EXPERIENCES OF PEOPLE LIVING WITH EPILEPSY IN SELECTED VILLAGES OF LIMPOPO AND MPUMALANGA PROVINCES

BY

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DECLARATION

I, Luvhengo Masane, declare that the research study entitled "**EXPERIENCES OF PEOPLE LIVING WITH EPILEPSY IN SELECTED VILLAGES OF LIMPOPO AND MPUMALANGA PROVINCES**" is my own work and that this work has never been submitted before for any other degree at this university or any other institution and all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

Luvhengo

15/August/2022

Ms Luvhengo M **Date**

PREFACE

This dissertation is presented in article format and is comprised of three sections: Section A presents the overview of the study including introduction, methodology and ethical considerations, Section B is a presentation of two manuscripts with the journal authors guidelines, and Section C presents the study conclusion, limitations, and recommendations. The dissertation is outlined in the following manner:

Section A: Dissertation Overview

This section provides the overview that details the background, problem statement, purpose and objectives of this study, research design and methods and the ethical considerations. Literature review has not been included in the dissertation as extensive literature has been systematically reviewed in the first manuscript.

Section B: Paper/Article/Manuscript

This section has a total of two manuscripts:

- The First manuscript is titled, “A closer look at the experiences of people living with epilepsy in South Africa: A systematic review”. Submitted to ***Journal of Psychology in Africa (Under Review)***

- The other manuscript is titled “Epileptic patients’ experiences in selected communities of Limpopo and Mpumalanga Provinces”. Submitted to ***Health SA Gesondheid: Journal of Interdisciplinary Health Sciences**. **(Under Review)***

Section C: Conclusion, Recommendations and Dissertation Limitations

This last section presents conclusions from this dissertation and makes dynamic recommendations. At the same time, the study limitations are reflected in all that was presented within each section and is informed by the whole research process.

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DEDICATION

This study is dedicated to:

- ✓ *My mother, Hangwani Carilone Luvhengo, for I am who I am today because of you.*
- ✓ *My husband Murangi Tshilande, your unconditional love, perseverance and encouragement have contributed significantly to my success.*
- ✓ *My son Lushaka Tshilande, for being a blessing that you are.*

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ABSTRACT

Epilepsy is a burdensome disease that affects a large number of people worldwide. In most developing countries such as South Africa. Epilepsy remains a public health issue. In some African countries, epilepsy causes are attributed to either indigenous or spiritual beliefs. This study aimed to explore and describe the experiences of People Living with Epilepsy (PLWE) in selected villages of Limpopo and Mpumalanga Provinces. A qualitative approach was employed guided by the phenomenological design, which enabled the researcher to understand the experiences of people living with epilepsy. Purposive sampling was used to select the participants with the most relevant characteristics to the population. The characteristics included PLWE and residing at the selected villages. The population consisted of people living with epilepsy who were eleven in number and living in the selected villages of Limpopo and Mpumalanga Provinces. Face-to-face in-depth interviews were used to collect data. The researcher used one central question to ascertain the experiences of people living with epilepsy. Interpretative Phenomenological Analysis was used to analyse data. Ethical issues were considered throughout the study as well as measures to ensure trustworthiness. Drawing from the results, the researcher concluded that epilepsy is a burdensome disease that affects people of different ages. The experiences of PLWE are influenced by many factors that need considerable attention. These factors include psychological, physiological and social experiences of PLWE. The results further revealed that epilepsy is a painful, burdensome disease. Two manuscripts have resulted from the study and the first manuscript is due for submission to the South African Journal of Psychology. The second manuscript is under peer review in the Health SA Gesondheid journal.

Keywords: Epilepsy, Experiences, People Living with Epilepsy, Treatment, Effects

OVERVIEW OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND

Epilepsy is a significant health problem worldwide, with 70 million sufferers; and developing countries carrying the majority of the burden (Nagarathnam & Latheef, 2018; Owolabi, Owolabi, Taura, Alhayi & Ogunniyi, 2019). About 80% of the affected individuals reside in developing countries (Santhosh, Sinha, & Satishchandra, 2014). Epilepsy is a neurological condition with no geographical, social or racial boundaries (Molavi, Ahari, Fattahzadeh- Ardalani, Almasi & Karimollahi, 2019). According to Resendiz-Aparicio et al. (2019), the current definition of epilepsy can be established from three possibilities depending on how they begin, the presence of consciousness and the description of the symptoms. The International League Against Epilepsy (ILAE) defines epilepsy as a disease characterized by two or more seizures or a diagnosis of epilepsy (Barger et al., 2017). A seizure is a brief change in normal electrical brain activity resulting in altered awareness, perception, behaviour, or movement (Cui, Kobau, Zack, Helmers & Yeargin-Allsopp, 2015).

Epilepsy, as a chronic condition of the brain, is characterized by an enduring propensity to generate epileptic seizures, neurological, cognitive, psychological and social consequences (Brissart, Forthoffer & Maillard, 2019). People Living with Epilepsy (PLWE) may have normal lives due to limited seizures, which affect their day to day activities (Song et al., 2017). PLWE suffer from severe social implications such as discrimination and stigma (WHO, 2018). Premature mortality is widespread in PLWE, especially in low-income countries (Thijs, Surges, O’Brien & Sander, 2019). In a study conducted in Kochi, the major cause of death in epilepsy was due to the lack of proper knowledge and availability of initial management during the epileptic attack (Soumyamol & Kanmani, 2017).

According to the World Health Organization (WHO), there are nearly 50 million PLWE worldwide, and 80% reside in developing countries (Radhakrishnan, 2016). And it affects people of all ages (Mameniskiene, Sakalauskaite-Juodeikiene & Budrys, 2015). The prevalence of epilepsy differs between developed and developing countries, with figures raging between 4 and 7 PLWE per 1 000 persons in developed countries and between 5 and 74 PLWE per 1 000 persons in developing countries such as Nigeria (Owolabi et al., 2020). The global estimation of people diagnosed with epilepsy may amount to 2.4 million (Pembroke, Higgins, Pender & Elliot, 2017). In South Africa, the burden of non-communicable diseases is reportedly growing, and concerning epilepsy, it is thought that about 1 in every 100 South Africans suffers from the condition (Keikelame, Hills, Naidu, de Sá & Zweigenthal, 2012).

People with epilepsy face multiple barriers that limit their access to physicians, nurses, and other professional health workers (Anand et al., 2019). To minimize epilepsy burden, the Centres for Disease Control and Prevention (CDC) in the United States has supported the Prevention Research

Centres Managing Epilepsy Well (MEW) Network, a research practice community dedicated to advancing care approaches that can improve health outcomes in people with epilepsy (Sajatovic et al., 2017). Despite the high prevalence of epilepsy in less developed countries, it is estimated that about 75% of PLWE in low- and middle-income countries (LMICs) do not receive proper biomedical care (Kpobi, Swartz & Keikelame, 2018). There may be others who experience a devastating psychological and psychiatric problems which may lead to death (Song, Liu, Yu, Wu, Poon, Demaio, Wang, Rudan & Chan, 2017). In developing countries, it is estimated that 40 million people have epilepsy, with the majority living in poverty and not receiving adequate treatment (Winkler et al., 2010). This may be due to lack of trained health care workers, poverty, illiteracy, socio-economic factors, inaccessible health facilities, inadequate supply of epilepsy medication, cultural beliefs, stigma and myths about epilepsy (Siriba, 2014).

In Ghana 270 000 people live with epilepsy, and only close to 15% are receiving treatment (Deegbe, Aziato & Attiogbe, 2020). In rural Tanzania, young people living with epilepsy suffer from stigmatization, and they feel embarrassed of having a seizure in public; thus, they usually withdraw from social activities (Goodall et al., 2018). Women in Sub-Saharan Africa find it strenuous to cope with epileptic seizures during pregnancy and even take care of the baby if they manage to give birth (Menon et al., 2019). Hunter et al. (2016) have attributed this to the treatment gap that exists mainly in rural areas such as Tanzania and Kenya, where PLWE adhere to traditional rather than medical treatment. Some of the reasons accounting for this wide treatment gap include the limited availability and access to primary care facilities or neurologists, cultural explanations for epilepsy and the stigma associated with such a condition (Kpobi, Swartz & Keikelame, 2018).

Considering the above, neurological attributions of epilepsy have received tremendous attention from the medical domain (Helbig & Ellis, 2020). Despite the attention, PLWE alternatively follows the traditional health practitioners whose explanations of epilepsy are based on cultural understandings and experiences of epilepsy (Kpobi, Swartz & Keikelame, 2018). In many ancient societies, including Africa, epilepsy is believed to be a result of sin and demonic possession, whilst the traditional African belief system; attributes epilepsy to witchcraft and blames the victim (Deegbe, Aziato & Attiogbe, 2019). Epilepsy misunderstanding based on myths and superstitions negatively influences the quality of life and social integration of PLWE (Mbelesso, Luna, Yangatimbi, Mboukou & Preux, 2019).

This switch in interest may be influenced by social and cultural factors that PLWE experiences. For example, a study by Anand et al.; (2019) indicates that PLWE seeks treatment from traditional healers because they may be easily accessible in the community, and provide more familial explanations of the cause of the disease.

In South Africa, there are about 25 000 traditional healers, and 60% of the population is estimated to use traditional healers, usually in conjunction with western medical doctors (Batjes, Swartz & Cembi, 2018).

One of the major factors that normally negatively affect PLWE is the social environment. Social support is unavailable, and thus, PLWE are likely to be picked on, mainly through stigmatization and discrimination (Dako-Gyeke & Donkor, 2018). In some African countries, like Ghana, PLWE may be excluded from society: exposed to social and religious taboos, isolated, sometimes with no right to have children or marry, are excluded from jobs, and are not allowed to have contact or to share meals with other people (Dako- Gyeke, Donkor, 2018 & Bounlu et al., 2020;). Epilepsy is an invisible chronic disease, unlike diabetes, it is usually associated with a negative impact of the stigma that causes a negative impact on PLWE's quality of life, which may result in poor self-esteem, anxiety to disclose and major depressive disorders (Pembroke, Higgins, Pender & Elliot, 2017). Thus, PLWE may find it difficult to acquire financial independence that enables them to establish interpersonal relationships and achieve a role in society. Unlike the general population, they face a higher unemployment rate (Gabriel et al., 2020). This may be due to their low educational achievements since most PLWE may also suffer from learning disabilities. Hence the current study aimed to explore the experiences of people living with epilepsy.

1.2 Conceptual Framework

The figure (Figure 1) outlines the conceptual framework developed by the researcher. This conceptual framework has been used to guide the study.

Figure 1: Conceptual Framework

For this particular study, the researcher has developed the conceptual framework. By utilizing this conceptual framework, the researcher was able to gain in-depth knowledge about the experiences of PLWE. The background of this study has clearly outlined that PLWE does not only have to cope with living with a chronic disease characterized by seizure and not knowing when the next seizure may strike or the pressure of adhering to treatment, but they have to adjust to the normative tasks associated with living in a family and community at large. Internalizing and externalising problems is more stressful for the PLWE and their families than for the community members. In turn, their ability to cope with all these demands depends on their adaptation to the disease.

1.2.1 Nature of their environment

The developed conceptual framework has placed PLWE in the centre where everything occurs around them. In a study conducted by Vrinda et al. (2017), whereby they were accessing the relationship between epilepsy and enriched environment, has found that an environment that has been specially designed for an individual with epilepsy will reduce the extent of seizures and level of depression or hyperactivity. The environment must have opportunities for monitoring, physical activity and motor, visual and somatosensory and cognitive stimulation. This availability of a conducive environment may provide a better experience for PLWE. Epilepsy SA (2017) advises that there are basic safety rules that may minimize the extent of injury in the likelihood of seizure, including a specially designed bathroom, way of sleeping, strict precautions during sporting activities, and identification of who they are.

1.2.2 Social experiences

People living with epilepsy have social lives just like any other normal person, but they should change their social lives to accommodate this condition or manage it (Pembroke, Higgins, Pender & Elliot, 2017). People living with epilepsy deal with cognitive processes determining social functioning in epilepsy ranging from brain lesions, epileptic activity, antiepileptic medications, psychiatric comorbidities and developmental trajectories (Steiger & Jokeit, 2017). Furthermore, they face the burden of interpersonal determinants of social functioning, including social and cultural environment, friends and peer groups, partner and family, health care, occupation and education (Steiger & Jokeit, 2017). Impaired social cognition in epilepsy contributes to low quality of life and social functioning among PLWE (Yogarajah & Mula, 2019). These social impairments negatively affect academic achievements, employment, housing and the ability to survive and function independently (Gabriel et al., 2020).

PLWE experience difficulties in their sexual relationships. There is a high marriage barrier among PLWE, and although lower, the divorce rate is reported to be almost similar to that of the general population (Gabriel et al., 2020). Research shows that some of the sexual problems among PLWE may be attributed to sexual disorders such as problems in libido, sexual arousal, achievement and orgasm in women and a decrease in sexual activity, abnormal ejaculation, orgasm and hypersexuality in men (Krasuski, Rozenek & Owczarec, 2015). Most men would be interested in having sexual relationships with PLWE, but they are usually not willing to commit themselves to a marital relationship (Mameniskiene, Guk & Jatuzis, 2016)

1.2.3 Perceptions towards epilepsy

In most cases, PLWE perceive epilepsy differently depending on how knowledgeable they are about the condition or their beliefs regarding epilepsy. Usually, their perceptions and beliefs are influenced by those around them, for example, family members (Harden, Black & Chin, 2016). Some PLWE perceive epilepsy as a chronic disease characterized by feelings of shame, embarrassment and loss of identity, but to some extent, they refer to it as a condition rather than an illness (Kilinc, Campbell, Guy & Wersch, 2018). Irrespective of age, level of education and duration of epilepsy, people with epilepsy appear to have poor knowledge about the condition (Eshiet, Okonta, & Ukwe, 2019). Lack of knowledge is a challenge noted among health practitioners, and this may have a negative impact o epilepsy care (Bhalla, 2017). This may have a negative impact on PLWE because the health practitioners are supposed to assist holistically so that the process of care and support may be achieved successfully.

1.2.4 Support received

PLWE require special care and attention. Some even go to the extent of hiring caregivers in cases where no close family members provide the necessary support (Mengoni et al., 2016). Parents taking care of children living with epilepsy have emphasized the need for support from a sibling, extended family members and practical advice from professional health workers (Harden, Black & Chin, 2016). Some PLWE report that social support from family, friends and church members enables them to cope with the difficulties they experience, such as lack of medication from health care institutions (Deegbe, Aziato & Attiogbe, 2020). Health professionals are of great importance to PLWE and their caregivers as they provide close and knowledgeable contact for support and guidance on successfully managing or treating epilepsy (Higgins, Downes, Varley, Doherty, Begley & Elliot, 2019).

1.2.5 Care received

Studies show that care for PLWE is more demanding than any other chronic disease because of the implications of living with epilepsy, such as seizures (Wardrope, Green, Norman & Reuber, 2019). In a qualitative study that explored the role of epilepsy specialist nurse from the perspective of PLWE, the role has been found to have enhanced the knowledge of epilepsy, satisfying support and advice

(Higgins et al., 2018). The health care workers are also responsible for psychosocial care, which includes providing the patients with information and answers to any questions (Akbarbegloo, Valizadeh, Zananzadeh & Jabarzadeh, 2015). In a study on health-seeking behaviours of people with epilepsy, the majority of people in rural areas engage in wrong health-seeking behaviours as they hold a strong belief that indigenous health care is better than anti-epilepsy medication. This was also found to be amplified by the distances they have to travel to obtain such care and other barriers that force them to opt for traditional care (Mutanana & Mutara, 2015).

1.2.6 Acceptance

When a person is diagnosed with epilepsy, several things have to be changed in the patient’s life, and this affects everyday functioning. Staniszewska, Religioni & Dąbrowska-Bender (2017) found that acceptance of an illness such as epilepsy may be based on the level of mental and physical support provided for the individual to attain full acceptance. PLWE often accept the condition if they receive adequate support from their spouse and family members (Molavi, Ahari, Fattahzadeh-Ardalani, Almasi & Karimollahi, 2019). Acceptance is one of the coping strategies that may be adopted by PLWE, along with avoidance of seizure triggers and seeking help for treating the condition (Deegbe, Aziato & Attiogbe, 2020). Acceptance may also pave the way for the successful management and treatment of epilepsy; once the patient accepts the condition, they can engage in activities that will assist in coping with it better (Kilinc, Campbell, Guy & Wersch, 2018).

1.2.7 Outcomes

All the experiences mentioned above will lead to different outcomes, and each outcome will depend on the form of experience. PLWE have different attitudes towards epilepsy, which is influenced by their level of knowledge about epilepsy and socio-cultural differences. In Ghana, people believe that epilepsy results from spiritual forces and the signs and symptoms require spiritual attention or healing (Deegbe, Aziato & Attiogbe, 2019). Furthermore, Molavi et al. (2019) found that PLWE develops a superstitious belief that illness results from God’s punishment and the treatment may be obtained from faith healers.

Apart from attitude, PLWE develops resilience towards the illness, which may be high or low depending on how they experience epilepsy. Resilience refers to an individual’s ability to recover from, adapt, or remain strong in adversity (Chew, Carpenter & Haase, 2018). Thus, PLWE adjusts to the condition, maintain competence regardless of the threats to their well-being (social life, education and employment), recover from traumatic seizures, which may be embarrassing at times (Chew, Carpenter & Haase,2018).

The outcome is acceptance, which is the ability to accept the condition or illness to a point where the patient can live with it and maintain a functional life. PLWE may live productive lives if they accept their condition and develop new ways of coping with the seizures (Rawlings, Brown, Stone & Reuber, 2017). Depending on their experiences with the condition, the attitude of PLWE may either be positive or negative. If their attitude is positive, they will find it easy to be resilient and develop other means of coping with the condition. It will be difficult for PLWE to accept their condition and function in a normal setting if their experiences of epilepsy are perceived as unnatural or are negatively appraised.

1.3 PROBLEM STATEMENT

The rate of non-communicable diseases including epilepsy, is rapidly rising in South Africa (Siriba, 2014). This increase is enough to raise concern about how it affects PLWE and society at large. Epilepsy remains a significant health problem because of its health implications and its social, cultural, and psychological effects. It affects 1 in every 100 people in South Africa with half a million South Africans based on a total estimated population of 52 million (Epilepsy South Africa, 2017). Thus, if every person with epilepsy has four immediate family members, at least another 2 million South Africans are affected by the condition (Epilepsy South Africa, 2017). The researcher has observed that from the selected villages, PLWE experience challenges that interfere with their daily lives; these include stigma and discrimination, educational challenges, inadequate healthcare, unemployment and difficulty finding or maintaining sexual relationships or marriage. Even family members or caregivers of PLWE are faced with the burden of stigma directed towards the person living with epilepsy. This in turn makes them keep the disease a secret, which delays the success of treatment. In a study conducted in Ghana, PLWE experience various types and levels of stigma which affects their physical and mental health and while the reasons for stigma may be different across communities and culture (Dako-Gyeke & Donkor, 2018). Additionally, barriers such as stigma may prevent PLWE from accessing the necessary support (Dako-Gyeke & Donkor, 2018). Moreover, although there are other studies conducted in Limpopo (Siriba, 2014), there are no known studies conducted in the selected areas, including the different cultural groups. On the other hand, among the selected villages in Mpumalanga, no known study has been conducted on epilepsy which makes this study necessary in that context. Moreover, most of the conducted studies usually focus on treatment rather than the experiences of PLWE. By disclosing the disease PLWE may isolate themselves from the rest of the community, thus resulting in psychological stress. In light of this, the study is aimed at exploring the experiences of PLWE in selected villages of Limpopo and Mpumalanga Provinces.

1.4 RATIONALE FOR THE STUDY

There is a global need of improving the quality of care for patients with chronic illnesses such as epilepsy. Studies that have been conducted are vastly available internationally, but there are limited studies that pay efficient focus on the experiences of PLWE (Keikelame and Swartz, 2018). Although there are recent studies on PLWE, such as that of Keikelame and Swartz (2018), which focused extensively on the stigma that is placed towards PLWE in South Africa, there is a need for more studies that will ponder upon the experiences of PLWE in the selected villages or cultures. The researcher observed within the selected villages that PLWE have different epilepsy experiences that are culturally based. The National Development Plan (NDP) 2030 aims to understand demographic trends in order to meet various nned and provide capabilities for individuals. Amongst other things it strives to provide better health and healthcare with more emphasis on provding sound education and skills training (National Developmant Plan, 2013). PLWE must be identified and their need taken into account. They require special care and the NDP 2030 is a good initiative that can make it possible that these needs are well met. Therefore, the researcher sought to research on the matter inorder add to the existing knowledge by focusing on PLWE experiences. This enabled the researcher to obtain first-hand experiences from the PLWE themselves.

1.5 AIM AND OBJECTIVES OF THE STUDY

1.5.1 Aim

This study aims to explore the experiences of people living with epilepsy in selected villages of Limpopo and Mpumalanga Provinces.

1.5.2 Objectives

The following objectives will guide the study:

- To explore the experiences of people living with epilepsy in selected villages of Limpopo and Mpumalanga Provinces.
- To describe the experience of people living with epilepsy in selected villages of Limpopo and Mpumalanga Provinces.

1.5.3 Research Questions

The following question will help in attaining the objetives of the study:

- What are the experiences of people living with epilepsy in selected villages of Limpopo and Mpumalanga Provinces?

1.6 SIGNIFICANCE OF THE STUDY

The study has brought a sense of advocacy for PLWE whereby the policymakers would, potentially, improve the existing policies to suit the proper needs of people living with epilepsy. The study is also assisting in bringing awareness to the communities so that they gain adequate knowledge about epilepsy and how they may best treat patients with epilepsy and modify their attitude towards PLWE. The western and traditional medicine practice is benefiting from the study by gaining insight into both perspectives and understanding why people opt for a particular treatment over the other. The treatment process would be improved, and the existing treatment gap lessened. The educational spectrum gained in-depth research on the experiences of people living with epilepsy through the articles produced. Through this study, more effective health education can be launched to enhance the quality of life of PLWE.

1.7 DEFINITIONS OF TERMS

Epilepsy- According to Resendiz-Aparicio et al. (2019), the current definition of epilepsy can be established from three possibilities depending on how they begin the presence of consciousness and the description of symptoms. The International League Against Epilepsy (ILAE) defines epilepsy as a disease characterized by two or more seizures or a diagnosis of epilepsy (Barger et al., 2017). A seizure is a brief change in normal electrical brain activity resulting in altered awareness, perception, behaviour, or movement (Cui, Kobau, Zack, Helmers & Yeargin-Allsopp, 2015). Epilepsy is defined as a disease characterized by multiple seizures in this study.

People Living with Epilepsy (PLWE) - People living with epilepsy have recurrent seizures due to an underlying disease of the brain or a brain disorder. In this study, PLWE are those who experience any form of seizures.

1.8 RESEARCH METHODOLOGY

The methodological steps which were followed are explained. The following discussion focuses on outlining the research design, study setting, study population, sampling, data collection methods and instruments used, techniques used for analysing data, trustworthiness and ethical considerations.

1.8.1 Research design

The study implemented a qualitative approach. This approach was ideal for the study because it taps into the social phenomena in a natural setting. Epilepsy as a social phenomenon occurs in a natural setting in rural communities (de Vos, Strydom, Founche & Delport, 2011). Hence the design employed for this study was phenomenological design. This design was appropriate in describing the lived experiences of PLWE as accurate as possible (de Vos, Strydom, Founche & Delport, 2011). A descriptive type of phenomenology design was used, and it enabled the researcher to explore and describe the lived experiences without attempting to give it meaning (Alase, 2017). The researcher used bracket or left aside any previous knowledge in order to see phenomena as experienced (Charlick, Pincombe, McKellar, & Fielder, (2016).

This study design proved to be the most suitable for the study as it assisted in achieving the set objectives. The study sought to understand the lived experience of which, in this case, the experiences of PLWE was explored and described (Hammarberg, Kirkman & Lacey, 2016). To achieve this, the researcher went to the participants' setting, where they exist in essence. This allowed the researcher to explore, grasp and understand these lived experiences as the participants reported them and through their insight (Maree, 2016).

1.8.2 Study setting

The study was conducted in six selected villages located in the Limpopo and Mpumalanga Provinces. The researcher observed that in these two provinces, several people were living with epilepsy, and their experiences of this condition tend to differ depending either on where they come from or which cultural group they belong to. Also, the beliefs they hold influence their differences in the experiences of epilepsy. These two provinces fall under South Africa's poorest Provinces and are comprised of low-income villages. Limpopo Province is situated in the northern part of the country with a population of 400 000, and most of the people from the selected villages speak Tshivenda, Xitsonga, Pedi (Stats SA, 2016). The selected villages include Mtiti, Malavuwe and Bochum. The unemployment rate in these areas is very high, and most people in the selected villages of Limpopo Province rely on farming and selling what they produce. The other province, Mpumalanga, has the same economic characteristics as the communities of Limpopo Province; its communities are also on the poverty rank since the education and employment rate is low. The selected villages in this province are Jerusalema, Clara and Acornhoek. The language used in this province is largely Seswati and Pulana. The poverty rate is influenced mainly by the high birth rate among women of different age groups. The healthcare provider system that is utilized in these two provinces is communal, and all patients meet at the same place to receive care or treatment.

1.8.3 Study Population and sample

1.8.3.1 Target Population

The target population is the people the study aimed to include for data collection. The target population for this study were PLWE, who reside in the selected villages. Because of the clinical characteristics of epilepsy, this population is faced with the burden of living with the disease on a day-to-day basis.

1.8.3.2 Sample and Sampling

The sampling method employed in this study was the non-probability sampling method since the researcher did not know the population size or the members (de Vos, Strydom, Founche & Delport, 2011). The approach or technique used was purposive sampling; because the sample chosen contains most of the characteristics representative of the population, and serve the purpose of the study. In this study, 11 participants were included. However, the sample size was determined by data saturation. The sample included anyone who was living or diagnosed with epilepsy and willing to participate in the study. Participants included both young and older people starting from 18 years and above. The researcher obtained information from the clinic to find out which community members have been diagnosed with epilepsy and how to locate them. The home-based care workers were the ones who assisted the researcher in identifying the participants

1.8.4 Data collection

Before the researcher commenced with the data collection process, identification with the participants was crucial. During this time, the purpose of the study was explained to the participants, and the researcher established rapport with the participants. To achieve rapport, the researcher engaged with the participants, enabling her to develop an open and trusting relationship with them (Babbie, 2017). This also enabled the participants to be comfortable with the researcher. They knew what was required from them and trusted the researcher (Alase, 2017). The researcher attended to all the participants' questions without judging or arguing with them. The researcher also engaged with the community health workers in identifying PLWE in the communities. The researcher requested permission to collect data at the selected villages from the villages' respective chiefs or tribal authorities.

The community health workers assisted the researcher in recruiting the participants since the health workers were able to identify PLWE at each village. The participants were provided with the information letter (Annexure A) to familiarize themselves with the study and how the data collection process would unfold. After that, they were provided with the consent form (Annexure B) to consent to participate in the study. Consnt was given verbally because the interviews were conducted telephonically.

Consequently, appointments were made with the participants for the commencement of the interviews.

During the data collection process, the method utilized in collecting data was face-to-face in-depth interviews. This method enabled the researcher to determine the nature of the experiences of PLWE (de Vos, Strydom, Fouche & Delport, 2011). The in-depth interviews allowed the researcher to probe into the issues and gain insight into their experiences through their responses. And through this technique, large amount of data were collected as there were different ways of recording what the participants said, such as audio recording and field notes that complemented the recording (Sutton & Austin, 2015). The researcher then utilized these methods of recording data in order to get as much accurate information as possible. The interviews were based on one central research question to be discussed in-depth. The interviewer explored the question through probing (Babbie, 2017). This enabled the researcher to elicit PLWE experiences and achieve the study objective. These interviews were conducted in the communities where the participants resided. The interview question was constructed in Tshivenda, Sepedi, Xitsonga, Sepulana and Swati. With the participants' permission, the interviews were audio-recorded, and notes were taken as well. The interviews took about 20-25 minutes, depending on the response rate.

During the interviews, some of the participants were no longer available for the interviews due to various reasons. The number of appointments made was also reduced because some PLWE experience severe symptoms to a point where they are unable to hold effective conversations. Hence the data collection only yielded 11 participants due to data saturation being reached.

1.8.5 Pre-testing

Pre-testing was done to test the interview skills of the researcher and to check the duration of the interviews. Pre-testing was done at Muledane village, a separate village from the ones chosen for the study, to avoid contamination of the sampling pool of subjects to be drawn for the study. The pre-test included five purposively chosen participants and the data received from the test is part of the main study as it was the honest responses of the participants who met the inclusion criteria. The purpose of pre-testing was to make sure that the participants understood the questions. The researcher was also able to refine the way of questioning to be the best way the participants understand (Perneger, Courvoisier, Hudelson, & Gayet-Ageron, 2015). The processes and procedures of collecting the data, such as the duration, were also tested. Pre-testing informed how best the researcher might adapt to her role.

1.8.6 Data management and analysis

The researcher made it a point that the data collected was secured and managed so that it was not lost or fell into the wrong hands. As the manager of the research database, the researcher was responsible for providing adequate security for the safekeeping of the data collected. As added protection, the researcher destroyed all audio and/or tape-recorded information after it was transcribed for the participants' protection and anonymity. All the information obtained was filed and encrypted by a strong password to protect it from outsiders (Alase, 2017).

The study employed the Interpretative Phenomenological Analysis. After data had been collected, the researcher returned to the interview data and focused on the meanings throughout the analysis process. Since there is no single or definite method that the researcher could have employed to undertake this form of analysis, the seven-step data analysis guide was utilized, as indicated in Figure 2.

1. Reading and rereading: the researcher immersed in the data or transcript of a single case.
2. Initial noting: the researcher read the case, recording the observations which were often noted in the margin of the transcript.
3. Developing emergent themes: the researcher 'chunked' or portion data relating to the observational 'notes' of the case
4. Searching for connections across emergent themes: the researcher will cluster the 'chunks of data' and 'notes' together and consider how they relate.
5. Moving to the next case: the themes derived from the previous case were 'bracketed' as the new case was considered with 'open and fresh eyes', again becoming immersed in the case.
6. Seeking patterns across cases: the researcher asked, are there any themes/qualities identifiable across cases? These were highlighted making a note of any idiosyncratic differences.
7. Moving the interpretation to a deeper level: the researcher reviewed the themes across the dataset and by using metaphors and temporal referents the researcher further elicited the meaning of the experience.

Figure 2: The seven-steps of IPA data analysis (Peat, Rodriguez & Smith, 2019)

In the final analysis stage, the researcher drew on the existent theory/concepts to further explore the data. IPA findings are presented as a coherent analytical account, including participant quotes and a detailed interpretative commentary (Peat, Rodriguez & Smith, 2019).

1.8.7 Measures to Ensure Trustworthiness

Lincoln and Guba (1985) have developed criteria that ensure trustworthiness in qualitative studies. Therefore, the present study adopted their criteria which are as follows:

1.8.7.1 Credibility

The researcher ensured credibility through various steps outlined by Shenton (2004). Firstly, the methods used to collect and analyse data for the study were adopted from approaches “that have been successfully utilized in previous comparable projects” (Shenton, 2004). Secondly, site triangulation was applied by creating a sample of participants from different villages. Thirdly, the participants were given thorough explanation about the nature of the study and the implications of their participation. Participants were made aware that they had the option to refuse to participate at any point without being required to provide an explanation. Fourthly, probing was used to acquire more clarity from participants and identify discrepancies in participants’ responses. Fifthly, the researcher was in contact with the participants for debriefing sessions. Lastly, criticism and inputs were given a platform during the presentation of the completed study for adjustments on areas overlooked by the researcher.

1.8.7.2 Transferability

Transferability can only be attained when a study is immersed in the existing literature with similar characteristics (Shenton, 2004). The researcher conducted extensive literature evaluations to determine the study's applicability in a variety of settings.

1.8.7.3 Dependability

Dependability is produced by a study that could be repeated in the same settings with the same procedure and produce similar findings, if not identical, findings (Shenton, 2004). The researcher gave a descriptive discussion on the methods used to attain the study results. Furthermore, the methods were repeatedly evaluated for errors to allow rectification.

1.8.7.4 Confirmability

Confirmability was attained through the researcher ensuring that her perception of the phenomenon under study does not have an influence on the study (Shenton, 2004). The above was accomplished by the researcher providing full disclosure on the final report revealing all decisions taken in the study and reasons behind the decisions from the study’s conception to its completion.

1.8.8 ETHICAL CONSIDERATIONS

Before the commencement of the study, the researcher considered several ethical issues that must be adhered to. The researcher also ensured that honesty and integrity were maintained throughout by observing confidentiality, informed consent and ethical clearance. All the information pertaining to the study was given to the participants before data was collected. To ensure all this, the researcher presented the study to the Department of Psychology, School Higher Degree Committee and the Executive School Higher Degree Committee. In all these departments and committees, the study was evaluated with the proper scrutiny and comments and suggestions were given to 'perfect' the study. The researcher then attended to the corrections and sought permission to conduct the study from the relevant stakeholders thereafter. The researcher sought permission to conduct the study from the Chief, Induna or ward counsellors. After that, full attention was given to the comments and suggestions for corrections. The consideration of ethics protected the researcher and the participants from any harm.

1.8.8.1 Confidentiality

To maintain confidentiality, the researcher made sure that any information provided by the participants was kept safe and private. This meant that no information was shared without the consent of the relevant participants. Even amongst the participants, there was no disclosure of another participant's responses.

1.8.8.2 Right to anonymity

The researcher considered anonymity by preventing any link that could be traced between the participants and their identity. This was done by replacing the participants' names with "participant 1" and so on.

1.8.8.3 Privacy

At no circumstance was private information shared without the knowledge and approval of the participants. This means that all the information obtained from the participants was kept safe. The researcher safeguarded the participants' privacy by keeping all the information under lock and key. This means that no person could access the information without seeking approval from the relevant person.

1.8.8.4 Informed consent

The researcher made sure participants were aware of the study purpose through the provision of necessary information before the study commenced. This enabled the participants to understand the purpose of the study before giving consent to participate. The participants were provided with an information sheet (see annexure A) which outlined the purpose of the study, and thereafter, they were provided with the consent form for them to sign.

1.8.8.5 Voluntary participation

The researcher made it clear to the participants that the research was for academic purposes only and that their participation was voluntary. The researcher further explained that no one is forced to participate, but they must do so willingly (Sutton & Austin, 2015).

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SECTION 2
MANUSCRIPTS

2.1 Author Guidelines for Journal of Psychology in Africa

Submission author's guidelines

The ***Journal of Psychology in Africa.***

All pages must be numbered consecutively, including those containing the references, tables and figures. The typescript of a manuscript should be arranged as follows:

• Title: this should be brief, sufficiently informative for retrieval by automatic searching techniques and should contain important keywords (preferably <13).

• Author(s) and Affiliation(s) of author(s): The corresponding author must be indicated. The author's respective affiliation where the work was done must be indicated. An e-mail address for the corresponding author must be provided.

• Abstract: Articles and abstracts must be in English. Submission of abstracts translated to French, Portuguese and/ or Spanish is encouraged. For data-based contributions, the abstract should be structured as follows: Objective – the primary purpose of the paper, Method – data source, participants, design, measures, data analysis, Results – key findings, implications, future directions and Conclusions – in relation to the research questions and theory development. For all other contributions (except editorials, book reviews, special announcements) the abstract must be a concise statement of the content of the paper. Abstracts must not exceed 150 words. The statement of the abstract should summarise the information presented in the paper but should not include references.

• Text: (1) Per APA guidelines, only one space should follow any punctuation; (2) Do not insert spaces at the beginning or end of paragraphs; (3) Do not use colour in text; and (4) Do not align references using spaces or tabs, use a hanging indent.

• Tables and figures: These should contain only information directly relevant to the content of the paper. Each table and figure must include a full, stand-alone caption, and each must be sequentially mentioned in the text. Collect tables and figures together at the end of the manuscript or supply as separate files. Indicate the correct placement in the text in this form <insert Table 1 here>. Figures must conform to the journals style. Pay particular attention to line thickness, font and figure proportions, taking into account the journal's printed page size – plan around one column (82 mm) or two column width (170 mm). For digital photographs or scanned images the resolution should be at least 300 dpi for colour or greyscale artwork and a minimum of 600 dpi for black line drawings. These files can be saved (in order of preference) in PSD, PDF or JPEG format. Graphs, charts or maps can be saved in AI, PDF or EPS format. MS Office files (Word, Powerpoint, Excel) are also acceptable but DO NOT EMBED Excel graphs or Powerpoint slides in a MS Word document.

Referencing

Referencing style should follow latest edition of the APA manual of instructions for authors.

- References in text: References in running text should be quoted as follows: (Louw & Mkize, 2012), or (Louw, 2011), or Louw (2000, 2004a, 2004b). All surnames should be cited the first time the reference occurs, e.g., Louw, Mkize, and Naidoo (2009) or (Louw, Mkize, & Naidoo, 2010). Subsequent citations should use et al., e.g. Louw et al. (2004) or (Louw et al., 2004). ‘Unpublished observations’ and ‘personal communications’ may be cited in the text, but not in the reference list. Manuscripts submitted but not yet published can be included as references followed by ‘in press’.

- Reference list: Full references should be given at the end of the article in alphabetical order, using double spacing. References to journals should include the author’s surnames and initials, the full title of the paper, the full name of the journal, the year of publication, the volume number, and inclusive page numbers. Titles of journals must not be abbreviated. References to books should include the authors’ surnames and initials, the year of publication, full title of the book, the place of publication, and the publisher’s name. References should be cited as per the examples below:

Journal article

Peltzer, K. (2001). Factors at follow-up associated with adherence with adherence with directly observed therapy (DOT) for tuberculosis patients in South Africa. Journal of Psychology in Africa, 11(2), 165–185.

Book

Gore, A. (2006). An inconvenient truth: The planetary emergency of global warming and what we can do about it. Emmaus, PA: Rodale.

Edited book

Galley. K. E. (Ed.). (2004). Global climate change and wildlife in North America. Bethesda, MD: Wildlife Society.

Chapter in a book

Cook, D. A., & Wiley, C. Y. (2000). Psychotherapy with members of the African American churches and spiritual traditions. In P. S. Richards & A. E. Bergin (Ed.), Handbook of psychotherapy and religiosity diversity (pp 369–396). Washington, DC: American Psychological Association.

Magazine article

Begley, S., & Murr, A. (2007, July 2). Which of these is not causing global warming? A. Sport utility vehicles; B. Rice fields; C. Increased solar output. Newsweek, 150 (2), 48–50.

Newspaper article (signed)

Landler, M. (2007, June 2). Bush’s Greenhouse Gas Plan Throws Europe Off Guard. New York Times, p. A7.

Unpublished thesis

Appoh, L. (1995). The effects of parental attitudes, beliefs and values on the nutritional status of their children in two communities in Ghana (Unpublished master’s thesis). University of Trondheim, Norway.

Conference paper

Sternberg, R. J. (2001, June). Cultural approaches to intellectual and social competencies. Paper presented at the Annual Convention of the American Psychological Society, Toronto, Canada

2.2 Manuscript 1

Title of the manuscript: Luvhengo Masane, Maphula Angelina and Makhado Lufuno. A closer look at the experiences of people living with epilepsy in South Africa: A systematic review. Journal of Psychology in Africa (***Under Review***).

Confirmation of Manuscript Submission

A closer look at the experiences of people living with epilepsy in South Africa: A systematic review

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Abstract

The current systematic review sought to assess the experiences of people living with epilepsy in Africa. Database searching was conducted on electronic databases including PubMed, Google Scholar, EBSCOHost, and Science Direct, published from 2012 to 2021. Qualitative studies were appraised using the Critical Appraisal Skills Programme (CASP). Line by line coding was applied, and organising themes into descriptive themes by using thematic analysis. After searching and screening the studies, data were extracted from a sample of 14 qualitative articles and examined. Three themes emerged from the findings and include epilepsy insight, the burden and coping mechanism. Cultural beliefs influence people's understanding of epilepsy. Witchcraft and spiritual powers have been reported to cause this illness. The experiences of PLWE in Africa require to be given enough attention due to the severity of seizures and the challenges they experience daily.

Keywords: Epilepsy, Experiences, Coping Mechanism, Impact, People Living With Epilepsy

Introduction

“Around fifty million people have epilepsy. Many of them suffer silently. Many of them suffer alone. Beyond the suffering and the absence of care lie the frontiers of stigma, shame, exclusion and, more often than we care to know, death” (Brundtland, 1998). Epilepsy is a global burden reported to affect about 50 million people globally, mostly in low and middle-income countries (Singh & Sander, 2020). 0ut of the 50 million 125 000 people die each year (Singh & Sander, 2020). About 80% of the people who have epilepsy in low and middle-income countries are most prevalent in sub-Saharan Africa (Ba-Diop et al., 2014). It is a common neurological disease that affects approximately 0.5 % to 1% of children (Aaberg et al., 2017).

Defining epilepsy has proved to be a very difficult task because of the different beliefs regarding epilepsy. Nevertheless, the International League Against Epilepsy (ILAE) has constructed a definition of epilepsy that is recurrent. That is, two or more, unprovoked seizures that are at least 24 hours apart, and an epileptic seizure is “a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain” (Beghi & Giussani, 2018).

More than 10 million people are directly affected by epilepsy, and most poor Sub-Saharan African countries have the highest prevalence of epilepsy (WHO, 2012).In Africa and other parts of the world, epilepsy has long been perceived as a result of supernatural forces that is contagious and shameful (Vodougnon et al., 2019). Similarly, in Ghana, epilepsy is believed to be caused by spiritual forces and is viewed as shameful (Kpobi et al., 2018). Due to this point, treating people living with epilepsy has proved to be difficult due to the different beliefs and attitudes held towards epilepsy (Saengsuwan et al., 2012). In most African populations or native tribes of Central and South America, people believe that epilepsy results from witchcraft and are associated with religious beliefs (Giuliano, 2018).

Thus, the different beliefs about what causes epilepsy influence people's attitudes towards it. The attitudes tend to differ from one region to the other depending on the beliefs regarding epilepsy and PLWE. Similarly, Kiyak and Dayapoglu (2017) highlight that people who know about epilepsy display a positive attitude towards epilepsy and PLWE. Most people are aware of epilepsy in developing countries, but their misconceptions about the illness pave the way for negative attitudes towards PLWE within the communities (Kaddumukasa, 2016). Moreover, most people believe that PLWE are not stable enough to sustain an interpersonal relationship to the point of marriage or even employment (Thabit et al., 2018; Saengsuwan et al., 2012). PLWE do experience other challenges (Mutanana & Mutara, 2015). With stigma at the very top of the list of negative factors that PLWE experiences and are prevalent across the globe (Lee et al., 2020). Stigma results from misconceptions that people hold against epilepsy, which influences negative attitudes towards PLWE (Tayeb, 2019). It may be experienced through a form of discrimination at places such as school, workplace, community, family and other social settings and may affect prospects for marriage, education and employment (Tedrus et al., 2017). Negative attitude towards PLWE has been well documented, but there remains a huge gap in research that pins at the experiences of PLWE.

Review Question

What are the experiences of people living with epilepsy in South Africa?

Methods

Search strategy

This systematic review aims to assess the experiences of PLWE in Africa. The information sources were obtained from three electronic databases, which include EBSCOHost, Google Scholar, Science Direct and PubMed. These sources were restricted to those that were written in English. The researcher used the problem statement and key terms such as “epilepsy in Africa”; “People living with epilepsy” and/or “People with epilepsy” to search for the sources. The systematic review only includes studies published between 2012 and 2021; conducted in Africa.

The systematic review is guided by Tawfik et al. (2019) step-by-step guideline for conducting a systematic review displayed in Figure 1. The steps that have been included are those that correspond with the study. The search conducted yielded 18 826 studies. After title and abstract review, only 66 studies were retrieved from the search conducted, and 18 760 studies were excluded. The excluded studies did not apply to the inclusion criteria adopted for this review. The studies selected for analysis were 14, and they were found to be most relevant to the review's aim.

Inclusion and exclusion criteria

The inclusion criteria for this systematic review include papers that have been written in English, peer-reviewed research and published from 2012 to 2021. The review also includes full texts related to the experiences of PLWE in Africa. Quantitative and mixed methods studies or those not available in the full text have been excluded from the study. Non-English studies have not formed part of the study either.

Appraisal of Included studies using CASP

The quality of the research has been assessed using the Critical Appraisal Skills Programme

(CASP) qualitative research checklist. This is a checklist or tool designed for appraising the strength and limitations of any qualitative research methodology. The checklist consists of ten questions, each measuring various methodological aspects of a qualitative study. This tool has been chosen because it is designed to be used as an educational tool for researchers with little or no formal experience in appraising the quality of qualitative research (Singh, 2013). Further, the review's focus is health-related; thus, the tool is suitable (Long et al., 2020). Table 1 shows how the chosen studies have been critically appraised using CASP.

Table 1: CASP for selected studies

Study authors & year	Title	Study Appraisal
Keikelame& Swartz, 2018	"I wonder if I did not mess up….": Shame and resistance among women with epilepsy in Cape Town,South Africa	**90%**
Eastman, 2019	Experiences of living with epilepsy	**60%**
Kandawire, 2016	Socio-economic experiences of epilepsy with epilepsy employed in the labour market in the Ekurhuleni region	**80%**
Keikelame& Swartz, 2016	"The others look at you as if you are a grave": a qualitative study of subjective experiences of patients with epilepsy regarding their treatment and care in Cape Town, South Africa	**80%**
Siriba, 2014	The experiences of people living with epilepsy in Nzhelele, Limpopo Province	**90%**
Chew et al., 2017	Young people's experiences of Epilepsy: A scoping review of qualitative studies	**90%**
Keikelame et al.,2017	Psychosocial challenges affecting the quality of life inadults with epilepsy and their careers in Africa: A review of published evidence between 1994 and 2014	**80%**
Deegbe et al., 2019	Beliefs of people living with epilepsy in the Accra Metropolis, Ghana	**90%**
Deegbe et al., 2020	Experiences of epilepsy: Coping strategies and health outcomes among Ghanaians living with epilepsy	**80%**
Dako-Gyeke & Donkor, 2018	Experiences and perspectives of stigmatization and discrimination against people with epilepsy in Accra,Ghana	**80%**
Catalao et al., 2018	Implementing integrated services for people with epilepsy in primary care in Ethiopia: a qualitative study	**70%**
Shabangu, 2013	Experiences of people living with epilepsy presenting for treatment at Umlazi Clinic	**60%**
Mhlari&Sodi, 2017	Understanding and management of epilepsy in a rural community in South Africa: An exploratory study	**70%**
Deegbe, 2015	Experiences of people living with epilepsy in the Accra Metropolis	**80%**

Results

Characteristics of the included studies

In this section, the characteristics of the studies included in this systematic review will be outlined with the aim of the review to indicate how the included studies contribute to the purpose of the review. These characteristics enable the researcher to assess each article; data were extracted on: objectives, setting, study design, population and sample, main findings, and study limitations (see Table 2). The extracted data are discussed by identifying any unique features that appear to be common in the included articles.

Table 2: Characteristics of the Selected Studies

Author (s)	**Title of the study**	**Objectives**	**Setting**	**Study design**	**Population & sample**	**Main findings**	**Study limitations**
Keikelame(2018)	“I wonder if I didnot mess up….”: Shame and resistance among women with epilepsy in Cape Town, South Africa	• Describe and analyse • Experiences of women with epilepsy to providean in-depth understanding of how women with epilepsy experience shame and resistance.	Cape Town township	Qualitative exploratory study design	12 Adult PLWE	• Two themes • Process of shame and resistance strategies	• Presentation of four small scope studies • Findings related to weight loss were not reported
Eastman (2019)	Experiences of living with epilepsy	• To describe the lived experiences and associated stigma of PLWE • To highlight reoccurring themes associated with stigma across participants	Cape Town, South Africa	Case studies	• Epilepsy patients • Purposive sampling • Ten epilepsy patients (7 pilot and 3 case studies)	• External forces mediate the experiences of PLWE. • The need for further research into the challenges of people with epilepsy in South African communities	• An unrepresentative number of individuals has measured the impact of having epilepsy • Only one interview was conducted with each person
Kandawire (2016)	Socio-economic experiences of people with epilepsy employed in the open labour market in the Ekurhuleni region	• Explore and describe • Different types of epilepsy • The influence of epilepsy on the social functioning and well-being • Socio-economic benefits in the open Labour Challenges in the workplace market	Ekurhuleni region	Phenomenological design.	• Sixty people with epilepsy were employed in the open labour market of the Ekurhuleni region. • 10 participants • Purposive sampling	• Themes • The potential to work in the open labour market • Coping with epilepsy • Knowledge regarding the rights of the worker • Availability of support systems	• Delayed time inaccessing participants • Data quality is affected by the anxiety of the participants.

Keikelameet al., (2016)	“The others look at you as if you are a grave”: a qualitative study of subjective experiences of patients with epilepsy regarding their treatment and care in Cape Town, South Africa	Explore subjective experiences of people with epilepsy and their perspectives on epilepsy	Cape town urban township	Qualitative design	• 12 people with epilepsy were interviewed • 24 potential people with epilepsy were selected	• Theme • Difficulty in accessing treatment and care	• Potential participants known by gatekeepers were not included • Study findings are too small to be generalized
Siriba(2014)	The experiences of people living with epilepsy in Nzhelele, Limpopo Province	• To investigate the subjective meanings that people living with epilepsy attribute to their condition • To determine the causal explanations that people living with epilepsy attribute to their condition • To understand and describe the psychological strategies that these individuals employ to manage the illness	Nzhelele Village, Limpopo Province	Qualitative, Phenomenological approach	• 6 People living with epilepsy • Snowball sampling	• Participants report their understanding of what is epilepsy with reference to what they perceive as the causes of epilepsy • Different psychological strategies are utilized to manage epilepsy	• Original material provided by participants may have been omitted or substituted when the interview data was translated from Tshivenda to English • The results of this study cannot be generalized to the larger South African population since the study was conducted on a tiny sample of individuals in the Vhembe district (Limpopo Province) suffering from epilepsy

Chew et al., (2017	Young people's experiences of Epilepsy: A scoping review of qualitative studies	Providing an overview of qualitative studies that explored young people's perspectives on living with epilepsy.	UK, US, Kenya, Italy, Sweden, Canada and Sub-Saharan Africa	• Qualitative • Mixed methods research designs	Young people diagnosed with epilepsy aged between 13 and 18	• Frustrations and misunderstandings regarding epilepsy medications • The impacts of seizures, brain injuries, burns, etc., • The high demand of the illness brings about challenges with family and friends relationships. • Issues of education and dealing with stigma and discrimination from teachers • Young people's reactions to living with epilepsy are usually coupled with frustration, loneliness, embarrassment, anger and sadness.	• Only English-language databases and journal articles were includedand reviewed,respectively. • Synthesis of qualitative findings was conducted without a critical appraisal of study quality.
Keikelame et al., (2017)	Psychosocial challenges affecting the quality of life in adults with epilepsy and their careers in Africa: A review of published evidence between1994 and 2014	To examine the kind of psychosocial challengesfrom published evidence and to identify gaps in current knowledge	Africa	Literature review	Adults with epilepsy	Psychosocial, cultural and socio-economic challenges do exist among people with epilepsy and their carers	Not a systematic review

Deegbe et al., (2019)	Beliefs of people living with epilepsy in theAccra Metropolis, Ghana	To describe the beliefs that People Living with Epilepsy (PLWE) have about the disease.	Accra Metropolis, Ghana	descriptive-exploratory qualitative design	Thirteen participants living with epilepsy	• Participants believed epilepsy was a disgraceful illness. • A high number of them believed epilepsy was caused by spiritual forces. • Moreover, seizures resulted in injuries and were believed to have affected the education, work and relationshipsof the PLWE.	A smaller sample size was used, which limits the generalization of the findings to PLWE in larger settings.
Deegbe et al., (2020)	Experiences of epilepsy: Coping strategies and health outcomes among Ghanaians living with epilepsy	To assess the coping strategies of people living with epilepsy (PLWEs) and their health outcomes	Ghana	descriptive-exploratory, qualitative study	A purposive sample of 13 PLWE	• Positive coping strategies: problem-focused coping, faith in God, social support,and lifestyle changes • Negative coping strategies: thinking and worrying and concealing diagnosis	The use of a small sample size
Dako- Gyekeet al.,(2018)	Experiences and perspectives of stigmatization and discrimination against people with epilepsy in Accra, Ghana	To investigate experiences and perspectives of people with epilepsy (PWE) and key informants	Accra, Ghana	Qualitative research approach	Twenty participants (14 PWE and 6 key informants) purposively sampled	PWE and key informants included in this study perceived epilepsy as a spiritual, curable, and medical condition	The findings of this study cannot be generalized because it was based on PWE and caregivers who resided in Accra and received services from Basic Needs-Ghana.
Catalao et al., (2018)	Implementing integrated services for people with epilepsy in primary care in Ethiopia: a qualitative study	To explore the perspectives of service users and caregivers on the accessibility, experience and perceived impact ofepilepsy treatment receivedin a task-shared model in a rural district of Ethiopia.	Ethiopia	Qualitative study	• 13 Service users and 3 caregivers • Purposively sampled	• Decrease in cost of transportation due to accessible local primary health care centres • Epilepsy imposes a high emotional and financial burden and the lack of continuous practical and emotional support	• The results may only be applied to specific social, economic and cultural characteristics of thestudy area and may not be generalizable to other settings. • Women and caregivers were under-represented in the sample

Shabangu (2013)	Experiences of people living with epilepsy presenting for treatment at Umlazi Clinic	To describe the lived experiences of PWE	Umlazi U21 PHC clinic at eThekwini District in KZN	Qualitative, descriptive study guided by a phenomenological approach	• PWE who were receiving treatment at Umlazi U21 PHC clinic at eThekwini District in KZN • Non-probability, convenience sampling	• The lack of knowledge among communitieshas led to negative experiences of people with epilepsy. • Family members often provide support to people with epilepsy; especially female partners support their husbands. • Community members show different reactions towards epilepsy • Community lack knowledge regarding epilepsy • Difficultiesin maintaining employment by PLWE due to occurrence of seizures • PLWE seek channels of support as a way of coping with thecondition	The study was conducted in a specific public PHC clinic in eThekwini District and, as such, is not be transferable to other districts
Mhlari et al., (2017)	Understanding and managementof epilepsy in arural community inSouth Africa: An exploratory study	To explore how people living with epilepsy in an indigenous rural South African community understood and managed their epilepsy	Vhembe District, South Africa	Qualitative design	• Six people living with epilepsy • Snowball sampling	• The participants' understanding of epilepsy is closely linked to their own experiences of the condition, as well as to cultural beliefs about seizure disorder • Epilepsy is managed through family, traditional and western medicine	• Due to data translation, some important information may have been altered • The results of this study cannot be generalised to the larger South African population since the study was conducted ona very small sample in the Vhembe district (Limpopo province)

Deegbe (2015)	Experiences of people living with epilepsy in the Accra Metropolis	• Describe the beliefs that PLWE have about the disease • Determine how PLWE cope with the disease. Assess the outcome of interventions carried out by PLWE to treat epilepsy	Accra Metropolis	Descriptive-exploratory design	• 20 PLWE living in the Accra Metropolis • Purposive sampling	• Most participants believed epilepsy is caused by spiritual forces • Injuries resulting from seizure disadvantaged participants with employment and educational opportunities. • Different treatment options are explored.	Some of the essential meanings in the data may have been lost in translation.

From the evidence above, the included studies have been articulated rigorously and each specific procedure used to carry out the study has been well explained (Koch et al., 2014; O'brien et al., 2014). The choice of appropriate qualitative design and selection of study objectives were clearly presented. The settings were well-motivated and the samples were well justified. Three themes have been developed from the extraction of the included articles: PLWE's insights of epilepsy, The burden of epilepsy on PLWE, Coping mechanisms employed by PLWE. Sub-themes have been developed under each theme and will be displayed in table 3 below.

Table 3: Themes and sub-themes

Themes	**Sub-themes**
PLWE's insights of their condition	Understanding of Epilepsy
	Awareness of measures to manage epilepsy
The burden of epilepsy on PLWE	Psychological challenges
	Psychosocial challenges
	Socio-economic challenges
Management of epilepsy	Coping strategies
	Treatment and care

PLWE's insights of their condition

People living with Epilepsy (PLWE) have insights into their condition. This may include their understanding of what they describe epilepsy to be, the perceptions they hold regarding epilepsy and their awareness regarding the measures they may explore to manage epilepsy. Two sub-themes have emerged within this theme and will be further explained below:

Understanding of epilepsy

Understanding epilepsy by PLWE was one of the sub-themes that emerged from the reviewed qualitative studies on the experiences of people living with epilepsy in Africa. The understanding of epilepsy across Africa differs according to the different cultures. But for the most part, most of them may relate to each other because of the similarities in the African traditional belief systems. The reviewed studies show that PLWE attributes their understating of epilepsy to what they believe is the cause of epilepsy (Siriba, 2014; Deegbe, 2019; Dako-Gyeke & Donkor, 2018; Mhlari & Sodi 2017). The authors reported that PLWE's understanding is usually influenced by their cultural backgrounds/beliefs (Siriba, 2014). From the top of the list, epilepsy is mostly believed to be caused by spiritual forces, including witchcraft and spiritual powers (Siriba, 2014; Deegbe, 2019, 2015; Dako-Gyeke & Donkor, 2018). Deegbe (2015) and Deegbe et al. (2019) reported that while most PLWE appeared to be strongly convinced that evil spirits cause epilepsy, others had no idea what causes epilepsy.

Epilepsy is understood as a disease that is disgraceful and an affliction caused by people due to resentment (Deegbe, 2015). This feeling of disgrace makes it difficult for PLWE to disclose their condition to other people, even close friends, because of fear that they may be prejudiced or discriminated against (Chew et al., 2017). This is a barrier that some PLWE deem unnecessary as their disclosure may enable people to know how to assist them in the event of a seizure episode (Shabangu, 2013). Mhlari and Sodi (2017) postulate that PLWE explains their understanding of their condition depending on how they experience it physically (Mhlari & Sodi, 2017). Some state that epilepsy is a shameful sickness of falling that interferes with their sense of personal control. On the other hand, Deegbe (2020) found that other PLWE understand epilepsy as a condition caused by starvation hence the falling.

Awareness of measures to manage epilepsy

From the studies included, it has been found that there are measures that PLWE adopt intended to manage their condition. Those aware of the condition explore different options for coping with epilepsy. Their level of awareness of these measures is of great significance. Most PLWE are aware of the different measures that are available for them to be able to manage epilepsy better, measures such as taking treatment, but others argue that the medications for epilepsy are not strong enough because of the side effects they require more than one type of treatment (Shabangu, 2013; Mhlari & Sodi, 2017). Although some PLWE prefer not to disclose their condition even with close family members because of their beliefs, some are aware of the significance of immediate family support as family members can protect them from any physical harm (Eastman, 2019).

The burden of epilepsy on PLWE

Epilepsy is a neurological condition that places a heavy burden on a person's day-to-day life. PLWE are faced with challenges that reduce their quality of life. From the studies included, three sub-themes speak to the burden of epilepsy on PLWE.

Psychological burdens of epilepsy

PLWE, when compared with matched healthy individuals, have been found to have low self-esteem (Siriba, 2014). This may also be prompted by the shame that PLWE experience due to the symptoms of seizure they experience (Keikelame & Swartz, 2018). Some of the symptoms experienced by PLWE that bring about shame include wetting themselves in public (Mhlari & Sodi 2017). Some of the reported shameful experiences experienced by PLWE include soiling themselves in public spaces or even at work (Shabangu, 2013).

Epilepsy is generally an emotional burden (Catalao et al., 2018). The emotions of PLWE are usually coupled with fear of the next seizure, embarrassment of the physical symptoms and frustrations of being different (Chew et al., 2017). As a result, PLWE often feel lonely and isolate themselves because they usually lose interest in being with other people, even if it's close family members (Deegbe, 2015). These feelings of loneliness usually influence suicidal thoughts due to the behavioural restrictions that PLWE experience and, sometimes, lack of support (Shabangu, 2013; Siriba, 2014).

Psychosocial burdens of epilepsy

Globally, stigma has been reported as the most prevalent psychosocial challenge experienced by PLWE (Suliaman et al., 2014). PLWE often feel stigmatized when people do not treat them as others; they feel different and inferior, making them anxious and demeaned (Shabangu, 2013). Another form of stigma is experienced when PLWE are discriminated against in their working environment or when they have been deprived of a job position because of their condition (Kandawire, 2016). As a result, some PLWE conceal their condition in fear of losing their jobs or being excluded from employment (Dako-Gyeke & Donkor, 2018). PLWE also experience enacted or felt stigma within them as they internalise what the society perceives about them or their condition (Eastman, 2019).

In the reviewed data, an interesting finding was that PLWE experiences challenges in maintaining healthy relationships, including family, peers and marriage (Chew et al., 2017). While some PLWE are lucky enough to find intimate partners who can accept them and understand their condition, others are not so lucky (Shabangu, 2013). Most PLWE usually get divorced/separated, whereas others find it challenging to retain a relationship (Keikelame & Swartz, 2018). Deegbe et al. (2020) found that PLWE may choose to conceal their condition in fear of losing their lover.

While some PLWE are grateful to have family members as their support system, others feel that family members are overprotective sometimes and deprive them of a chance to have some sort of autonomy (Shabangu, 2013). Young people living with epilepsy expressed anger over their parents' controlling behaviour, depriving them of privacy and independence (Chew et al., 2017). Society's ignorance about epilepsy makes it hard for PLWE to disclose their condition to their peers due to fear of being treated differently by bullying, labelling or rejected (Keikelame & Swartz, 2018).

Socio-economic burdens of epilepsy

PLWE usually find it hard to maintain a static job because of the disruption they experience from the seizures (Deegbe, 2019). This form of disruption also affects the academics of PLWE, and some resort to staying at home because they fear getting injured when they fall at school (Siriba, 2014; Deegbe, 2015). Moreover, the seizure symptoms also make PLWE to be excluded in most activities which makes them feel isolated and discriminated against (Chew et al., 2017). Though some PLWE find it easier to fit in with a new job because of no or limited seizure attacks, some experience more dominant and recurrent seizures, which discourages them from even wanting to work in the open labour markets (Kandawire, 2016). If PLWE gets a job, they often choose not to disclose their condition because they fear being treated differently or losing the job (Dako-Gyeke & Donkor, 2018; Kandawire, 2016).

For the most part, PLWE experiences financial difficulties, making them depend on family members or carers for financial support (Keikelame & Swartz, 2018; Deegbe, 2015). Kandawire (2016) has found that PLWE cannot live the lives they want because they are restricted in their types of jobs and income level.

Management of epilepsy

Coping strategies

PLWE explores different coping strategies, which may include activities carried out to manage or deal with the challenges of living with epilepsy. In Ghana, Deegbe, Aziato and Attiogbe (2020) discovered that PLWE explores different coping strategies when dealing with epilepsy, including different treatment methods such as western and traditional medicines. This coping strategy was also evident in a study conducted by Siriba (2014) in Nzhelele and Mhlari and Sodi (2017), South Africa. Siriba (2014) also found that PLWE uses acceptance as a coping mechanism that effectively manages their condition. On the same note, Shabangu (2014) and Deegbe (2015) discovered that PLWE also uses support, specifically from family members and health care professionals, as a form of coping strategy. This means that once family members accept and understand the condition, it is easier to provide the necessary care for the PLWE.

Treatment and care

In most African studies, it has been found that PLWE often chooses their treatment method depending on what they believe caused their sickness (Siriba, 2014; Keikelame & Swartz, 2018). For example, Deegbe et al. (2019) found that PLWE, who believed in God, understood that God would completely cure their illness through the medications they take. A similar observation was made by Deegbe (2015) in Ghana, where PLWE believed that prayer would remove the evil spirits that cause epilepsy and provoke healing.

Among other things, PLWE experience difficulties in accessing care. For instance, Keikelame and Swartz (2016) found that PLWE felt that they do not receive proper care as the health care workers and doctors seem to be only concerned about ensuring adherence to the medications rather than providing proper care. This contradicts the findings of Cataloa et al. (2018), where PLWE in Ethiopia reported that they found the health care service to have improved and is more preferable to an extent where they referred other PLWE to consider taking treatment and visiting the centres.

Findings and discussion

In this systematic review, we explored the experiences of PLWE in Africa and findings in various studies published from 2012 to 2021. Three significant results were observed in the form of themes. The studies were systematically selected to suit the inclusion criteria. This was necessary to obtain rich data to increase our understanding of the phenomenon under investigation. The experiences of PLWE vary across cultures. From the results of the review, it is evident that the experiences of epilepsy are significantly similar across most African countries. This is partly influenced by the similarities in culture and traditions amongst the African countries. Another reason for the consistency in the experiences is the beliefs and understandings of what epilepsy is among PLW. The beliefs often influence the treatment options that PLWE would explore to manage their condition.

In general, the overall characteristics were consistent with those presented in the introduction (Mutanana, & Mutara, 2015; Kpobi et al., 2018). For instance, many authors reported that PLWE holds misconceptions about what epilepsy is and its cause thereof (Chew et al., 2017; Deegbe, 2015; Shabangu, 2013). Moreover, most PLWE are not well informed about the different measures that they may practice to manage their condition.

The burden of epilepsy has been well displayed in the studies included. These indicate that PLWE are faced with the same challenges because of the disease, and physical symptoms of seizures decrease their quality of life. Different spheres of their lives are affected by epilepsy, which places a lot of limitations on what they can do (Kinyanjui et al., 2013). The most consistent challenge that has been evident throughout the different studies is stigma. PLWE suffered the burden of being stigmatized because of how other individuals perceive epilepsy. The stigma affects them psychologically, and they experience difficulties in other areas of life.

In the effort to manage the challenges of epilepsy, it is evident from the results that PLWE develops activities that they carry out to manage or treat epilepsy. The most prevalent strategy used among African cultures is taking Anti-Epileptic Drugs (AEDs). Most PLWE have reported that the drugs limit the effects and occurrences of the seizures. This is not the case in Zimbabwe, where Mutanana and Mutara (2015) found that some PLWE cannot access the AEDs; some prefer to use the traditional way of care or treatment. This traditional universal belief that epilepsy is caused by the evil forces of witchcraft influences the traditional way of care or treatment.

The study has sought to assess the experiences of PLWE across African countries. There is a thin line between these experiences, and PLWE are faced with both internally and externally imposed challenges. PLWE then explore different coping and management strategies to mitigate the severity of their illness. However, most of the studies report that there are activities that PLWE utilizes to lessen the extent of the seizures. Still, the level of stigmatization makes it difficult for them to effectively employ these coping strategies (Keikelame & Swartz, 2018). The level of shame resulting from the stigma discourages most PLWE from seeking treatment and care (Bora et al., 2015).

Conclusion

The current aimed to assess the experiences of PLWE in Africa. This was achieved through the analysis of the studies included due to meeting the eligibility criteria of this study. During the analysis, three themes with seven sub-themes were discussed. It is evident from the findings that the burden of epilepsy is a global issue. Furthermore, the findings report that the experiences of epilepsy are not given enough attention in research. There is a significant gap in the attention given to developing countries that are faced with high rates of epilepsy. In this light, the findings of this study will be of good use in the efforts to develop measures that can reduce stigma in epilepsy and improve the effects of treatment and care across different cultures. Health care professionals may utilise the findings to increase the quality of life for PLWE.

Limitations and recommendations for future research and policy

The overall findings showed different experiences of PLWE in Africa; although we tried to include as many sources as possible, we only included those published between 2012 and 2021. This limitation may affect the bias of the review. Due to the limitation of published sources on experiences of PLWE in Africa, it creates difficulty in comparing our results with other continents. Given the multicultural nature of the experiences of PLWE, further qualitative research is needed to identify additional factors specifically from the participants' perspective and explore the context-specific experiences thereof.

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Conflict of interest

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Data availability statement (DAS)

The authors declare that data is available since all references used are publicly available from the database.

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2.3 Author Guidelines for Health SA Gesondheid - Journal of Interdisciplinary Health Sciences

Submission guidelines manuscript 2

Health SA Gesondheid - Journal of Interdisciplinary Health Sciences

Title: The article's full title should contain a maximum of 95 characters (including spaces).

Abstract: The abstract, written in English, should be no longer than 250 words and must be written in the past tense. The abstract should give a succinct account of the objectives, methods, results and significance of the matter. The structured abstract for an Original Research article should consist of six paragraphs labelled Background, Aim, Setting, Methods, Results and Conclusion.

- Background: Summarise the social value (importance, relevance) and scientific value (knowledge gap) that your study addresses.
- Aim: State the overall aim of the study.
- Setting: State the setting for the study.
- Methods: Clearly express the basic design of the study, and name or briefly describe the methods used without going into excessive detail.
- Results: State the main findings.
- Conclusion: State your conclusion and any key implications or recommendations.
- Contribution: Concise statement of the primary contribution of your manuscript.

Do not cite references and do not use abbreviations excessively in the abstract.

Introduction: The introduction must contain your argument for the social and scientific value of the study, as well as the aim and objectives:

- Social value: The first part of the introduction should make a clear and logical argument for the importance or relevance of the study. Your argument should be supported by use of evidence from the literature.
- Scientific value: The second part of the introduction should make a clear and logical argument for the originality of the study. This should include a summary of what is already known about the research question or specific topic, and should clarify the

knowledge gap that this study will address. Your argument should be supported by use of evidence from the literature.

- Conceptual framework: In some research articles it will also be important to describe the underlying theoretical basis for the research and how these theories are linked together in a conceptual framework. The theoretical evidence used to construct the conceptual framework should be referenced from the literature.
- Aim and objectives: The introduction should conclude with a clear summary of the aim and objectives of this study.

Research methods and design: This must address the following:

- Study design: An outline of the type of study design.
- Setting: A description of the setting for the study; for example, the type of community from which the participants came or the nature of the health system and services in which the study is conducted.
- Study population and sampling strategy: Describe the study population and any inclusion or exclusion criteria. Describe the intended sample size and your sample size calculation or justification. Describe the sampling strategy used. Describe in practical terms how this was implemented.
- Intervention (if appropriate): If there were intervention and comparison groups, describe the intervention in detail and what happened to the comparison groups.
- Data collection: Define the data collection tools that were used and their validity. Describe in practical terms how data were collected and any key issues involved, e.g. language barriers.
- Data analysis: Describe how data were captured, checked and cleaned. Describe the analysis process, for example, the statistical tests used or steps followed in qualitative data analysis.
- Ethical considerations: Approval must have been obtained for all studies from the author's institution or other relevant ethics committee and the institution's name and permit numbers should be stated here.

Results: Present the results of your study in a logical sequence that addresses the aim and objectives of your study. Use tables and figures as required to present your findings. Use quotations as required to establish your interpretation of qualitative data. All units should conform to the **SI convention** and be abbreviated accordingly. Metric units and their international symbols are used throughout, as is the decimal point (not the decimal comma).

[For Qualitative Research - Measures of Trustworthiness] **Measures of Trustworthiness:** This refers to the findings of the study being based on the discovery of human experience as it was experienced and observed by the participants. The following are the criteria of trustworthiness, credibility, transferability, dependability and confirmability to be discussed.

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- The rigor with which the study was conducted (e.g. the study's design, the care taken to conduct measurements and decisions concerning what was and was not measured).
- The extent to which the designers of a study have taken into account alternative explanations for any causal relationships they explore.

Discussion: The discussion section should address the following four elements:

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- Strengths and limitations: Describe the strengths and limitations of your methods and what the reader should take into account when interpreting your results.
- Implications or recommendations: State the implications of your study or recommendations for future research (questions that remain unanswered), policy or practice. Make sure that the recommendations flow directly from your findings.

Conclusion: Provide a brief conclusion that summarises the results and their meaning or significance in relation to each objective of the study.

Acknowledgements: Those who contributed to the work but do not meet our authorship criteria should be listed in the Acknowledgments with a description of the contribution. Authors are responsible for ensuring that anyone named in the Acknowledgments agrees to be named. Refer to the acknowledgement structure guide on our *Formatting Requirements* page.

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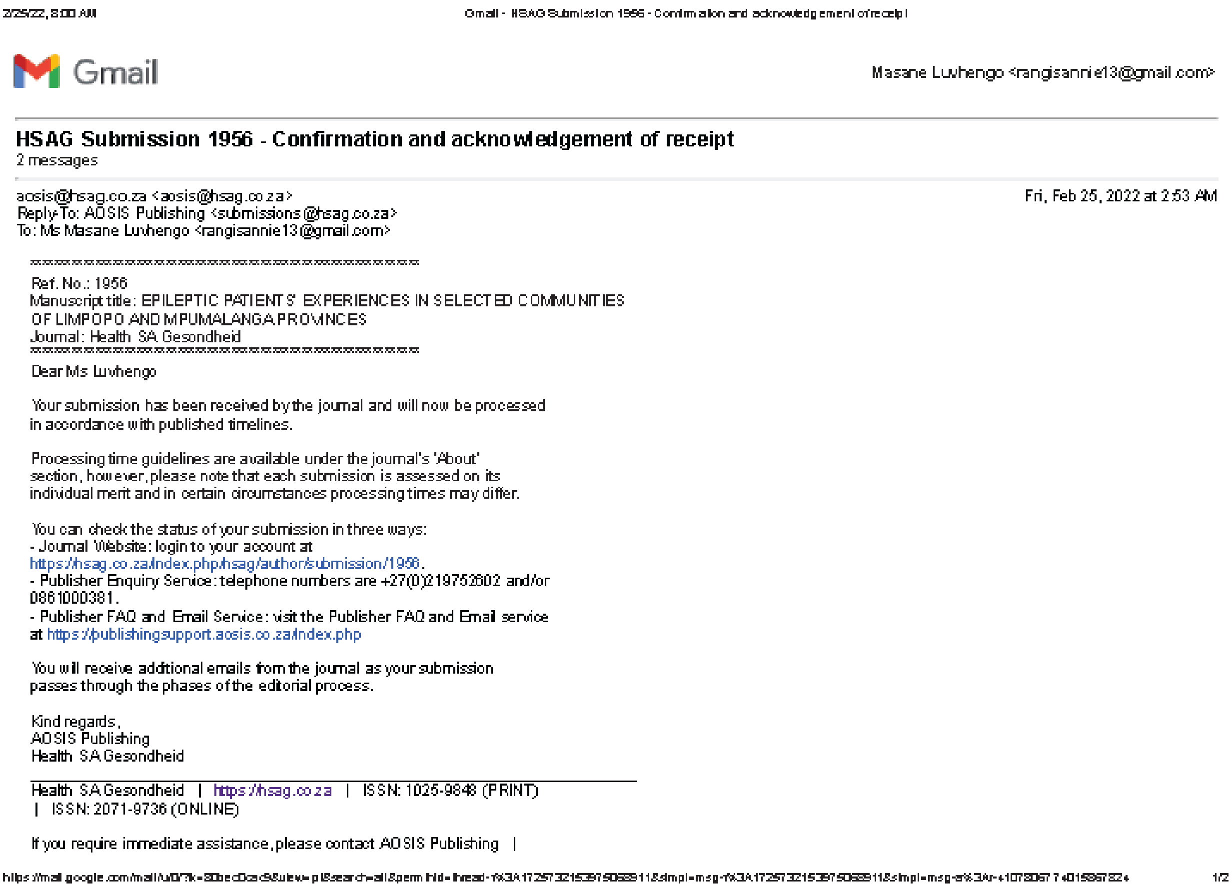

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2.4 Manuscript 2

Title of the manuscript: Luvhengo Masane, Maphula Angelina and Makhado Lufuno. Epileptic patients' experiences in selected communities of Limpopo and Mpumalanga provinces. **Health SA Gesondheid - Journal of Interdisciplinary Health Sciences** (***Under Review***).

EPILEPTIC PATIENTS' EXPERIENCES IN SELECTED COMMUNITIES OF LIMPOPO AND MPUMALANGA PROVINCES

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ABSTRACT

Background: Epilepsy affects the individual's quality of life, and the person alters his/her life so that the condition may be manageable. These individuals are faced with the burden of living with epilepsy and the pain resulting from the seizures, but also experience stigma from society.

Aim: The study aimed to explore the subjective experiences of PLWE in selected communities of Limpopo and Mpumalanga Provinces.

Setting: The study was conducted in rural communities of two provinces, Limpopo and Mpumalanga. The provinces are at identical economic and social statuses, with higher poverty rates, with most people depending on the government.

Methods: The study was qualitative; the data were collected through face-to-face in-depth interviews. Data were analysed using the Interpretive Phenomenological Analysis. Eleven participants were interviewed

Results: Four main themes emerged with 12 sub-themes. PLWE expressed epilepsy as a painful condition. Moreover, it is evident from the results that PLWE are constantly seeking treatment options that will make their experiences better and cure the condition for good.

Conclusion: PLWE described strategies like improving treatment and care services to ensure compliance in taking the medications. The suggested strategies may be used for awareness and to improve the quality of life for PLWE by providing conventional treatment.

Contributions: The current study will bring more insight into future research studies about the experiences of PLWE. Considering the stigma associated with epilepsy revealed, the study may educate the South African communities about epilepsy and how PLWE should be treated.

Keywords: Epilepsy, Experiences, People living with epilepsy, Rural Communities, Stigma, Seizure

INTRODUCTION

Epilepsy is one of the most common neurological diseases and is prevalent in Sub-Saharan Africa. The WHO defines epilepsy as a non-communicable disease that affects mainly the brain, with up to 50 million people suffering from epilepsy worldwide (WHO 2019). The incidence of epilepsy has been higher in low/middle-income countries than high-income countries, with 61 per 100,000 person-year (Beghi 2020: 185-191; Fazekas, Megaw, Eade, & Kronfeld 2021: 116). Epilepsy is a burdensome mental illness to both young and old age groups, sex and social classes (Thijs 2019: 689-701; Batchelor & Taylor 2021: 118). However, the experiences of young adults and children have been found to be different compared to that of adults and hence their varying coping mechanisms (Thijs 2019: 689-701).

In a recent systematic review conducted in South Africa (Carter et al. 2020), it was highlighted that lack of knowledge about epilepsy is most consistent among African countries, leading to misconceptions and deterred beliefs regarding the causes of epilepsy. This confirms the need for the International League against Epilepsy to organize a global campaign in 2002 that aimed to bring epilepsy "out of the shadow". The campaign focused on increasing awareness of epilepsy among health professionals, improving people's knowledge regarding epilepsy, and identifying the need for PLWE (Musekwa, Makhado, Maphula, & Mabunda 2020: 13).

The beliefs held by people regarding epilepsy vary across different social groups depending on the beliefs that people hold. From western countries including, America, Australia and Europe, some of the misconceptions that people have about epilepsy include the ideas that epilepsy is a form of madness or mental disorder; faith, herbal medicines or teas can treat epilepsy; PLWE should be isolated and cannot have normal social roles (Elliott, & Shneker, 2008: 547-556). More or less similar to the Western misconceptions, the Sub-Saharan Africa misconceptions highlight epilepsy as an incurable disease that healers must treat as it is caused by witchcraft; PLWE are insane and should not be employed or play sports (Herrmann, Welter, Berg, Perzynski, Van Doren, & Sajatovic, 2016: 165-173). These misconceptions influence a negative attitude and stigma towards PLWE and epilepsy as a disease. Kaddumukasa et al. (2018: 85) have found that epilepsy poses tremendous disruption to young adults' lives. They experience social exclusion, which lowers their self-esteem and disrupts their day-to-day functioning (Kaddumukasa et al., 2018: 85). The severity of the stressors may not only affect young people but may be significant enough to affect their family members (Chew, Carpenter, & Haase, 2019: 241-250).

Generally, at the top of stressors that are caused by living with epilepsy is the stigma (Chew, Haase, & Carpenter 2017: 19-26). Collard and Ellis-Hill (2019: 24) have added to say that stigma may not only result in low self-esteem as a psychosocial consequence but is also characterized by social withdrawal and isolation. This stigmatization may also influence a person living with epilepsy not to disclose that they live with epilepsy even to their closest family members (Cooke 2017). On the other hand, Dako-Gyeke and Donkor (2018: 87) have found that some people choose not to disclose because of fear of being discriminated. Concealing the diagnosis may be a risk factor to PLWE as they may have a seizure with no one to assist them.

Several contrary treatment methods characterize epilepsy. PLWE explores various treatment options that are mainly influenced by their beliefs (Deegbe, Aziato & Attiogbe 2020: 104). PLWE often follow a treatment option depending on what they believe caused the illness.

RESEARCH METHODS AND DESIGN

The study aimed to explore the experiences of PLWE to minimize the stigma and shape a positive attitude towards PLWE and epilepsy as a whole by answering the following question: What are the experiences of PLWE in selected communities Limpopo and Mpumalanga Provinces?

Study design

A qualitative, phenomenological design has been used to explore the experiences of PLWE. PLWE were studied in their most natural setting, which is their homes. This created a familiar environment for the participants as they narrated their experiences in a natural setting.

Setting

The study setting was six rural communities of Limpopo (n=3) and Mpumalanga provinces (n=3). This included Clare, Arcornhoek and Jerusalema in Mpumalanga and Mtititi, Malavuwe/Nweli and Bochum in Limpopo Province. These provinces are similar in characteristics. They both fall on the high poverty rank, with most people depending on government grant money. There is a high birth rate in both provinces, with teenage pregnancy being at its highest rate.

Study population and sampling strategy

Eleven (11) participants were included in the study from Limpopo and Mpumalanga Province. The participants included both males (7) and females (4) from different age groups (18 to 49 years). The population was people living with epilepsy at selected Limpopo and Mpumalanga Province communities. All participants were from the black ethnic group with their languages ranging from; Tshivenda, Sepulana, Xitsonga, Sepedi and Swati.

Data collection

Data were collected through in-depth interviews conducted at the comfort of the participants' homes to explore their experiences regarding epilepsy in their natural setting. The study is nested within a bigger project (GladAfrica Epilepsy Research Project). Hence, translation of the collected data was done in a team effort with language professionals for linguistic consistency. Before data collection, the questions were translated from English to Tshivenda, Sepulana, Tsonga and Swati by the researcher and back to English by a language professional. Participants were coded based on their participation order, gender, and age, such as P9. M, 23 years represents Participant number 9, a male of 23 years. The average length of the interviews was 20 minutes, the shortest being 9 minutes and the longest being 25 minutes.

The data collection process was conducted by the researcher being assisted by the home based-care workers. The Home-based care workers also assisted in recruiting the participants for the interviews. Interviews were conducted telephonically, hence verbal consents to participate in the study were obtained from the participants. Some of the appointments were not successful as other PLWE were not mentally stable enough to hold an interview. However, the interviews were conducted, and data were collected until saturation was reached.

Data analysis

Data were analysed using The Interpretive Phenomenological Analysis. The researcher went back to the data, focusing on the responses' meanings and applying the seven steps of Interpretive Phenomenological Analysis data. The data were transcribed verbatim, read, and re-read to get the exact meaning of the participants' responses. Four main themes emerged and additional twelve sub-themes. By drawing interpretation on a deeper meaning, the researcher was able to elicit the meaning of the experiences of PLWE (Peat, Rodriguez & Smith 2019: 35).

Ethical considerations

The researcher thought about some ethical considerations before starting the investigation. By following ethical approval, confidentiality, permission and informed consent, the researcher also guaranteed that honesty and integrity were preserved throughout. The researcher presented the study to the Department of Psychology, the School Higher Degree Committee, and the Executive School Higher Degree Committee to confirm that everything was in place. The study was scrutinized in all of these departments and committees, and adjustments were made to improve the study. After making the necessary changes, the researcher requested authorization from the appropriate stakeholders to conduct the study. The Chief, Induna, or ward counsellors were all approached for permission. The comments and ideas for revisions were then given full attention. Ethics safeguarded not only the researcher but also the participants.

RESULTS

Introduction

This section will concentrate on the presentation and discussion of the results. The results are outlined in themes and sub-themes that emerged from the data collected. The researcher used numbers, gender and age to distinguish the participants. The purpose of the study was to explore the experiences of people living with epilepsy in selected villages of Limpopo and Mpumalanga Provinces. And the objective which guided the study was:

- To explore the experiences of people living with epilepsy

Data were collected from eleven (11) participants, who included seven (7) males and females (4) from selected villages of Limpopo and Mpumalanga Provinces. The ages of the participants ranged from 18 to 48 years. They were all Christians, with the highest standard passed being standard ten (10) or Grade 12 and one participant who received no formal schooling. The eligible participants were interviewed until saturation was reached. The presentation and discussion of the results are as follows:

Table 1: Demographic Characteristics

Participant	Gender	Marital status	Highest standard	Age	Religion	Setting
Participant 1	Male	Single	9	18	Christian	Mpumalanga
Participant 2	Male	Single	1	35	Christian	Mpumalanga
Participant 3	Female	Single	9	39	Christian	Limpopo
Participant 4	Male	Single	5	27	Christian	Mpumalanga
Participant 5	Female	Married	4	36	Christian	Limpopo
Participant 6	Male	Single	0	48	Christian	Limpopo
Participant 7	Male	Married	10	43	Christian	Limpopo
Participant 8	Male	Single	10	18	Christian	Limpopo
Participant 9	Female	Married	1	39	Christian	Limpopo
Participant 10	Male	Single	8	33	Christian	Mpumalanga
Participant 11	Female	Married	10	28	Christian	Limpopo

Data Analysis

The interpretive Phenomenological Analysis was used to analyse raw data, which yielded four major themes, which are as follows: Experiences of living with epilepsy, effects of epilepsy, management of epilepsy and suggested strategies to improve the quality of life for people living with epilepsy. Each theme has been outlined according to the sub-themes.

Theme 1: Experiences of living with epilepsy

Participants' experiences of living with epilepsy have yielded four sub-themes: The pain of living with epilepsy, Embarrassment experienced by PLWE, acceptance of epilepsy and the on-set of epilepsy. These may attribute to the challenges that PLWE experience in their lives. The experiences do seem to be consistent across ages and gender.

Table 2: Themes and sub-themes

Themes	Sub-Themes
1. Experiences of living with epilepsy	1.1 The pain of living with epilepsy
	1.2 Embarrassment experienced by PLWE
	1.3 The on-set of epilepsy
	1.4 Acceptance of epilepsy
2. Effects of epilepsy	2.1 Psychological effects
	2.2 Social effects
	2.3 Effects of seizures
3. Management of epilepsy	3.1 Support for PLWE
	3.2 Suggested treatment options and their effectiveness
4. Suggested strategies to improve the quality of life for people living with epilepsy	4.1 Suggested treatment options
	4.2 Need for improvement in providing care

Sub-theme 1.1: The pain of living with epilepsy

The sub-theme of pain emerged as most participants showed that living with epilepsy is a very painful experience. This concerns the burden that epilepsy places on their lives. Most of them reported that their lives were no longer the same once they started to experience the seizures. The seizures caused them much pain as they were forced to adjust to their day-to-day living. Even the injuries that result from the seizures also cause pain because some of them fall and hurt themselves in different ways. The following participants have endorsed this idea:

> "*It is very painful, even when I play soccer, I have to balance it because if it is hot, I have to wait for the sun to cool down*", the participant continued to add**,** "*I feel that it is very painful eish... This is a very painful illness*" **P 1. Male, 18 Years**

> "*In 1995 April, I was admitted to the hospital until August of the same year because I got burned after falling in the fire*" **P 5. Female, 36 Years**

Sub-theme 1.2: Embarrassment experienced by PLWE

Most of the participants expressed that they experience embarrassment because of their illness. This embarrassment is mostly influenced by the shame linked to epilepsy by the different cultural groups. Most participants also indicated that they are most embarrassed when the seizures occur in public. How people react to a person having a seizure due to epilepsy makes the person feel ashamed and embarrassed. Some participants also highlighted being ashamed of how people who are not familiar with epilepsy react when they are having a seizure.

> "*Well, yes, I kinda feel ashamed because I am not sure how the people will take if maybe I meet new people who don't know about it they take it differently compared to people who know about it now*" **P 8. Male, 8 Years**

> "*I heard that I was carried back home, and it was embarrassing*" **P 11. Female, 28 Years**

> "*I feel shy, I would be in front of people, and sometimes I would be at school or at other times at the soccer field, and I feel shy*" **P 1. Male, 18 Years**

Sub-theme 1.3: The on-set of epilepsy

Many participants have reported that epilepsy is on-set makes them more anxious. The unexpected diagnosis (on-set) of epilepsy is a challenge to them. Most of the participants alluded that they were not born with the illness, but it surfaced as they grew up. Most of them indicated that they would just be surprised when they fell and woke up at the hospital. These participants also added that they could only remember that they were at a young age when they first experienced a seizure. Others reported their experiences of a seizure occurring while they had started school. The following participants also indicated this:

> "*I did not get sick from birth until 2008, and I have never had an episode of seizures while at school. My first episode happened when I was at my in-laws, I just fell, and when I woke up, I was at the hospital*" **P 11. Female, 28 Years**

> "*The next thing I found myself in the hospital, I had just collapsed and fell*" **P 7. Male, 43 Years**

Regardless, some participants indicated that they did not even know when they were diagnosed with epilepsy. Either they cannot remember because they were too young or have a blurred memory of the event.

> "*I don't even know if I was still at school or not, but the way my mother explained to me, she said when it started, I was nine (9) years old*" **P 9. Male, 39 Years**

> "*It started… I can't remember the exact year, but I think it was when I was in grade 4 in primary school*" **P 1. Male, 18 Years**

Sub-theme 1.4: Acceptance of epilepsy

Participants expressed different levels of accepting epilepsy. Most of them indicated that they had accepted their condition as any other illness. Some of the participants attributed their acceptance of epilepsy to their treatments. The treatments vary from traditional to western treatments. From the participants' responses, the acceptance by family members also plays a role in accepting the condition.

> "*Yes, I have accepted it. This means it is something I am used to, and I have to continue taking the medication*" **P 7. Male, 43 Years**

> "*Up to so far, I have accepted the illness as any other illness*" **P 2. Male, 35 Years**

> "*I now understand and have accepted that is why I'm taking treatment*." **P11. Female, 28 Years**

Theme 2: Effects of epilepsy

The participants reported different ways in which their lives are affected by epilepsy. Participants indicated how the different effects of epilepsy affect their lives. Three sub-themes have resulted from this central theme: psychological effects, social effects and physiological effects of seizures.

Sub-theme 2.1: Psychological effects

Most participants have indicated the psychological effects of epilepsy. These include the experience of shock due to the onset of seizures. Some participants expressed that they experience fear and anxiety because of the uncertainty of when the subsequent seizure might occur. Some are anxious about when the seizures might happen in public.

> "*Ummm...I can say it is full of anxiety, and in most cases, I would be anxious about when is it going to happen again, you know? And the fear of being in public because what if I just have an episode while I am in public, things like that [sic]*" **P8. Male, 18 Years**

One of the participants indicated that she experiences depression because she cannot attend school and the pain of seeing others going to school. At the same time, she is at home because the condition caused her much distress.

> "*Yes, I always complained when I saw other children going to school while I was at home, but I was told that I could not attend school because of my problem of falling. And I was always depressed because of that*" **P5. Female, 36 Years**

Sub-theme 2.2: Social effects

Most of the participants reported that there are social effects that are influenced by the occurrence of seizures. These social effects include social exclusion and limited interaction. Another factor influencing this is the limited opportunities PLWE has to achieve their goals.

> “*I am not working. And I have gone to school for cleaning. I have a certificate. But I don’t think I will be able to work because I now have a baby and my sickness too. So, I want a disability grant for my sickness*” **P11. Female, 28 Years**

Although some do not get to start with schooling, some get the opportunity to start but are forced to drop out of school due to the severity of the seizures. This indicates how the occurrence of seizures can disrupt the lives of PLWE. Some participants said they dropped out of school because their reliance on others burdened them.

> “*At school when I went, I was no longer attending because when we realized I had the illness, I had just passed grade 7 in 1993, and I started staying at home*” **P5. Female, 36 Years**
>
> “*Now I am no longer going to school, and I was told that I become a nuisance when I am at school*” **P9. Female, 39 Years**

Sub-theme 2.3: Physiological effects of seizures

Participants reported several experiences with the effects of seizures. Most of them outlined how the seizures occur, and the effects include headaches, dizziness and changes in behaviour. Some of them expressed that sometimes when the seizures occur, they are unconscious and would not know what had happened until they woke up and someone explains to them.

> “*It is very difficult, this sickness. I am not mentally ill, but sometimes I feel like I am mentally ill after an attack because I even do things unaware like putting clean clothes in the washing basin to wash them again*” **P11. Female, 28 Years**
>
> “*I start by feeling a headache and dizziness, yah, after that I can’t feel myself I just fall. People do explain to me that this and that happened, but I would not feel anything; Ehhh... I produce foam and sometimes pee on myself*” **P1. Male, 18 Years**

Theme 3: Management of Epilepsy

Participants expressed that treatment outcomes determine if they continue or stop adhering to treatment. The sub-themes include support for PLWE, treatment explored and effectiveness of the treatments.

Sub-theme 3.1: Support for PLWE

Participants have described the significance of having a strong support system to be of paramount importance. Most participants expressed that they find their experiences of epilepsy to be easier when they have a good support system. Some indicated that the support is received from family members, health care workers and religious leaders. These support agencies were highlighted to play different roles in supporting PLWE in various settings.

> "*They would make sure that they put blankets and pillows next to me so that when I fall, I don't hurt myself, and they would stay with me until I regain full consciousness*" **P5. Female, 36 Years**

> "*As for health care workers, Ummm.... it was a matter of me going for check-ups and getting my medication; and they would make sure that I always take my medication, and always encourage me to do so, and as for religious leaders, they are just there for moral support and praye*rs" **P8. Male, 18 Years**

Sub-theme 3.2: A search for different treatment options in pursuit of a cure

Most of the participants shared the treatment methods they have explored in searching for the cure for epilepsy. Most of them were referred to seek treatment by family members, relatives or friends. In the hope that their illness will be better, most participants indicated that they receive treatment from the hospitals or clinics and believe that they are surviving due to such treatment. Whereas other participants shared that they interchange between traditional and western medicines.

> "*Since that time, they prescribe pills which I use even today. Since then, I had to understand I have to survive on this drug*" **P7. Male, 43 Years**

> "*My parents took me to the traditional healer, and they invited my husband too. The traditional healer used his bones to explain that I was witched because I got married. So, he wanted a black male chicken, so we went to the mountain. It was a very big mountain, and he used the blood from the chicken to wash me. It did not stop the sickness.* **P11. F, 28 Years**

> "*They have taken me for Sotho based treatment for some time, but I would not get any better. Since they took me to the hospital, I have been much better; we received the tea from the church. At the moment, I just collect the pills only*" **P9. F, 39 Years**

Some participants reported that the treatments they are using effectively reduce the occurrence of seizures. They also expressed that they have chosen to stick to the pills since they feel better after taking them.

> "*For me, the improvement I have seen is from the pills I collect from the hospital; since they took me to the hospital, I have been much better"* **P9. F, 39 Years**

> "*It is because now I am able to go to the hospital and collect medicines that are able to protect me; It helps in reducing the occurrence of falling*" **P2. M, 35 Years**

Theme 4: Suggested strategies to improve quality of life for PLWE

This theme outlines the suggestions recommended by PLWE, which may improve their lives and lessen the severity of the experiences. Most people expressed these suggestions depending on their experiences.

Sub-theme 4.1: Suggested treatment options and their effectiveness

Some participants indicated that the quality of life for PLWE may be improved if the proper treatment options are followed. Most of them noted that PLWE must utilize the hospitals to receive the necessary care. Some participants suggested that PLWE must not seek treatment from traditional healers since they could not get assistance or cure.

> "*I think they must go to the hospital and the family member would explain how the person is affected by the illness and there at the hospital, they will decide what kind of treatment is suitable for that condition, and that would assist in making the person feel better, I think people should know that they must not go to traditional healers because I was not able to get healed from there I don't see any importance of going there.*" **P5, Male. 36 Years**

> "*It is helping me as I am able to survive. I don't know where I would be if I were not taking the treatment. I use a car for travelling it might happen that I go off the road while driving and die because I would not have taken the treatment. As I am following the treatment accordingly, I am to say today that I am still alive.*" **P7. Male, 43 Years**

Sub-theme 4.2: Need for improvement in the providing care

Most participants expressed the need to improve how care is rendered for PLWE. The health care providers and workers need to consider the needs of the patients and give proper care and assistance where necessary.

> *"Those that are providing the treatment must have respect for the patients, and then if they can respect the patients and understand them, I think they can end up giving us effective assistance, but if they continue doing as I see them doing in hospitals and clinics, might end up fighting with patients if they don't change their behaviours towards the patients."* **P10, Male. 33 Years**

> *"I would wish that they knew epilepsy is just a brain disorder, and it does not determine a person's*

> *character and who the person is. It is just a normal sickness of which people should not be treated any differently from other people because they have epilepsy."* **P8. Male, 18 Years**

> *"I think people should know that they must not go to traditional healers because I was not able to get healed from there. I don't see any importance of going there."* **P5. Female, 36 Years**

Discussion

The study at hand aimed to explore the experiences of PLWE in selected villages of Limpopo and Mpumalanga Provinces. There are very few studies that have focused on the experiences of PLWE. Furthermore, this study included participants from different cultural groups. This enabled the researcher to understand how epilepsy affects individuals from various cultures and tap into the different challenges, management, and treatment of epilepsy.

The data that resulted from the study yielded four themes that will be discussed in this section. The themes outlined the experiences of living with epilepsy under which there are four sub-themes. The participants indicated that living with epilepsy is very painful to the point where they find epilepsy a burden. This condition causes them great pain and disrupts their daily living. Although most of them have learned to accept it, they still find it difficult to live with it because of its effects on their lives, as also argued by Kaculini, Tate-Looney and Seifi (2021: 13). It is evident from the results that the onset of epilepsy changes an individual's life. As a condition that can start at any stage, it changes the life of an individual and this cause much distress and anxiety because the patients lose hope in achieving their goals. Besides this, much distress and anxiety are caused by the ill-treatments that PLWE receives from society. Most reported that they feel ashamed and embarrassed for their condition to be known by the public. This feeling of shame is influenced by the stigma attached to epilepsy. Also, the lack of knowledge regarding epilepsy may elicit misconceptions about the condition.

Another thing is that PLWE finds it easier to live with the condition when they allow themselves to accept it. The kind or level of support may also influence this acceptance that the individual receives either from the family members, religious groups or the health care institutions. These forms of support relieve the individual from the burdens of living with epilepsy. The support of collecting medicines is also crucial because PLWE find it hard to travel, especially in communal transport. Even having economical support may lessen the wait of struggling to find proper employment since most PLWE do not manage to go to school and get any or enough formal education to a point where they can provide for their families or even themselves (Yennadiou & Wolverson 2017: 87-93). Moreover, most of the jobs available for PLWE are limited because these individuals are at higher risk of experiencing injuries at work due to seizures (Antimov, Tournev, Zhelyazkova & Sander 2020: 108). All these experiences are an indication that PLWE requires as much support as they can get, and this support will ease the burdens that come with living with the and illness; in that way, they would be less anxious and fearful of the occurrence of seizures because they know they will be assisted when necessary.

The experiences of epilepsy may also be outlined by indicating the effects of epilepsy. These effects range from psychological and social effects and effects of the seizure. The psychological effects include anxiety and fear of when the subsequent seizure will occur (Chandrasekharan, Menon, Cherian, and Radhakrishnan 2021: 114). PLWE experiences anxiety and stress about how a seizure attack may occur. Some also stress about where the seizure may take place. This anxiety is also influenced by people's stigma towards PLWE (Ak, Atakli, Yuksel, Guveli & Sari 2015: 50-54). People's attitudes towards PLWE or epilepsy as an illness causes much distress for PLWE. This is because people react mostly in public places when a person experiences a seizure. Much of this results from the beliefs held about epilepsy.

PLWE are also faced with the social effects of epilepsy. These include the exclusion of PLWE to excess formal education. Most PLWE are usually excluded at school because they may be told that their condition cannot be managed properly in a school setting; hence they opt to stay at home. This places an economic burden on PLWE because they find it hard to find proper employment opportunities to sustain themselves and their families. This increases the poverty rate because PLWE are forced to depend on the people for support and sustainability. Besides the economic burden, PLWE are usually restricted from social and leisure activities because of their condition. It may be that a person living with epilepsy may have aspirations to become a soccer player, but because of their condition, the person may be excluded. This may cause a lot of distress for PLWE because they are deprived of the success of their dreams.

It also emerged from the data that PLWE also experiences difficulties with the effects of seizures. These effects include headaches, dizziness, numbness in the body and sweating. Some participants reported that the seizures limit them from performing even the most specific duties. This inability to perform such duties may require an individual always to have someone to monitor the behaviour. The person will be able to assist in the event of a seizure occurring. Epilepsy is a neurological illness that may cause an individual to feel as if they are mentally ill due to the severity of the seizures.

Research findings also revealed that the effects of seizures and epilepsy as an illness influence PLWE to seek ways to manage or treat the illness. The treatment and management options that are explored usually result from referrals or the patients' beliefs regarding epilepsy. Besides the treatment and management, PLWE also uses support as a form of management for their condition. This may be evident when the seizures occur because there is a need for assistance to ensure that the person does not suffer from any form of injury. As for the treatment methods, most participants alluded that the treatments they receive in pills help manage the seizures. However, some reported that they had tried various treatments, including religious and traditional treatment. However, most participants who have explored such treatment options have not received certifying results. These reports are about the effectiveness of the treatment options explored. The majority of the participants reported that they prefer western medicine because it can minimize the occurrence of seizures. This thought also received a common agreement with the study by Nakhutina, Gonzalez, Margolis, Spada, and Grant (2011: 584-586).

Another aspect highlighted that strategies might improve the quality of life for PLWE. These strategies include the treatment options that PLWE explore. Most participants suggested that PLWE must avoid seeking treatment from traditional and religious healers because, from their own experiences, they did not get any treatment or assistance regarding the management of epilepsy. Another concern dealt with the need for improvement in the provision of care. PLWE indicated that there must have specific care provisions for PLWE which will cater to their particular needs.

MEASURES OF TRUSTWORTHINESS

The four measures were considered to ensure trustworthiness: confirmability, transferability, dependability, and credibility (Shenton 2004: 63-75). Confirmability was achieved by providing that the researcher's perspective of the phenomenon under investigation had no bearing on the study (Shenton 2004: 63-75). From the study's conception to conclusion, the researcher provided full disclosure in the final report, exposing all decisions made in the study and the reasoning for those judgments. Only when a study is immersed in existing literature with similar features can it be transferable (Shenton 2004: 63-75). After a thorough literature review, the researcher revealed the study's applicability in various situations. This study's dependability was determined by its capacity to be replicated in the same surroundings using the same procedure and yield comparable, if not identical, results (Shenton 2004: 63-75). The researcher presented a detailed explanation of the methodology utilized to arrive at the study's final results. Furthermore, the procedures were checked for faults regularly to enable correction.

Shenton detailed many methods that the researcher followed to establish trustworthiness (2004: 63-75). The study's data collection and analysis methodologies were based on approaches "that have been effectively implemented in past comparable initiatives" (Shenton, 2004). Second, site triangulation was used by assembling a group of people from several communities. Finally, the participants were fully informed about the study's purpose and the implications of their participation. Participants were informed that they could refuse to participate at any time and were not asked to explain. Fourth, probing was utilized to elicit more information from participants and discover inconsistencies in their responses. Finally, the researcher communicated with the participants for debriefing.

LIMITATIONS OF THE STUDY

The study does have limitations. Secondly, PLWE usually has memory deficiencies, which may affect the accuracy of their responses. The translation of the interview data from Tshivenda, Tsonga, Sepulana and Swati may have resulted in omission or inappropriate substitutions of the original data provided by the participants.

Recommendations

More research is needed that will focus on the subjective experiences of PLWE. There should be more awareness programs that will educate people about epilepsy and the possible and available treatment options that are safe and effective. Support groups must be formed for PLWE who are from disadvantaged homes. Future research and intervention programmes may focus on empowering PLWE to be independent and assist them with skills and knowledge of how they may best manage their condition and live a some what normal life. This will assist them in receiving the necessary care they may require. Opportunities for PLWE may be widened, both educational and occupational. Furthermore, future studies will bring insight into the lived experieces of PLWE knowledge, attitudes and misconceptions will be challenged through awareness programmes.

CONCLUSION

It can be argued that the experiences of PLWE can best be understood from the patients' experiences. All these experiences can either be positive or negative depending on the individuals' environment and the level of support or care received to promote the proper management of seizures. Acknowledging the stigma towards PLWE will provide an opportunity to improve the awareness of epilepsy to be implemented. This study explored the experiences of PLWE and could help bring strategies to support PLWE to achieve their maximum potential. This can be achieved by bringing conventional medical treatment strategies to PLWE who need them the most and designing stigma-reducing interventions.

ACKNOWLEDGMENTS

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Competing interests

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

Authors' contribution

L.M, M.A and M.L made equal contributions to the conceptualization of this article. All authors contributed to the collection of data writing of the initial draft, which was then verified. All authors contributed to the writing and reviewed the article's final draft.

Funding

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Data availability

The data that support the findings of this study are available from the corresponding author, L.M., upon reasonable request.

Disclaimer

The views and opinions expressed in this article are those of the authors and do not necessarily reflect the official policy or position of any affiliated agency of the authors.

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SECTION 3: CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

3.1 INTRODUCTION

This section will outline the conclusion of the manuscript. After that, the limitations will be indicated together with the recommendations. And then, the concluding remarks will be given based on the assessment of the whole study. All these will be informative regarding the significance of the study and whether the objectives were achieved.

3.2 CONCLUSIONS

3.2.1 CONCLUSIONS OF THE MANUSCRIPT

Significant findings in the study were that PLWE finds epilepsy as a burdensome disease that causes them pain, either physically or psychologically. This often results from the seizures that PLWE experience. The effects of seizures make it difficult for them to maintain normal lives and participate in any social and leisure activities without any restrictions.

Another key finding was that PLWE explored various treatment options for managing their condition. These treatment options are often explored depending on how they manage the seizures. The more the treatment reduces the occurrence of seizures, the more an individual will consider the treatment. It is evident from the data that lack of awareness regarding the proper treatment options continues to be a barrier for PLWE to make informed decisions about their treatment.

3.2.2 OVERALL CONCLUSION

The study aimed to explore the experiences of PLWE in Limpopo and Mpumalanga Provinces. The researcher was able to achieve this while focusing on the most significant factors that affect the lives of PLWE. One of the things that came up was how the experiences differed. The type of seizures, the environment, the quality of support, the treatment options, and other factors all contribute to these disparities. However, the data show that PLWE can function similarly to other individuals. These people may achieve things that they never thought possible if they are given the proper assistance.

The results demonstrate that the type and severity of the seizures have a different impact on the lives of PLWE. With such gravity, extreme caution is essential. Thus, the management and treatment of epilepsy are essential, and there are a variety of treatment and management options that have proven to be beneficial when used correctly. This includes both western and traditional treatment and management approaches. Education and awareness are crucial for PLWE and society to overcome the stigma and adverse attitudes related to epilepsy.

3.3 LIMITATIONS

The study used non-probability sampling, which yielded 11 participants who may hold different views from those of PLWE in other parts of the country. PLWE suffer from both neurological and psychological disorders, which is a factor that limited the study from accessing a larger number of participants because some PLWE are not able to hold effective conversations.

3.4 RECOMMENDATIONS

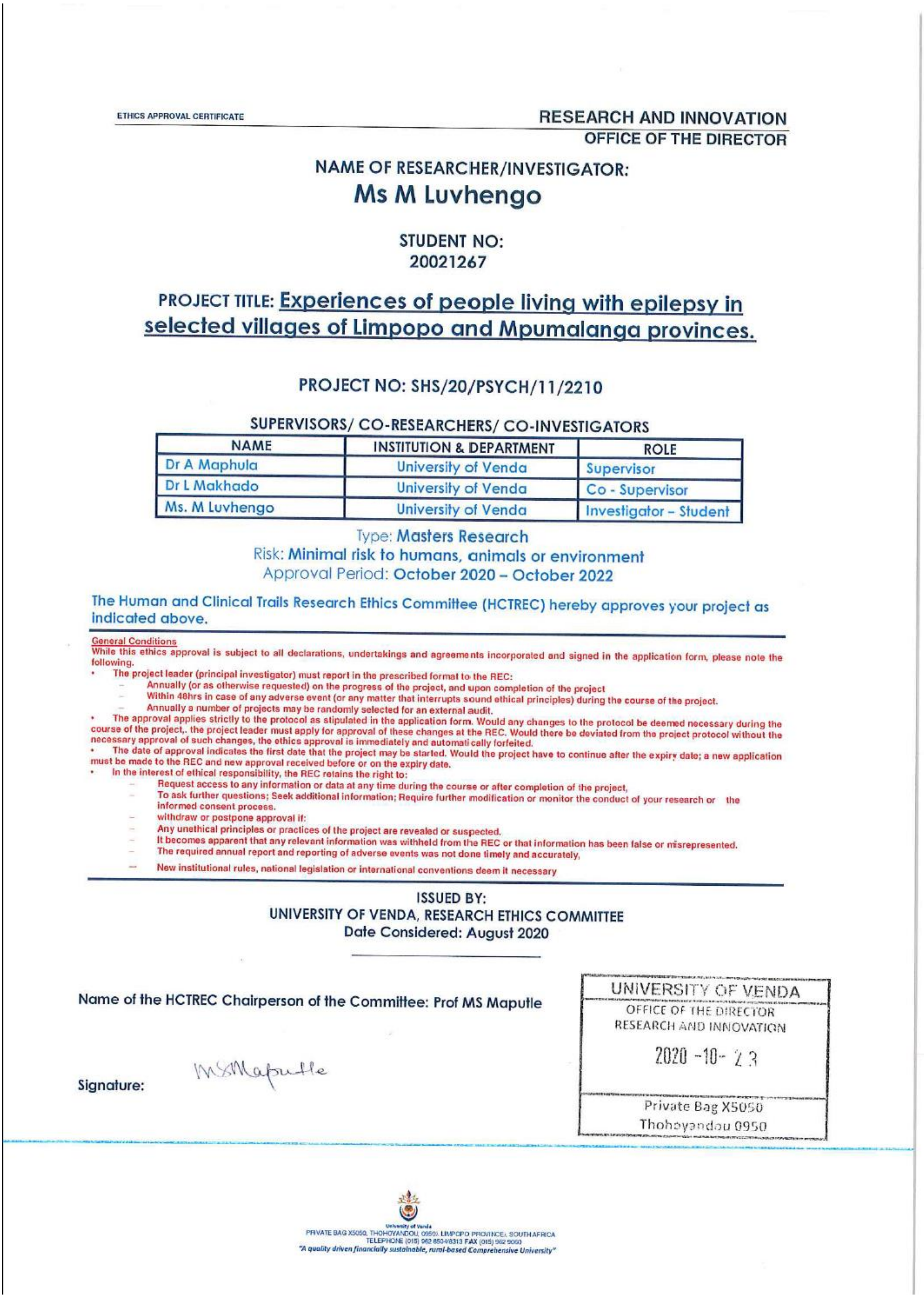
The following recommendations were made based on the findings of the study:

- Health centres and other service providers must be more accommodative to PLWE and cater for their needs
- Education and awareness programmes need to be utilized to educate and inform society about epilepsy
- There is a need to conduct qualitative studies based on a larger sample to get a fairly representative view of experiences of PLWE in villages.
- Given the misconceptions and stigma regarding epilepsy, there is a need for more effective awareness programs that will educate the community about epilepsy.

3.5 CONCLUDING REMARKS

The study aimed to explore the experiences of PLWE. The participants' responses were subjective, and they are of much use to policymakers and researchers to develop strategies that can be implemented to improve the quality of life for PLWE. The study also adds to the body of knowledge relating to experiences of PLWE.

ANNEXURE A: ETHICAL CLEARANCE



ETHICS APPROVAL CERTIFICATE

RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
Ms M Luvhengo

STUDENT NO:
20021267

PROJECT TITLE: Experiences of people living with epilepsy in selected villages of Limpopo and Mpumalanga provinces.

PROJECT NO: SHS/20/PSYCH/11/2210

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Dr A Maphula	University of Venda	Supervisor
Dr L Makhado	University of Venda	Co - Supervisor
Ms. M Luvhengo	University of Venda	Investigator – Student

Type: **Masters Research**
Risk: **Minimal risk to humans, animals or environment**
Approval Period: **October 2020 – October 2022**

The Human and Clinical Trails Research Ethics Committee (HCTREC) hereby approves your project as indicated above.

General Conditions

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following.

- The project leader (principal investigator) must report in the prescribed format to the REC:
  - Annually (or as otherwise requested) on the progress of the project, and upon completion of the project
  - Within 48hrs in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.
  - Annually a number of projects may be randomly selected for an external audit.
- The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project,. the project leader must apply for approval of these changes at the REC. Would there be deviated from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.
- The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date; a new application must be made to the REC and new approval received before or on the expiry date.
- In the interest of ethical responsibility, the REC retains the right to:
  - Request access to any information or data at any time during the course or after completion of the project,
  - To ask further questions; Seek additional information; Require further modification or monitor the conduct of your research or the informed consent process.
  - withdraw or postpone approval if:
  - Any unethical principles or practices of the project are revealed or suspected.
  - It becomes apparent that any relevant information was withheld from the REC or that information has been false or misrepresented.
  - The required annual report and reporting of adverse events was not done timely and accurately,
  - New institutional rules, national legislation or international conventions deem it necessary

ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE
Date Considered: August 2020

Name of the HCTREC Chairperson of the Committee: Prof MS Maputle

Signature: MSMaputle

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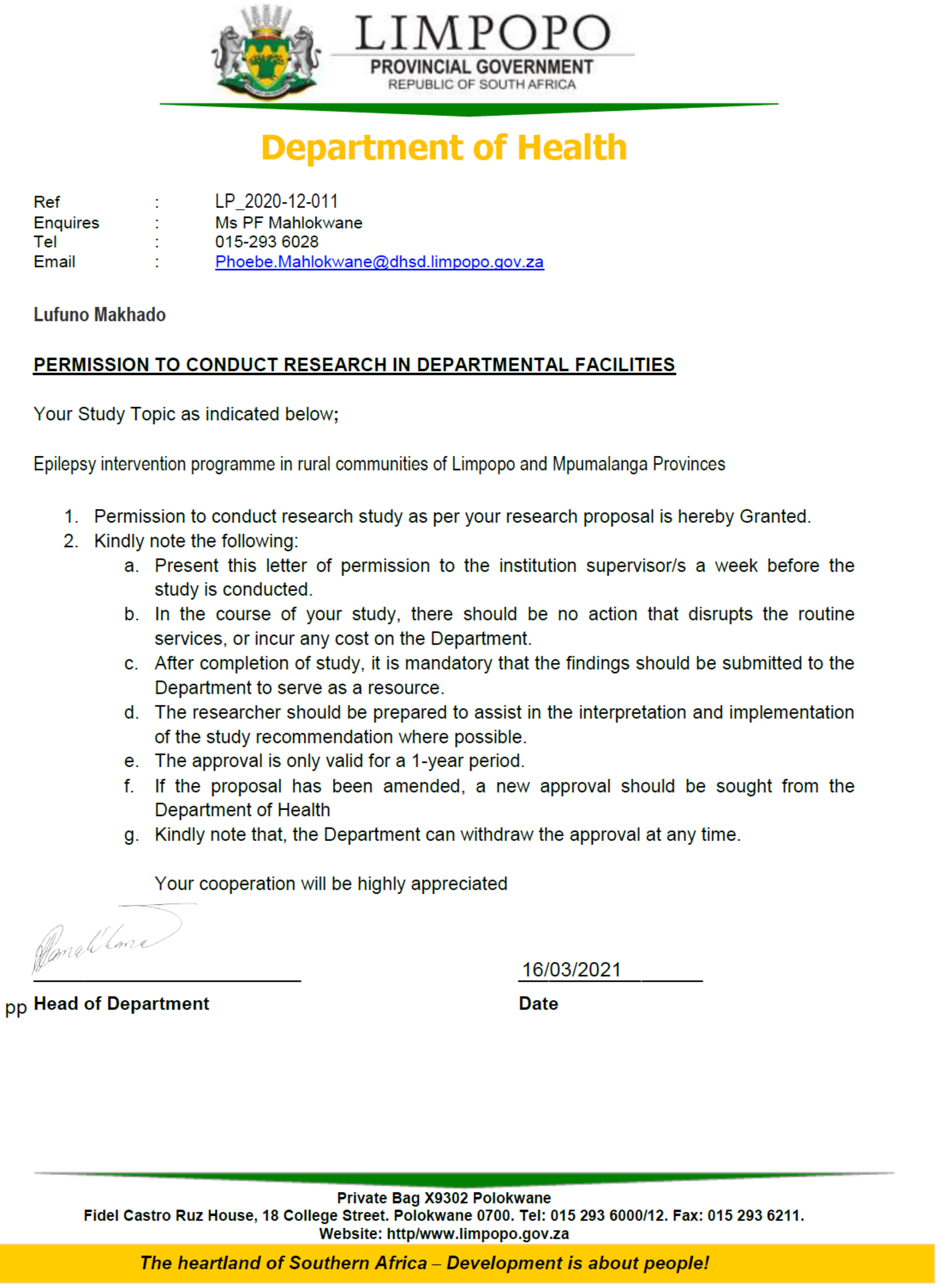
ANNEXURE B1: DEPARTMENT OF HEALTH APPROVAL LETTER LIMPOPO PROVINCE



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

Department of Health

Ref : LP_2020-12-011
Enquires : Ms PF Mahlokwane
Tel : 015-293 6028
Email : Phoebe.Mahlokwane@dhsd.limpopo.gov.za

Lufuno Makhado

PERMISSION TO CONDUCT RESEARCH IN DEPARTMENTAL FACILITIES

Your Study Topic as indicated below;

Epilepsy intervention programme in rural communities of Limpopo and Mpumalanga Provinces

1. Permission to conduct research study as per your research proposal is hereby Granted.
2. Kindly note the following:
    a. Present this letter of permission to the institution supervisor/s a week before the study is conducted.
    b. In the course of your study, there should be no action that disrupts the routine services, or incur any cost on the Department.
    c. After completion of study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
    d. The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
    e. The approval is only valid for a 1-year period.
    f. If the proposal has been amended, a new approval should be sought from the Department of Health
    g. Kindly note that, the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated

pp **Head of Department**

16/03/2021
Date

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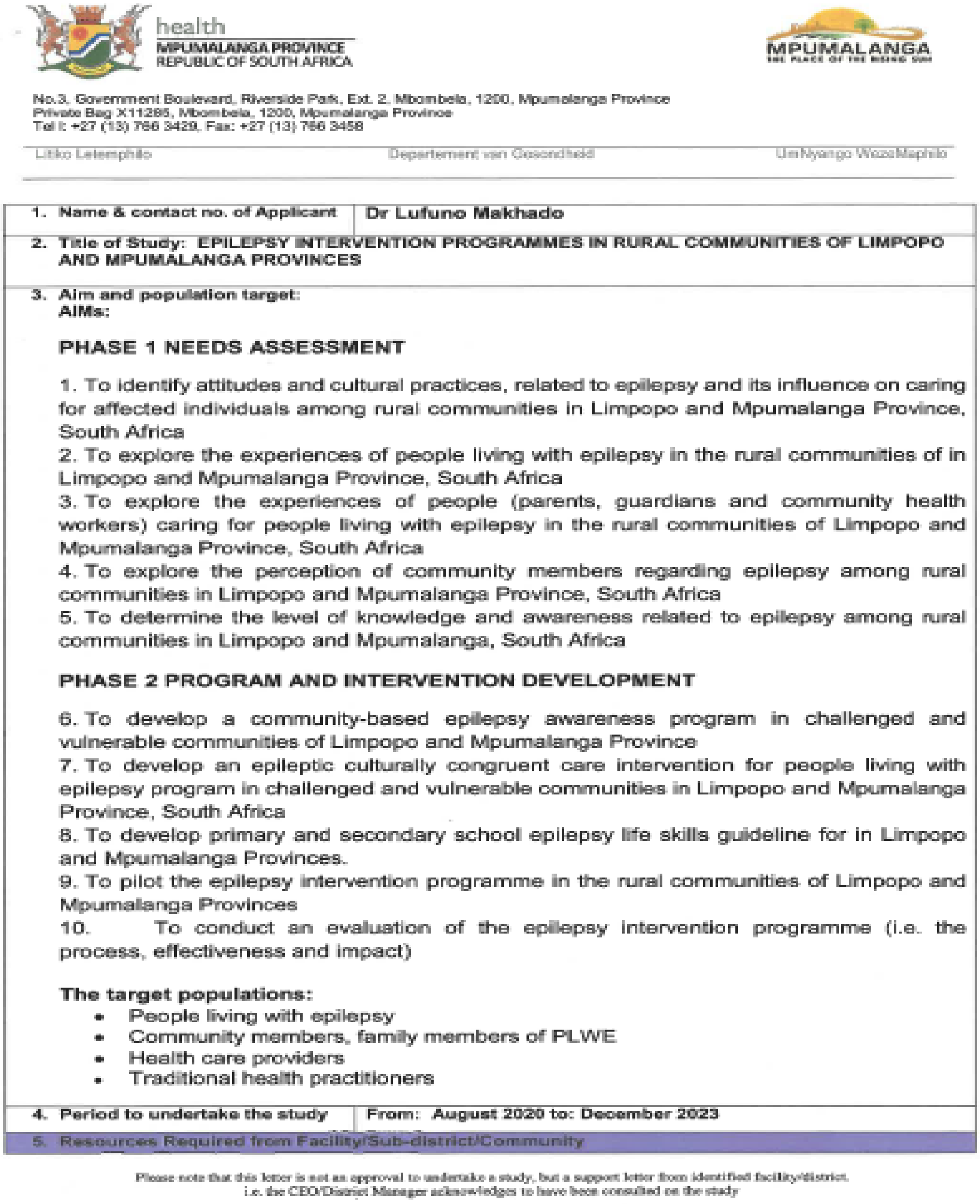
ANNEXURE B2: DEPARTMENT OF HEALTH APPROVAL LETTER MPUMALANGA PROVINCE



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Litiko Letemphilo | Departement van Gesondheid | UmNyango WezeMaphilo

1. Name & contact no. of Applicant | **Dr Lufuno Makhado**

2. Title of Study: EPILEPSY INTERVENTION PROGRAMMES IN RURAL COMMUNITIES OF LIMPOPO AND MPUMALANGA PROVINCES

3. Aim and population target:
AIMs:

PHASE 1 NEEDS ASSESSMENT

1. To identify attitudes and cultural practices, related to epilepsy and its influence on caring for affected individuals among rural communities in Limpopo and Mpumalanga Province, South Africa
2. To explore the experiences of people living with epilepsy in the rural communities of in Limpopo and Mpumalanga Province, South Africa
3. To explore the experiences of people (parents, guardians and community health workers) caring for people living with epilepsy in the rural communities of Limpopo and Mpumalanga Province, South Africa
4. To explore the perception of community members regarding epilepsy among rural communities in Limpopo and Mpumalanga Province, South Africa
5. To determine the level of knowledge and awareness related to epilepsy among rural communities in Limpopo and Mpumalanga, South Africa

PHASE 2 PROGRAM AND INTERVENTION DEVELOPMENT

6. To develop a community-based epilepsy awareness program in challenged and vulnerable communities of Limpopo and Mpumalanga Province
7. To develop an epileptic culturally congruent care intervention for people living with epilepsy program in challenged and vulnerable communities in Limpopo and Mpumalanga Province, South Africa
8. To develop primary and secondary school epilepsy life skills guideline for in Limpopo and Mpumalanga Provinces.
9. To pilot the epilepsy intervention programme in the rural communities of Limpopo and Mpumalanga Provinces
10. To conduct an evaluation of the epilepsy intervention programme (i.e. the process, effectiveness and impact)

The target populations:
- People living with epilepsy
- Community members, family members of PLWE
- Health care providers
- Traditional health practitioners

4. Period to undertake the study | **From: August 2020 to: December 2023**

5. Resources Required from Facility/Sub-district/Community

Please note that this letter is not an approval to undertake a study, but a support letter from identified facility/district, i.e. the CEO/District Manager acknowledges to have been consulted on the study

ANNEXURE C1: INFORMATION SHEET

Title of the Research Study: Experiences of people living with epilepsy in selected villages of Limpopo and Mpumalanga Provinces
Principal Researcher: Luvhengo Masane Master of Psychology Student
Supervisor: Dr Maphula A
Co-supervisor: Prof Makhado L

Brief Introduction and Purpose of the Study:

Introduction

I, **Luvhengo Masane,** am a psychology master student at the University of Venda embarking on a research titled "**Experiences of people living with epilepsy in selected villages of Limpopo and Mpumalanga Provinces''**. I would ask you to participate in the study. You are not forced to participate in the study. You can ask anyone you feel comfortable with regarding this research. If you come across any unusual words or words that you do not understand, please ask me to stop as we go through the information and I will explain.

Purpose of the study: The aim of this study is to explore the experiences of people living with epilepsy in selected villages of Limpopo and Mpumalanga Provinces.

Outline of the Procedures: The research will employ a qualitative, explorative and descriptive approach. Purposive sampling will be used to sample PLWE from each of the selected villages who will be willing to participate in the study. Population will comprise of PLWE residing in the selected villages. Sample size will be 25 participants per province. Data will be collected through face-to-face in-depth interviews.

Type of intervention: This research will require your participation for at least 40-50 minutes interview.

Participation selection: You are being invited to take part in this research because I feel that your experiences with epilepsy can contribute to the understanding of these experiences in Limpopo and Mpumalanga Provinces.

Voluntary participation: Your participation in this research will be voluntary. It is your choice to participate. If you choose not to participate, you are free to do so.

Procedure: You will participate in an interview with me (Luvhengo Masane). I will sit down with you during the interview in a comfortable and safe place. If you do not wish to answer the question, I will move to the next question. The information you provide will be confidential. My supervisors, Dr Maphula A and Prof Makhado L, and I will be the only people who will access the information you provided. If we would like to change anything, you will be asked for your permission.

Risk: I will ask you to share some very personal and confidential information with me. You may feel uncomfortable talking about some of the topics. You do not have to answer any question or participate in the interview if you do not wish to do so.

Benefit: There will be no direct benefit to you except the knowledge that will help you and your fellow community members find more insight into the experiences of PLWE in selected villages of Limpopo and Mpumalanga Provinces.

Remuneration: No money will be paid to you as a reward or incentive.

Cost of study: You will not be expected to pay any money for affiliation for participating in the research or interview.

Confidentiality: The researcher will conduct the study at your place of residence, and being confidential, no one will get access to the findings except for the research team. No sharing of information shall occur outside the research team. The information will be kept private. No name will be attached to the information you provided. You are only entitled to have a number.
Only the GladAfrica Foundation, GladAfrica Epilepsy Project, Univen Higher Degrees Committee and my supervisors, Dr Maphula A and Prof Makhado L, will access the information.

Sharing the results: No information will be shared with anybody outside the research team, and nothing will be attributed to you by name. The knowledge that I get from this research will be shared with you before it is available to the public.
Persons to contact if there are problems: My supervisors (Dr Maphula A and Dr Makhado L) please contact the researcher at the following cell numbers: 079 7494 349 or University Research Ethics Committee Secretary on 0159629058. For complaints, report to the Director: Research and Innovation, Prof GE Ekosse on 015 962 8313 or GeorgesIvo.Ekosse@univen.ac.za.

General: Potential participants will be assured that participation is voluntary, and the approximate number of participants will not be disclosed. The researcher will issue a copy of the information letter to participants. The information letter and consent form will be translated and provided in the primary spoken language of the research population.

ANNEXURE C2: INFORMED CONSENT

Statement of Agreement to Participate in the Research Study:

I hereby confirm that the researcher, **Luvhengo Masane**, has informed me about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number:

I have also received, read and understood the above-written information (Participants Letter of Information) regarding the study.

I am aware that the study results will anonymously be processed into a study report, including personal details regarding my sex, age, date of birth, initials and diagnosis.

Because of the research requirements, I agree that the data collected during this study can be processed in a computerized system by the researcher.

Without prejudice, I can withdraw my consent and participation from the study at any stage.

I have had enough opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

I understand that significant new findings developed during this research, which may relate to my participation, will be made available to me.

Full Name of Participant ...., Date........... Time................. Signature.............

I, Luvhengo Masane, herewith confirm that the above participant has been informed fully about the nature, conduct and risks of the above study.

Full Name of Researcher: Luvhengo Masane	Date……………….	Signature…………
Full Name of Witness (If applicable)……	Date…………	Signature…................
Full Name of Legal Guardian (If applicable)…	Date………	Signature……………

ANNEXURE D: A LETTER TO SEEK PERMISSION FROM THE TRIBAL AUTHORITIES

University of Venda
Private Bag X5050
Thohoyandou
0950

Dear: sir/ Madam

RE: REQUESTING PERMISSION TO CONDUCT A RESEARCH STUDY

I, Luvhengo Masane (20021267), hereby request permission to conduct my research study in your village entitled “**Experiences of people living with epilepsy in selected villages of Limpopo and Mpumalanga Provinces’’**. I am currently a Masters student in Psychology at the Faculty of Health Sciences. The study aims to explore the experiences of people living with epilepsy in selected villages of Limpopo and Mpumalanga Provinces. All ethical measures will be adhered to protect both the participants and the researcher from any harm or exploitation.

I hope my request will receive positive feedback. Yours faithfully
Luvhengo Masane

Researcher’s signature................................. Date....................

ANNEXURE E: INTERVIEW GUIDE

EXPERIENCES OF PEOPLE LIVING WITH EPILEPSY IN SELECTED VILLAGES OF LIMPOPO AND MPUMALANGA PROVINCES

INTERVIEW GUIDE

Introductions: Introducing the researcher and the study. Developing rapport by engaging with the participants at a social level.

Research question: What are your experiences of living with epilepsy (paraphrasing and probing depending on what the participant had provided).

Do you have any aspects you feel you want to ask me ?
Thank the participant for taking time to participate in this study.

The end

ANNEXURE F: SELECTED INTERVIEW TRANSCRIPT

Demographics

Gender: Female

Setting: Nweli

Age: 28 years

Employment status: Unemployed

Highest Standard passed: 28 Years

Religion: Christian

Interviewer: Good morning, how are you?

P11: Morning, I'm good and how are you?

Interviewer: I'm good, thank you for welcoming me in your home.

P11: Yes, you are welcome.

Interviewer: I am Luvhengo Masane, a student at the University of Venda. My visit today is engaging with you in an interview. So be free to ask or pause the interview in case you feel so. The interview is supposed to be recorded, so I will need you to give consent on that before we go further. The record will only be used on this study and won't be given to anyone out of the study, you don't have to mention your names or any form of identity during the interview. Do you agree?

P11: I wanted to ask if my names will be recorded, but since you explained very well, I understand. Yes, we can continue while you are recording.

Interviewer: Thank you. *Clears his throat*. May you please explain to me how it is living with epilepsy?

P11: Yoh…I feel so burdened by living with this sickness. What I can tell you is that I was not born with this sickness. It just came around 2008, I was around 24 years. I was supposed to write my matric exam supplementary.

Interviewer: "Nodding". Yes, yes.

P11: Yah, I did not get sick from birth until 2008, and I have never had episodes of seizures while at school. My first episode happened when I was at my in-laws, I just fell and when I woke up, I was at hospital.

Interviewer: Alright…

P11: The nurses explained to me that I had seizures; I was shocked because I did not know that I have the sickness. They explained that it happens, I must accept that I am sick and to take treatment. I now understand and have accepted that is why I'm taking treatment.

Interviewer: Yes, that's good

P11: Just that, I'm not that free everywhere I go I don't feel comfortable. I'm scared that in case I am in town alone carrying my baby at the back, what will I do if I fall. This sickness is unpredictable. It is not easy to accept this sickness.

Interviewer: "Nodding" …

P11: I remember when I was with my husband in Johannesburg, it was during the day, I suddenly felt dizzy. I told him that I'm about to fall, I just fell and he just stopped what he was doing and carried me. I heard that I was carried back home, and it was embarrassing.

Interviewer: Alright, I understand…you can continue

P11: It is not easy; I wish the sickness only occurred while I am at home. Sometimes I feel it when I am in public where there is too much noise, even bright colours. Sometimes it happened because I saw someone I know and I was not expecting to see, I felt that I am about to fall. At that time, I fell; but luckily, I was seating next to someone who knows that I have the sickness.

Interviewer: Yes, yes.

P11: After the sickness is gone, the driver suggested that I get out of the bus and go to the clinic. I told him I was fine. When I am at home I don't sleep on the bed because I woke up one day and I saw blood on the floor, I realised that I fell hence I now sleep on the floor. I even put my baby far from me because if the sickness attacks me while she is next to me I might hurt here.

Interviewer: "Nodding", alright.

P11: This sickness is not good at all. When you see me like this, I have gone to different places seeking for help to be cured.

Interviewer: Places? What kind of places if you may share?

P11: I went to "sangomas" or traditional healers at some village. But I have accepted it and I am now taking treatment.

Interviewer: Alright.

P11: Actually, let me go a bit back, I had a twin sister who was having the sickness also. She used to fall almost all the time; unlike me I only get sick once in a month. Unless if I have problems and stress. I fall maybe twice or three times a week.

Interviewer: So, what other types of treatment have you tried besides the western treatment?

Participant: My parents took me to a traditional healer and they invited my husband too. The traditional healer used his bones to explain to us that I was bewitched because I got married. So, he requested that we bring a black male chicken to the mountain. It was a very big mountain he used the blood from the chicken to wash me.

Interviewer: Then what happened after, did that help in any way?

P11: It did not stop the sickness; I mean I called the traditional healer to inform him that the treatment did not work. My sickness is continuing. Then we went back to him, he did the same thing of washing me with the blood from the chicken. My cousin said I came back home because my husband left me due to the sickness. My husband is very supportive, he said "I will be with you, no matter what". He has accepted my sickness, every time the sickness attacks me, I call him when I am conscious that I fell.

Interviewer: What kind of treatment are you currently using?

P11: I am using medications now, Tegretol and folic acid three times a day. There was a time when I omitted to take them on time instead of 10am I took them around 12pm then I took another dose at 3pm. That made me feel dizzy. But mostly I don't omit at all. The tablets are really working; I don't have frequent sickness.

Interview: How do you think your treatment can be improved?

P11: what I can say is that I’m very open when it comes to communication, even with the home-based caregivers, I just call them to visit me and to check-up on me because I am sick. Then I had someone who suggested that I should try another “maine” (traditional healer) who is cheaper; only R600.00 and the person got healed instantly. That lady said her son was having the same sickness of falling but now he is cured and no longer having the sickness. So, I think I will try it because I am seriously tired of this sickness. I even called my parents to tell them about the traditional healer.

Interviewer: I understand you.

P11: It is very difficult living with this sickness. I am not mentally ill but sometimes after attack I feel like I am mentally ill, because I even do things unaware, like putting clean clothes in the washing basin to wash them again.

Interviewer: So, do you think the tablets you get from the clinic are not working, since you still want to try traditional healers again.

P11: The tablets are helping here and there, but not to my satisfaction. Because I still fall regardless.

Interviewer: Have you tried to explain to the nurses during your visits to the clinic?

P11: Yes, I have and they encourage me to continue using them. I won’t stop taking them (tablets) until I get help that will cure this sickness.

Interviewer: Thank you, I think we have reached the end of our interview, do you have any question?

P11: Yes, I am not working. And I have gone to school for a cleaning certificate. But I don’t think I will be able to work of my sickness ad my baby too. So, I would like to receive the disability grant for my sickness.

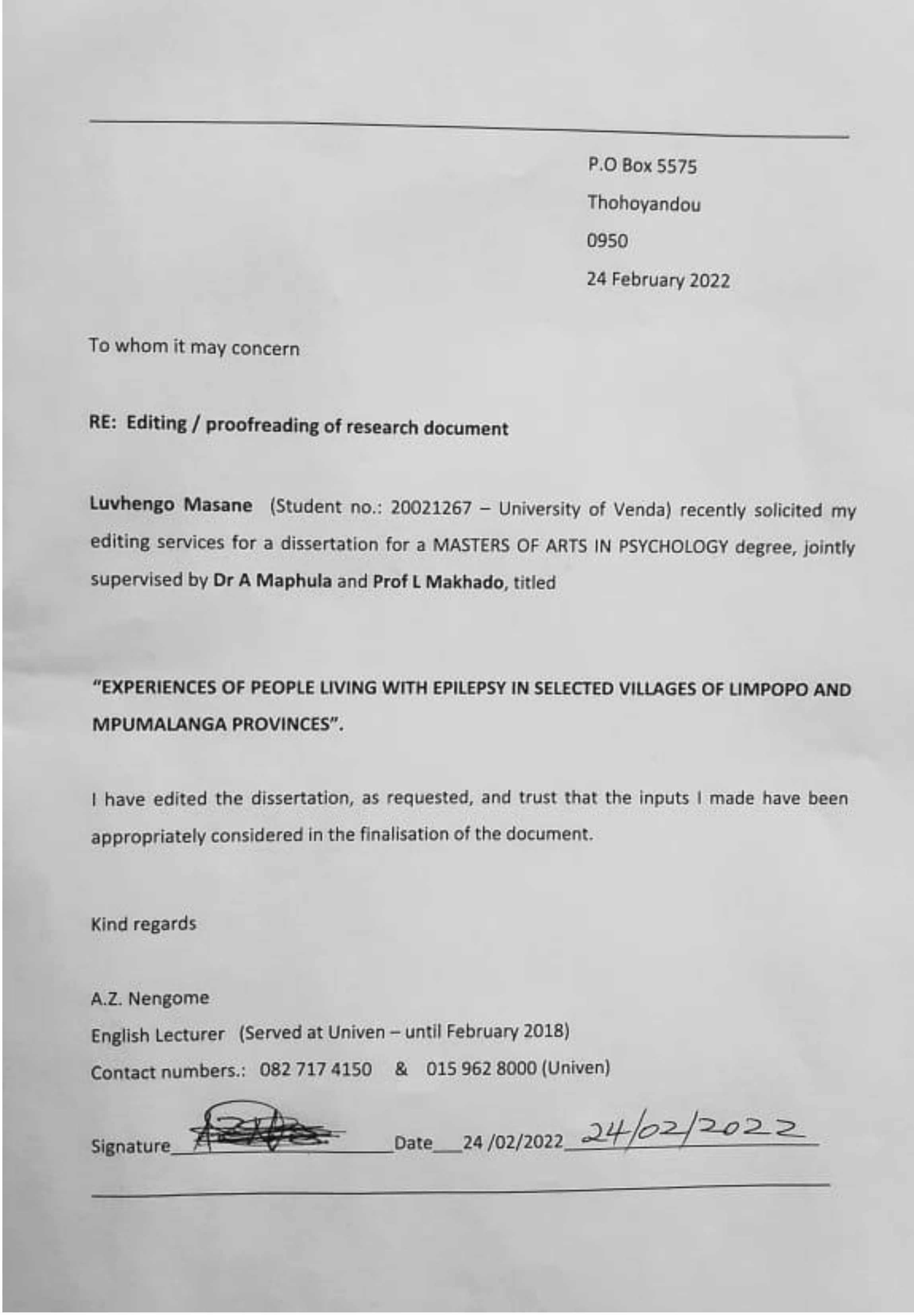
Interviewer: Alright, I can advise you to ask the nurses at the clinic concerning that, disability grant is available for persons living with epilepsy. You can get more information from the nurses or doctors at the clinic.

P11: Thank you.

Interviewer: I appreciate that you welcomed us to your home, and able to share with us about your condition.

The end

ANNEXURE G: LANGUAGE EDITION CERTIFICATE



P.O Box 5575
Thohoyandou
0950

24 February 2022

To whom it may concern

RE: Editing / proofreading of research document

Luvhengo Masane (Student no.: 20021267 – University of Venda) recently solicited my editing services for a dissertation for a MASTERS OF ARTS IN PSYCHOLOGY degree, jointly supervised by **Dr A Maphula** and **Prof L Makhado**, titled

"EXPERIENCES OF PEOPLE LIVING WITH EPILEPSY IN SELECTED VILLAGES OF LIMPOPO AND MPUMALANGA PROVINCES".

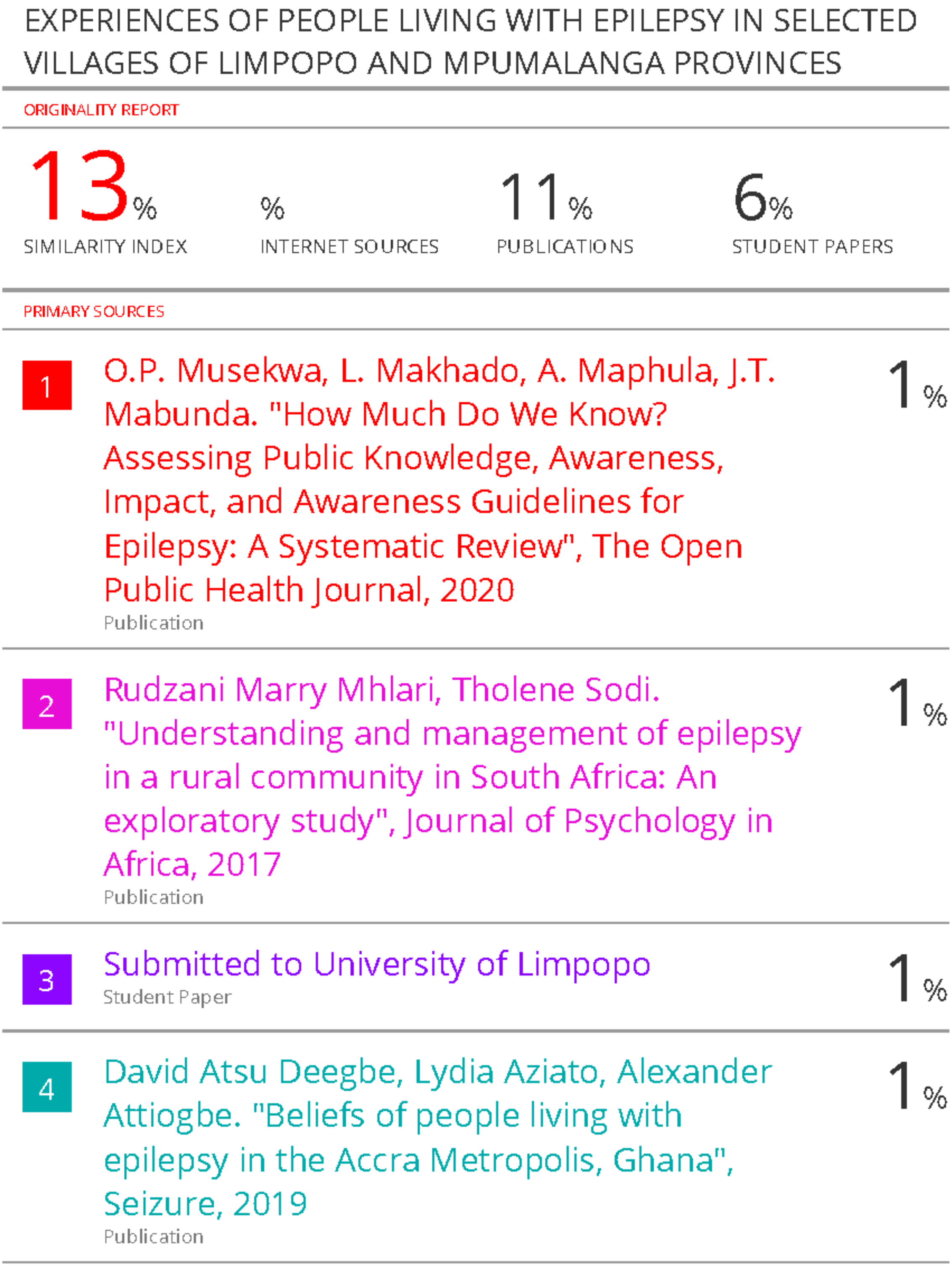
I have edited the dissertation, as requested, and trust that the inputs I made have been appropriately considered in the finalisation of the document.

Kind regards

A.Z. Nengome
English Lecturer (Served at Univen – until February 2018)
Contact numbers.: 082 717 4150 & 015 962 8000 (Univen)

Signature____________ Date___24 /02/2022 24/02/2022

ANNEXURE H: TURNITIN REPORT



EXPERIENCES OF PEOPLE LIVING WITH EPILEPSY IN SELECTED VILLAGES OF LIMPOPO AND MPUMALANGA PROVINCES

ORIGINALITY REPORT

13%	%	11%	6%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	O.P. Musekwa, L. Makhado, A. Maphula, J.T. Mabunda. "How Much Do We Know? Assessing Public Knowledge, Awareness, Impact, and Awareness Guidelines for Epilepsy: A Systematic Review", The Open Public Health Journal, 2020 Publication	1%
2	Rudzani Marry Mhlari, Tholene Sodi. "Understanding and management of epilepsy in a rural community in South Africa: An exploratory study", Journal of Psychology in Africa, 2017 Publication	1%
3	Submitted to University of Limpopo Student Paper	1%
4	David Atsu Deegbe, Lydia Aziato, Alexander Attiogbe. "Beliefs of people living with epilepsy in the Accra Metropolis, Ghana", Seizure, 2019 Publication	1%