATION

You will not be paid to participate in this study; participation is wholly voluntary and no reimbursement will be forthcoming.

CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of assigning a code instead of using the participant's name. Participants will have the right to review/edit audio recordings of interviews. Only the researcher and her supervisor will have access to the information obtained during the study. All the collected data will be kept secure in a locked cabinet in the researcher's office and it will be appropriately destroyed and discarded after a period of three years.

No confidential or identifying information will be used in the event that results from the study are published. Results from the study will be used to generate descriptions only.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so, although it is not anticipated that any circumstances can arise that would warrant such withdrawal.

IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact the Principal Investigator: Anina du Toit on 081 149 0010 or Supervisor: Dr Poonam Dhaka on +264 61 206 3800.

RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Mr SD Lumbu [slumbu@unam.na; 061 206 3855] regarding UNAM Research Ethics and Policies.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE
--

By signing below, I, _____ agree to take part in a research study entitled:

AN EXPLORATORY STUDY INVESTIGATING THE EXPERIENCES OF ADULTS LIVING WITH EPILEPSY IN KHOMAS REGION, NAMIBIA

I declare that:

- The information above was described to me in a language that I understand.
- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I have been given a copy of this form.

Signed at (*place*) _____ on (*date*) _____ 2017.

Signature of participant

Signature of witness

SIGNATURE OF INVESTIGATOR

I (*name*) _____ declare that:

- I explained the information in this document to _____
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.
- I did not use an interpreter.

Signed at (*place*) _____ on (*date*) _____ 2017.

Signature of investigator

Signature of witness

Appendix F: Participant Profiles

P1

This was the first interview and it was conducted with a 40-year-old Coloured woman. Although I was not entirely sure what to expect, it went really well and I was able to gather a lot of valuable information. She was open about her epilepsy and is also very involved in raising awareness among children. She appeared completely relaxed and in charge of the process and was willing to share some of her deeper feelings regarding the condition. I left the interview feeling motivated and excited about the interviews to come.

P2

This interview was conducted with a 19-year-old woman who was accompanied by her mother. It was a very long interview and they openly shared the disillusionment and unhappiness that they suffered at the hand of the young woman's school the previous year. The tone of the interview was negative although they raised some valid concerns about some of the challenges encountered by younger people with epilepsy. This interview made me realise that the life of a PWE is sometimes complicated and that there is much to be learnt about how especially younger people cope with this debilitating condition.

P3

This interview, which was conducted with a 24-year-old German-speaking woman, was truly insightful and inspiring. This participant managed to overcome huge barriers since being diagnosed with epilepsy. Her condition was precipitated by a long list of

other medical conditions that she managed to overcome to a large extent. She is the epitome of how people can cope with epilepsy. She freely elaborated on how she deals with challenges in her everyday life. Although she was not entirely well on the day of the interview, this did not seem to dampen her enthusiasm and I was able to record valuable information for the study.

P4

This 38-year-old Black female truly suffers as a result of her epilepsy. I was touched by her story despite the sombre tone of this interview. She was completely relaxed and open and freely elaborated on her life since being diagnosed with epilepsy. The information gathered during this interview opened my eyes to the incredible impact that this condition has on people. She appeared sad and frustrated at various times during the interview, which was a true reflection of the many feelings experienced by PWE.

P5

This 27-year-old White male was able to provide me with a completely different view on how people manage to live with epilepsy. He was very eager to provide as much information as possible and spoke non-stop for most of the interview. He was a breath of fresh air after some of the previous interviews. He entertained me with some comical incidents and how he overcame some of the difficulties that he experienced as a young child with epilepsy. This was a very light and positive interview and provided some balance to the research.

P6

This interview with a 33-year-old Black male was completely different to any of the other interviews that I conducted before this. Although he answered all the questions and appeared open and friendly, I experienced a sense of distance during the interview. He had an interesting way of relating to himself and narrating his story. At times I felt as though I wasn't entirely sure about his answers. However, he provided some good insights and by regularly clarifying his responses, I was able to gather some valuable feedback.

P7

This discussion was probably the hardest of all the interviews that I conducted during this research. The participant was a 36-year-old Black male and watching him become tearful during the interview really touched my heart. I experienced an overwhelming feeling of wanting to help him and wishing that things could have been different for him. He elucidated some harrowing experiences and seemed a good candidate for continued psychotherapy. His current circumstances are dire and possibly reflect the lives of many other PWE.

P8

This interview was conducted with a 20-year-old Black male. It truly reflected the exuberance of youth and how even a condition such as epilepsy fails to contain optimism. Although he elaborated on his share of challenges and uncertainties, life very much continues as he wants it. It was a very positive interview and I left feeling lighter and more motivated about the future of PWE in Namibia.

P9

This second last interview was conducted with a 54-year-old White male. Although he was open and friendly during the interview, it felt a bit rushed. His answers were brief and to the point, and he seldom took the opportunity to elaborate on his circumstances. It felt as though he had not yet completely come to terms with his epilepsy, an observation that is confirmed by some of his responses. However, I appreciated the time he took to see me and he was able to provide an alternative view of the challenges experienced by PWE.

P10

The final interview was conducted with a 47-year-old white female. This discussion afforded me the opportunity to end this process on a positive note. She was very friendly and willingly shared her everyday concerns and challenges. I managed to gather some final insights into the life of a PWE and concluded the process feeling satisfied and ready to draw my own conclusions regarding the information gathered.

Appendix G: Research Ethics Committee Clearance



ETHICAL CLEARANCE CERTIFICATE

Ethical Clearance Reference Number: FHSS/238/2017 Date: 27 September, 2017

This Ethical Clearance Certificate is issued by the University of Namibia Research Ethics Committee (UREC) in accordance with the University of Namibia's Research Ethics Policy and Guidelines. Ethical approval is given in respect of undertakings contained in the Research Project outlined below. This Certificate is issued on the recommendations of the ethical evaluation done by the Faculty/Centre/Campus Research & Publications Committee sitting with the Postgraduate Studies Committee.

Title of Project: An Exploratory Study Investigating the Experiences of Adults Living With Epilepsy in Khomas Region, Namibia

Researcher: Anina du Toit

Student Number: 201601574

Faculty : Faculty of Humanities and Social Sciences

Supervisor: Dr. Poonam Dhaka

Take note of the following:

- (a) Any significant changes in the conditions or undertakings outlined in the approved Proposal must be communicated to the UREC. An application to make amendments may be necessary.
- (b) Any breaches of ethical undertakings or practices that have an impact on ethical conduct of the research must be reported to the UREC.
- (c) The Principal Researcher must report issues of ethical compliance to the UREC (through the Chairperson of the Faculty/Centre/Campus Research & Publications Committee) at the end of the Project or as may be requested by UREC.
- (d) The UREC retains the right to:
 - (i) Withdraw or amend this Ethical Clearance if any unethical practices (as outlined in the Research Ethics Policy) have been detected or suspected,
 - (ii) Request for an ethical compliance report at any point during the course of the research;

UREC wishes you the best in your research.

Prof. P. Odonkor: UREC Chairperson

A handwritten signature in black ink, appearing to be "P. Odonkor", written over a horizontal line.

Ms. P. Claassen: UREC Secretary

A handwritten signature in black ink, appearing to be "P. Claassen", written over a horizontal line.

Appendix H: Turnitin Report

2017 10 19 Epilepsy
by Anina du Toit

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Appendix I: Declaration of Language Editing



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DECLARATION OF LANGUAGE EDITING

I, Christina Maria Etrechia Terblanche, hereby declare that I edited the research study with the title:

AN EXPLORATORY STUDY INVESTIGATING THE EXPERIENCES OF ADULTS LIVING WITH EPILEPSY IN THE KHOMAS REGION, NAMIBIA

for **Anina du Toit** for the purpose of submission as a research study for examination. Changes were suggested in track changes and implementation was left up to the author.

Regards,

CME Terblanche

Cum Laude Language Practitioners (CC)

SATI accreditation nr: 1001066

Full member of PEG