



INDIGENOUS PRACTICES FOR THE MANAGEMENT OF EPILEPSY BY TRADITIONAL AND FAITH-BASED HEALERS: A CASE STUDY IN SELECTED RURAL COMMUNITIES OF MPUMALANGA AND LIMPOPO PROVINCES

by

Chabangu Qolile

Student Number: 14005084

Dissertation Submitted in Fulfilment of the Requirements for the Degree:

Master of Nursing

Department of Advanced Nursing Science
Faculty of Health Sciences
University of Venda

Supervisor Co-Supervisor

Prof M.S. Maputle Prof R.T. Lebese

June 2022

©University of Venda





DECLARATION

I, Chabangu Qolile, declare that the dissertation, Indigenous Practices for the Management of Epilepsy by Traditional and Faith-Based Healers: A Case Study in Selected Rural Communities of Mpumalanga and Limpopo Provinces hereby submitted to the University of Venda for the Master of Nursing degree in Advanced Nursing Science, is my own work in design and execution, and all reference material contained herein has been duly acknowledged.

Chabangu Qolile :

Student Number : 14005084

Place : University of Venda

Date : June 2022



DEDICATION

This study is dedicated to:

My mother, Linneth, for her unconditional support. My siblings, Harry, Sbusiso and Simon, for their encouragement and support. My son, Cairo, for the inspiration.

All people living with epilepsy.



ACKNOWLEDGMENTS

I thank God, the Almighty, who strengthened me and created a path throughout this study.

- My supervisors, Prof M.S. Maputle and Prof R.T. Lebese, thank you for the guidance and moral support you gave me during the challenging times of my studies.
- Prof L. Makhado, for guiding me through the process of science communication and peer-reviewed journal article writing.
- Glad Africa team, thank you for not giving up on me. Your support is much appreciated.
- * Ofhani, Muofeni and other fellow students, thank you for always being there for me, and your support is noted; you are much appreciated.
- ★ Special thanks to Glad Africa Epilepsy Foundation for financial support.
- * Community health care workers of all selected communities in Limpopo and Mpumalanga, I am very grateful for your support and willingness to participate in the study.
- ★ My son, Cairo Chabangu, you are my source of inspiration.
- Participants, who provided me with insightful information that helped me to achieve the goal of the study.
- ♣ Prof Donavon Hiss, for editing and typesetting the thesis (Annexure 7).





ABSTRACT

Background: The prevalence of epilepsy is high in low- and medium-income countries, but more so in rural areas. There are efforts to assist people suffering of epilepsy at government hospitals, clinics, and non-governmental organizations (NGOs). Despite these efforts, studies have shown that there is less uptake of anti-epilepsy medication and more reliance on cultural and religious practices to manage the condition.

Purpose: This study aimed to determine the indigenous practices used by traditional healers and faith-based healers in the selected rural communities of Mpumalanga and Limpopo Provinces.

Methodology: Manuscript 1 represents a systematic review was conducted to analyze the gaps regarding the management of epilepsy in Africa. The literature search was conducted electronically from 2000 to 2021. Manuscripts 2 and 3 were informed from the study findings of the systematic review. The reseach project adopted a qualitative, ethnographical approach that was exploratory and descriptive. Non-probability purposive and snowball sampling methods were used to sample 17 traditional healers and seven faith-based healers in the selected rural communities of Mpumalanga and Limpopo. Data were collected through in-depth individual interviews. Thematic analysis was used to analyze data by using six steps as outlined in Creswell (2014) and eight steps in forming codes by Tesch (1990). Trustworthiness was ensured using four criteria: dependability, confirmability, transferability, and credibility. Ethical considerations were adhered to, and the ethical clearance was received from the Ethics Committee of the University of Venda, then permission from the chief or ward counsellor to access the villages where data collection took place.



Findings of Manuscript 1: The findings for the systematic review demonstrated that there are two methods used to manage epilepsy in Africa, namely, a Western approach by using anti-epilepsy drugs, or a traditional approach through consultation with traditional doctors. Many people believe that epilepsy is spiritual and management should be traditional, resulting in less uptake of anti-epilepsy medication.

Findings of Manuscript 2: The findings show that traditional healers have a different perspective on the origins of epilepsy, and their treatment plans are based on their knowledge of the disease. Traditional healers use plants and alternative measures to treat epilepsy, in addition to Western medicine.

Findings of Manuscript 3: The findings revealed that faith-based healers use light tea, prayer, and fasting to manage epilepsy and have good collaboration with primary health care professionals.

Recommendations: Training in all aspects of epilepsy diagnosis and management is required for all health care workers. This includes epilepsy management knowledge, attitudes, and behaviours in the community. Health care providers should inform persons with epilepsy about the potential side effects of epilepsy drugs before they start taking them. Furthermore, health care providers must recognize the significance of indigenous religious beliefs in epilepsy management. They should urge primary and secondary health care personnel to interact with indigenous practitioners and encourage persons with epilepsy to seek Western medicine. They should accept non-harmful indigenous medicines while insisting on using biomedicine.

Keywords: communities, epilepsy, faith-based healers, indigenous practice, traditional healers





TABLE OF CONTENTS

DECLARA	.TION	ii
DEDICATI	ON	iii
ACKNOW	LEDGMENTS	iv
ABSTRAC	т	v
TABLE OF	CONTENTS	vii
LIST OF F	IGURES	xii
LIST OF T	ABLES	xii
LIST OF A	BBREVIATIONS	xiii
SECTION	1	1
GENERAL II	NTRODUCTION	1
1.1	Introduction and Background	1
1.2	Problem Statement	4
1.3	Purpose of the Study	6
1.4	Research Objectives	6
1.5	Research Question	6
1.6	Rationale of the Study	6
1.7	Significance of the Study	7
1.8	Conceptual Framework	7
1.8.1	The Health Belief Model	7
1.8.2	Application of the Health Belief Model to This Study	8
1.8.2.1	Perceived Susceptibility	8
1.8.2.2	Perceived Seriousness	8
1.8.2.3	Perceived Benefits	9
1.8.2.4	Perceived Barriers	9
1.8.2.5	Cues to Action	10
1.9	Definition of Terms	10
1.9.1	Epilepsy	10
1.9.2	Indigenous Practices	10
1.9.3	Health Care Providers	10
1.9.4	People Living with Epilepsy	11
1.10	Research Methodology	11
1.10.1	Introduction	11
1.10.2	Research Approach	11



1.10.3	Research Design	12
1.10.3.1	Exploratory Design	12
1.10.3.2	Descriptive Design	13
1.10.4	Study Setting	13
1.10.5	Study Population and Sampling	14
1.10.5.1	Study Population	14
1.10.5.2	Sample and Sampling	15
1.10.5.3	Sample Size	15
1.10.5.4	Inclusion and Exclusion Criteria	16
1.10.6	Measurement Instruments	16
1.10.6.1	Interview Guide	16
1.10.6.2	Pre-Testing	17
1.10.7	Plan for Data Collection	18
1.10.7.1	Recruiting the Participants	18
1.10.7.2	Data Collection Method	18
1.10.7.3	Contradicting	19
1.10.7.4	Linking	19
1.10.7.5	Encouraging	19
1.10.7.6	Showing Understanding and Allowing Time for Elaboration	19
1.10.7.7	Acknowledging	20
1.10.7.8	Direct Questions	20
1.10.8	Trustworthiness	20
1.10.8.1	Credibility	20
1.10.8.2	Transferability	21
1.10.8.3	Confirmability	21
1.10.8.4	Dependability	21
1.10.9	Data Analysis	22
1.10.10	Ethical Considerations	24
1.10.10.1	Approval to Conduct the Study	24
1.10.10.2	Informed Consent	25
1.10.10.3	Freedom of Choice	25
1.10.10.4	Privacy	25
1.10.10.5	Anonymity	25
1.10.10.6	Freedom from Harm	26
1.10.10.7	Confidentiality	26
1.10.11	Delimitation	26
1.10.12	Plan for Dissemination	26
1.11	References	27
SECTION 2	2	30
	PT 1	
	Title: Management of Epilepsy Through Traditional and Western	



	Approaches in Africa: A Systematic Review. Health SA Gesondheid (Under Review)	30
2.2	Authors and Affiliations	
2.3	Abstract	30
2.4	Introduction	31
2.5	Methods	33
2.5.1	Search Strategy	33
2.5.2	Inclusion and Exclusion Criteria	33
2.5.3	Study Selection	33
2.5.4	Study Appraisal	35
2.6	Findings	40
2.6.1	Theme 1: Traditional Methods of Epilepsy Management	40
2.6.1.1	Sub-Theme 1.1: Christian Healers	40
2.6.1.2	Sub-Theme 1.2: Traditional Healers	41
2.6.2	Theme 2: Western Methods of Epilepsy Management	44
2.6.2.1	Anti-Epilepsy Medication	44
2.7	Discussion	45
2.8	Conclusion	46
2.9	Recommendations	47
2.10	Acknowledgments	47
2.11	Authors' Contributions	47
2.12	Funding	47
2.13	Conflict of Interest Statement	47
2.14	References	48
SECTION	3	51
MANUSCRI	PT 2	<i>5</i> 1
3.1	Title: Exploring Indigenous Practices for Management of Epilepsy by Traditional Healers at Rural Villages of Limpopo and Mpumalanga Provinces	51
3.2	Authors and Affiliations	
3.3	Abstract	51
3.4	Introduction	52
3.5	Materials and Methods	54
3.5.1	Methods	54
3.5.2	Study Setting	54
3.5.3	Population and Sampling	55
3.5.4	Ethical Considerations	55
3.5.5	Data Collection	56
3.5.6	Data Analysis	
3.5.7	Trustworthiness	57
3.6	Results and Data Presentation	57
3.6.1	Theme 1: Participants' Perceptions on the Contributory Causes of	





	Epilepsy	59
3.6.1.1	Sub-Theme 1.1: Physical and Environmental Factors	59
3.6.1.2	Sub-Theme 1.2: Traditional Beliefs Associated with the Occurrence of Seizure	61
3.6.2	Theme 2: Participants' Description of How They Diagnose a Person with Epilepsy	62
3.6.2.1	Sub-Theme 2.1: Observation of Occurrence of Epileptic Seizures	62
3.6.2.2	Sub-Theme 2.2: Family History of Epileptic Condition	62
3.6.3	Theme 3: Participants' Descriptions of Indigenous Practices of Managing the Seizures	63
3.6.3.1	Sub-Theme 3.1: Use of Alternative Indigenous Measures	63
3.6.3.2	Sub-Theme 3.2: Working Collaboratively with Primary Health Care Professionals	66
3.6.4	Theme 4: Participants' Expression of How They Felt About Sharing on How They Manage the Condition Information	67
3.6.4.1	Sub-Theme 4.1: Positive Attitudes Towards Sharing Treatment Information	67
3.6.4.2	Sub-Theme 4.2: Negative Attitudes Towards Sharing Treatment Information	68
3.7	Discussion	68
3.8	Conclusion	74
3.9	Conflict of Interest	74
3.10	Acknowledgements	74
3.11	References	74
SECTION	4	77
	PT 3	
4.1	Title: Faith-Based Healers' Understanding of Epilepsy Management in Rural Villages of South Africa	
4.2	Authors and Affiliations	
4.3	Abstract	
4.4	Introduction	78
4.5	Material and Methods	80
4.5.1	Study Setting	80
4.5.2	Methods	80
4.5.3	Population and Sampling	81
4.5.4	Ethical Considerations	81
4.5.5	Data Collection	81
4.5.6	Data Analysis	82
4.5.7	Trustworthiness	82
4.6	Results and Data Presentation	83
4.6.1	Theme 1: Participants' Perceptions of the Cause of Epilepsy	84
4.6.2	Theme 2: Participants' Description of How They Diagnosed Epilepsy	85
4.6.3	Theme 3: Participants' Descriptions of the Different Ways of Managing Seizures	86





4.8	Limitation	91
4.9	Conclusion	91
4.10	Conflict of Interest	91
4.11	Acknowledgement	91
4.12	References	92
SECTION 5		94
	SCUSSION, LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS	
5.1	Summary of Key Findings	
5.2	Limitations	96
5.3	Recommendations	97
5.3.1	Recommendations for Biomedical Practitioners	97
5.3.2	Recommendations for Indigenous Practitioners	98
5.3.3	Recommendations for a Multi-Cultural Approach in Epilepsy Management	98
5.3.4	Recommendations for Policymakers	98
5.3.5	Recommendations for Future Studies	99
5.4	Conclusion	99
ANNEXURE	<u> </u>	101
	ROVAL CERTIFICATE FROM THE UNIVERSITY OF VENDA HUMAN AND CLINICAL	
TRIALS RESI	EARCH ETHICS COMMITTEE (HCTREC)	101
ANNEXURE	<u> </u>	102
LETTER TO 7	RIBAL AUTHORITY REQUESTING PERMISSION TO CONDUCT RESEARCH	102
ANNEXURE	3	103
PERMISSION	FROM MPUMALANGA PROVINCE DEPARTMENT OF HEALTH TO CONDUCT	
		103
ANNEXURE	<u> 4 </u>	106
	FROM LIMPOPO PROVINCE DEPARTMENT OF HEALTH TO CONDUCT	
		106
ANNEXURE	5	107
LETTER OF I	NFORMATION	107
ANNEYLIRE	· 6	100
	DRM	
	······································	103
ANNEVLIDE		
_		





LIST OF FIGURES

Figure 2.1:	PRISMA 2009 flow diagram	3
Figure 2.1:	PRISMA 2009 flow diagram	٠.

LIST OF TABLES

Table 2.1:	CASP study appraisal	3
Table 2.2:	Characteristics of the included studies	37
Table 3.1:	Demographic characteristics of traditional healers	5
Table 3.2:	Themes and sub-themes reflecting traditional healers' indigenous practices of managing epilepsy	59
Table 4.1:	Demographic characteristic of faith-based healers	8



LIST OF ABBREVIATIONS

AEM Anti-Epileptic Medication

AIDS Acquired Immunodeficiency Syndrome

CP Cultural Practices

HBM Health Belief Model

HCP Health Care Practitioner

HCTREC University of Venda Human and Clinical Trials Research Ethics Committee

HCW Health Care Worker

HIV Human Immunodeficiency Virus

LP Limpopo Province

MOE Management of Epilepsy

MP Mpumalanga Province

PLWE People Living with Epilepsy

RP Religious Practices

THS Traditional Healers

WHO World Health Organization



SECTION 1

GENERAL INTRODUCTION

1.1 Introduction and Background

This study focused on the indigenous practices for the management of epilepsy in the selected rural communities of Mpumalanga and Limpopo. This section looked at the introduction and background of the problem, problem statement, research question, purpose, objectives and significance of the study. The conceptual framework, research methodology, research designs and data collection methods were described. Furthermore, data analysis measures to ensure trustworthiness and ethical considerations are described in this section.

The belief about epilepsy in central South America is different from other cultures in Africa. In Mexico, the religion of the community called Tzeltal Maya, known as the deeply traditional group from Central America, was not yet influenced by Western culture (Mutanana, 2018). In this traditional group, epilepsy was not considered an inborn disorder; people living with epilepsy (PLWE) were perceived as wizards in the community. The condition had no cure, but can be improved by drinking for a week two herbs in combination diluted in cold water (Carod-Artal and Vazquez-Cabrera, 2007). However, the abovementioned authors indicated that in Brazil, amongst the community called Kamayura, epilepsy was believed to be caused by killing an animal called armadillo. Still, it can be treated traditionally through the use of two plants. According to Chaundry (2007), people from India sought help from traditional healers rather than anti-epileptic drugs.



The reason is that a large proportion of the population in India fails to get epilepsy treatment because of the non-availability of the drug in the facilities, alternative faith treatment and limitations imposed by cultural beliefs. In Nepal, indigenous healers make a house call to treat people with epilepsy. In African countries like Nigeria, Sudan, and Ghana, people believe in African traditions to manage epilepsy medicine and believe epilepsy is linked to spiritual causes.

Eker and Ekripo (2015) stated that even though biomedication is available in these countries, they prefer traditional and spiritual medicines. Mutanana (2017) observed that anti-epilepsy drugs were associated with several challenges in rural communities in Zimbabwe. People were not educated about the side effects of the drug and therefore turned using traditional and spiritual medicines. African people living with epilepsy have difficulty achieving positive feelings about themselves, and about 80% of the African population consult traditional healers when they are not feeling well (Stafford et al., 2008).

In South Africa, keen efforts were taken to assist people with epilepsy at government hospitals, clinics, and non-governmental organizations (NGOs). Still, despite these efforts, studies have shown less uptake of anti-epilepsy medication (Dewa, 2012). Mpumalanga and Limpopo are rural provinces, and indigenous practices by traditional and faith-based healers form part of epilepsy treatment. However, PLWE in these rural provinces prefer cultural and religious practices to manage their condition (Mutanana, 2018).

Epilepsy is a common neurological disease that affects 1 in every 100 people in South Africa, and the challenge is that about 66% of the underlying cause of epilepsy is unknown (WHO, 2019). Cultural and psychosocial issues are considered to be significant concerns that affect people living with the condition and their family



members (Wolf, 2010). Evidence illustrates that matters like stigma, discrimination, depression, discrimination, low self-esteem, anxiety and misperception about the causes and management of the condition affect the treatment and care for people living with the condition (Baker, 2002; Diop et al., 2003, Quintas et al., 2012).

Epilepsy is ranked as one of the six top non-communicable diseases (WHO, 2015). However, it has not been reported as one of the emerging non-communicable diseases and, therefore, is not receiving equal attention as other top non-communicable diseases that are managed at primary care settings (Laikhen and Mash, 2015). Furthermore, more than 50 million people affected by epilepsy worldwide were reported as one of the serious health issues (WHO, 2015).

It was estimated that roughly 70% of people with the condition could have successful seizure freedom if using anti-epilepsy treatment. However, epilepsy was considered poorly managed in South Africa in health care facilities (Keikelame, Hills, Naidu, De Sa and Zweigenthal, 2012). Presently, the country's health system has an emerging increase of non-communicable diseases in rural and urban areas, characterised by poverty and marginalisation (Mayosi and Benatar, 2014).

Epilepsy has been largely agreed as a medical condition that mainly received responsiveness from medical doctors (McQueen and Swartz, 1995). According to Mutanana (2018), the mental health illness epidemic like epilepsy had been neglected within the development sphere. Zenden (2014) stated that despite the impact epilepsy had on people's lives, it had not received the same amount of attention as other infectious disease outbreaks and non-communicable diseases.

Mpofu (2001) believed that those who default epilepsy treatment use traditional healers and religious leaders such as prophets. According to Keikelema and Swarts (2015), the study conducted in Cape Town indicated that traditional medicine could



have an important role in treating epilepsy when used together with modern approaches. Local traditional healers could help identify patients in the community and refer them to hospitals, whilst practitioners believed that the combination of traditional medicine and Western anti-convulsive agents could be more effective.

Mpumalanga and Limpopo are rural provinces with limited health resources, and the use of traditional health practitioners is considered the most sought treatment option. However, indigenous practices that are used to manage epilepsy in these provinces remain unknown. It was against this background that this study was pursued. This study explored how the local indigenous practices, traditions, and beliefs must be considered in the management of epilepsy.

1.2 Problem Statement

Mpumalanga and Limpopo are low-income rural provinces. The prevalence of epilepsy is highest in low- and medium-income countries, but yet two to three times higher in rural areas, especially with high prevalence figures reported in Sub-Saharan Africa (Ba-Diop, Marin, Druet-Cabanac et al., 2014; Preux and Druet-Cabanac, 2005). The researcher works as a nurse in the rural areas of Mpumalanga. Through her work experience she has observed that PLWE and their caregivers find it difficult to understand and manage epilepsy because they seek help from different health care providers, which includes traditional healers, faith-based healers, and health care practitioners.

Moreover, many patients would not show up for treatment at the clinic. When follow-ups were done with the home-based care worker, parents or family members reported that they brought the patient to traditional healers that served as a reason for not showing up during their booked date. This may be affecting PLWE if traditional healers failed to manage the patient, and, if the patient used traditional and Western medicines



interchangeably, drug interaction might occur, resulting in treatment failure. Caregivers may be affected as well financially without benefiting because they should pay for expenses while the results were very poor due to mixed management approaches. The management of PLWE by health care practitioners is known and structured. However, the management of PLWE by traditional healers and religious leaders has not yet been determined. It is believed that their management approach contradicted one another because of their different backgrounds and knowledge, understanding, processes, and explanation of the illness. According to Ntsusi (2015), discrepancies in understanding the condition may negatively affect the health-seeking behaviours of the caregivers and patients.

In South Africa, many studies had been conducted on epilepsy, but only a few incorporated indigenous practices used to manage epilepsy. The study on traditional healers' explanations of epilepsy and perspectives on collaboration with biomedical care in Cape Town by Keikelema and Swartz (2015) concentrated on traditional healers even though it dwelled much on the collaboration with Western medicine. The traditional practice was not at the forefront.

However, another study on indigenous practices for sustainable management of epilepsy in Zimbabwe (Mutanana, 2018), also focused more on both Western and traditional practices even though the study was not done in South Africa, but it was considered because it was still part of the continent. In Africa, it is believed that epilepsy treatment is not taken into consideration because of the cultural environment of PLWE.

These insufficiencies should explain the current treatment gap of PLWE. The literature in the field of Western and traditional practices does not adequately explain the inadequacies in research and none had indicated what traditional healers use to



manage epilepsy. Therefore, in this study, the researcher wanted to know what traditional and faith-based healers used to manage epilepsy.

1.3 Purpose of the Study

The purpose of this study was to determine the indigenous practices that traditional and faith-based healers used for the management of epilepsy in rural communities of Mpumalanga and Limpopo provinces.

1.4 Research Objectives

The following specific objective guided this study:

Describe the indigenous practices that traditional and faith-based healers used to manage epilepsy in rural communities.

1.5 Research Question

The following question guided this study:

★ What were the indigenous practices that traditional and faith-based healers used for the management of epilepsy in the selected rural communities?

1.6 Rationale of the Study

Several studies have shown that in countries such as Brazil, India, and Mexico, an indigenous form of epilepsy treatment was at the forefront, and disease management was well known. Unlike in South Africa, numerous studies suggested that there was not much attention given to the indigenous form of treatment. Yet, most PLWE depend on it to manage their condition (Mutanana 2018). In South Africa, limited studies have been conducted on indigenous epilepsy management practices by traditional healers and faith-based healers. Therefore, a gap exists in the care and treatment of epilepsy insofar traditional and faith-based healers are concerned. The researcher felt a need



to conduct the study to gain new insight and knowledge on indigenous practices regarding epilepsy management by traditional and faith-based healers to improve the quality of life for PLWE.

1.7 Significance of the Study

The research findings could help the government to ensure a multicultural approach in epilepsy management through the ministry of health and child care and provide appropriate background information, education, and treatment programmes to be adapted in a holistic way to ensure best cultural practices. The research findings could help coordinate the modern health care and traditional epilepsy management systems to resolve the conflict concerning epilepsy management and work together as a team and complement each other in epilepsy management. The research findings could help the community at large, caregivers, and PLWE with information and education to enable and empower people to make informed choices concerning the treatment of epilepsy. The research findings could benefit the community with new insights and knowledge on indigenous practices of epilepsy management. The research findings could also help policymakers to adopt a new strategies and procedures regarding epilepsy management in the rural communities that support both biomedical and indigenous practices.

1.8 Conceptual Framework

1.8.1 The Health Belief Model

In this study, the Health Belief Model (HBM) was used to predict the health-seeking behaviour of PLWE concerning the management of epilepsy. Chin and Mansori (2019) defined the HBM as a health behaviour change model, and it was used to predict individuals' responses and changes in their behaviour to prevent disease. The HBM attempts to explain the thought processes behind an individual's decisions relating to health behaviour change and maintenance (Romockers and Shea, 2011).



It is a cognitive model that suggests that the behaviours of an individual are determined by several health threats and beliefs that the individual possesses about his/her well-being as well as the effectiveness and outcome of behaviour or action (Becker, 1974). Hochbaun (1958) stated that health behaviour is determined by an individual's belief and perception about the disease and strategies available to decrease the occurrence of the disease.

For example, Bertha (2015) pointed out that some PLWE believed that epilepsy was caused by evil spirits and strategies available to manage the condition were traditional. There are four perceptions identified and tested that served as the main constructs of the HBM. These perceptions/concepts are: perceived seriousness, susceptibility, benefits, and barriers. In addition to these four perceptions, the HBM suggested that cues influenced behaviour to action and self-efficacy (Graham, 2002). All perceptions are discussed based on epilepsy management in this study, but only self-efficacy was excluded from the discussion.

1.8.2 Application of the Health Belief Model to This Study

1.8.2.1 Perceived Susceptibility

According to Janz and Becker (1984), Rosenstock (1974), and Glanz et al. (2008), perceived susceptibility is the subjective assessment of the risk of developing a health problem. This model had predicted that people who felt they were susceptible to a health problem could engage in behaviours that reduce the risk of developing that health problem. For instance, in this study about epilepsy, if family members or caregivers perceived a high risk in developing the condition, they were likely to engage in behaviours that decrease the risk of developing the health problem.

1.8.2.2 Perceived Seriousness

Perceived seriousness refers to the subjective assessment of the severity of the health



problem and the potential consequences (Janzand Becker, 1984; Glanz, Rinner and Viswanath, 2008). The HBM proposed that people who perceived a health problem as serious were more likely to engage in behaviour that prevented the health problem from occurring or reduce its severity. In this study, people may perceive epilepsy as a serious health problem because it interfered with their daily activities; therefore, they engaged in behaviours that prevented this health problem from occurring or reduced its severity.

1.8.2.3 Perceived Benefits

The likelihood and type of action taken to a perceived threat is dependent on an individual's perceived benefit of taking action. One must have seen actions as beneficial or effective against preventing a perceived threat before action was taken (Janz et al., 2002). For instance, if a person believed that taking anti-epilepsy medication would help improve the condition, then that person was more likely to take the medication, unlike the person who believed anti-epilepsy medication was not useful. Similarly, one who believed in traditional and faith-based practitioners would make use of them irrespective of the objective facts by medical doctors regarding the effectiveness of the indigenous practices on epilepsy management.

1.8.2.4 Perceived Barriers

Perceived barriers are dependent on the level of how beneficial an individual may perceive an action. Perceived barriers interfere with an individual's willingness to take appropriate action. Individuals may perceive barriers due to the cost of action, potential harm, inconvenience, or time-consuming, among others (Janz et al., 2002). For example, a medical doctor may prescribe an anti-epilepsy drug for an individual living with epilepsy in this study. Perceived side effects of the medication may be a barrier to this health-seeking behaviour.



1.8.2.5 Cues to Action

Cues to an action refer to the stimulus needed to trigger the decision-making process to accept a recommended health action. For instance, an individual closely related to a traditional healer or faith-based healer who believed in indigenous remedies for management was more likely to be interested in getting traditional medicine for epilepsy treatment.

1.9 Definition of Terms

1.9.1 Epilepsy

Epilepsy is caused by a brain disease defined by at least two unprovoked seizures occurring in more than 24 hours apart, resulting in any abnormal clinical behaviour (WHO, 2019). In this study, epilepsy refers to a condition that is characterised by two or more unprovoked recurring seizures that may result in shaking and twinkling of the body.

1.9.2 Indigenous Practices

Indigenous practices refer to people naturally belonging to a place, plants and animals, and practices are simple means to organize knowledge developed by culture for practical purposes. For example, this can be traditional and spiritual medicine developed by locals for epilepsy management (Mutanana, 2018). In this study, an indigenous practice refers to the people living in a particular community who have specific knowledge developed by locals to manage epilepsy.

1.9.3 Health Care Providers

Health care providers refer to people who act in providing care for controlling unprovoked seizures before or after they happened (Newman, 2011), and this were viewed in both Western-trained health care providers like professional nurses, doctors, pharmacists, psychologists, and traditional epilepsy management including traditional





healers and faith-based healers (Keikelema, 2016). In this study, a health care provider refers to anyone taking care of PLWE, such as caregivers (mother, family member), health care professionals, traditional healers, and spiritual believers.

1.9.4 People Living with Epilepsy

People living with epilepsy (PLWE) refer to people who had experienced two or more unprovoked seizures, and through seeking health, they were diagnosed with epilepsy and taking epilepsy medication (Rosenstock, 1974). In this study, PLWE refers to people who had a seizure episode more than two times, acquired assistance from health care providers, diagnosed with epilepsy and take medication.

1.10 Research Methodology

1.10.1 Introduction

This section describes the research method which was used. The ethnographical approach that was adopted is briefly described. The sampling and data collection methods are also presented. The steps followed in data analysis are outlined, whilst ethical considerations are also discussed.

1.10.2 Research Approach

The study adopted a qualitative research approach because the researcher sought to understand and explore indigenous practices for the management of epilepsy by traditional healers and faith-based healers in the selected communities of Mpumalanga and Limpopo (De Vos, 2011, 315). The researcher wanted the participants (traditional healers and faith-based healers) to give information on the non-Western management of epilepsy that each one of them has experienced in real life (Creswell, 2018, 13). It was significant to use a qualitative research approach in this study rather than a quantitative research approach because it focused more on the participant's points of view rather than questionnaires or instruments developed by researchers or what the



researcher knows (De Vos et al., 2011). A qualitative method was more relevant because it allowed the researcher to ask in-depth questions and use combined data collection methods such as observation, interviews, documentation, and audiovisual information rather than relying on single data sources (Creswell 2016, Marshall and Rossman, 2016). The researcher explored all the unknown epilepsy management practices by using face-to-face interviews with the selected population. This enabled the researcher to collect large amounts of data from a small number of participants (De Vos et al., 2011).

This study followed the ethnographical approach. Ethnography is the study of an entire cultural or social group based on primary observations over a prolonged period spent by the researcher in the field (Creswell, 2018). This approach focused on a specific group's social and cultural world (Brink, Van der Walt and Van Rensburg, 2018). It was essential to use the ethnography approach in this study because the researcher required spending a considerable amount of time in the selected communities to observe and gather information on the indigenous practices for the management of epilepsy by the traditional healers and faith-based healers (Brink et al., 2018). This approach was suitable for this study because it focused on the role of culture in shaping the experience, which differed from the phenomenology that looked at the meaning of experience. Thus, ethnography enabled the researcher to interview people knowledgeable about the indigenous practices for the management of epilepsy which were traditional healers and faith-based healers since they rendered such services (Brink et al., 2018).

1.10.3 Research Design

1.10.3.1 Exploratory Design

An exploratory research design was used in this study to explore the indigenous practices used by traditional healers and faith-based healers for PLWE to manage their





condition. According to Brink et al. (2018), an exploratory design was conducted to understand the indigenous practices for the management of epilepsy by traditional and faith-based healers in the selected rural communities of Mpumalanga and Limpopo province. This research design was deemed suitable for this study because there was a high level of uncertainty and ignorance about the indigenous practices for the management of epilepsy by traditional healers and faith-based healers. There was little existing research about the subject matter observed (De Vos et al., 2011). However, the need for an exploratory design arose from a lack of basic information on a new area of interest or getting acquainted with a situation to formulate a problem or develop a hypothesis (De Vos et al., 2011). The exploratory design had been used in this study because it encompasses a fundamental goal of providing a better-researched model to a problem that was not well researched before (De Vos et al., 2011).

1.10.3.2 Descriptive Design

The qualitative research in this study aimed to describe in detail the indigenous practices for the management of epilepsy by traditional and faith-based healers in the selected communities of Mpumalanga and Limpopo provinces. A descriptive design was used to obtain information concerning the status of the indigenous practices used to manage epilepsy by traditional healers and faith-based healers and to describe what existential beliefs and experiences concerning epilepsy. The management was observed differently from an unchanged and natural environment, while analyzable data collected during interviews were described in detail.

1.10.4 Study Setting

The research setting implied a place where data were specifically collected. The kind of data to address the research question and the location determined the study setting before conducting the study (Brink et al., 2018). The study took place in selected rural communities of Mpumalanga and Limpopo provinces. Mpumalanga is situated in the



far east corner of South Africa, bordered by Limpopo in the north, Mozambique and Swaziland in the east, Gauteng, and Free State in the west and KwaZulu-Natal in the south. The dominant languages in Mpumalanga includes Ndebele, Zulu, Northern-Sotho, Swati, and Tsonga. The climate allows a variety of agricultural activities, and forestry is extensive around Sabie, far north-east of the province. For this research, selected areas included Acornhoek in Bushbuckridge Municipality, Ehlanzeni District, Clara in Bushbuckridge Municipality, Bohlabela District, and Jerusalema in Mbombela Local Municipality, Ehlanzeni District.

Limpopo lies in the far north of South Africa, bordered by Zimbabwe, Botswana, and Mozambique. The population of Limpopo is primarily composed of rural blacks of Pedi, Tsonga, Venda, and a minority of Afrikaans-speaking whites. Limpopo is also one of the most affluent agricultural areas in the country. The study took place in the following rural communities: Bochum in Blouberg Local Municipality, Capricon District, Malavuwe, Thulamela Local Municipality in Vhembe District, and Mtititi Thulamela Local Municipality in Vhembe District.

1.10.5 Study Population and Sampling

1.10.5.1 Study Population

The population is the entire group of persons or objects of interest who met the criteria the researcher has predetermined for a study (Brink et al., 2018; Pilot and Beck, 2017). A target population is the entire set of elements or individuals who met the sample criteria for a study (Grove and Gray, 2019). This study's target population was traditional healers and faith-based healers 18 years and above residing in the selected rural communities of Mpumalanga and Limpopo provinces. An accessible population is the portion of the target population to which the researcher had reasonable access (Grove and Grey, 2019). Accessible populations in this study were traditional healers and faith-based healers of 18 years and above who were available in the households



on the days of data collection. In the context of this study, the population comprised traditional and faith-based healers. It was assumed that traditional healers and faith-based healers had first-hand experience in the management of epilepsy.

1.10.5.2 Sample and Sampling

Sampling refers to the process of selecting the sample from a population to obtain information regarding a phenomenon in a way that represents the study population (Brink et al., 2018). In this study, the sample was identified using purposive and snowball sampling. Purposive sampling is also called judgemental sampling and is another type of non-probability sampling. This technique is based on the researcher's judgment regarding participants or objects that are typical or representative of the study phenomenon or exceptionally knowledgeable (Brink et al., 2018). Therefore, purposive sampling was used to select faith-based and traditional healers, specifically because they were presumed to be knowledgeable about the traditional management of epilepsy in the selected communities. Snowball sampling was also used to get assistance from study participants in obtaining other potential participants, especially when it was difficult for the researcher to gain access to the population. This was suitable for the study because the researcher identified a few required characteristics. They then helped to identify more people who have similar characteristics. The process continued until the researcher was satisfied that the sample size was sufficient.

1.10.5.3 **Sample Size**

The sample size is the number of available people during the study (Polit and Beck, 2017). The target populations were traditional healers and faith-based healers. Sampling was identified using purposive and snowball sampling. However, in each community, 3 participants were interviewed per their characteristics, and the data saturation determined the sample size in each community and within each stratum per selected community.



1.10.5.4 Inclusion and Exclusion Criteria

According to Burns and Grove (2011), sampling criteria mean a list of characteristics essential for eligibility or membership in the target population.

Inclusion Criteria

Traditional and faith-based healers were included from 18 years and above for their first-hand experience in epilepsy management.

Exclusion Criteria

Any member under 18 years because in South Africa, any individual under 18 years is considered not yet legally responsible for their actions.

1.10.6 Measurement Instruments

1.10.6.1 Interview Guide

Interviewing is the predominant mode of data or information collection in qualitative research. Researchers obtained information through direct interchange with an individual or group known or expected to possess the knowledge they seek (Depoy and Gilson, 2008; De Vos et al., 2011). The researcher used the interview guide specifically for each category to collect data. The method was used to interview traditional healers and pastors or prophets in the selected communities of Mpumalanga and Limpopo.

The interview method was applicable in this study because it allowed open-ended questions and interviewees to express their feelings freely. This type of interview required both the researcher and the participants to be at ease to discuss and brainstorm on the topic. The researcher and the participants determined the direction of the interview guide to generate rich data, ideas, and information. Questions were asked according to the level of the participant's knowledge. The advantage of using



the interview method for collecting data was that the researcher observed nonverbal communication and was allowed to probe further rather than asking the question on the paper and even explaining the question in case participants did not understand. The disadvantage associated with this method was that it was not suitable for a large group. Some participants would not freely articulate their views because they were afraid from being watched by the researcher and other people.

1.10.6.2 Pre-Testing

The researcher arranged with the community health workers in the selected communities and identified two participants: one traditional healer and one faith-based healer. Pre-testing in this area reduced the number of anticipated problems by allowing the researcher to redesign the study to overcome difficulties in the main study (Grove and Gray,2019).

- * Step 1: Respondents who met the inclusion criteria were interviewed by the researcher, but did not form part of the sample.
- * Step 2: The researcher asked the participants for feedback to identify uncertainties and challenging questions.
- * Step 3: Recording the time taken to complete the interviews and decide if it was reasonable.
- ★ Step 4: Reword and refine all difficult questions and all difficult words.
- * Step 5: Assessing if the asked question gave enough response range and whether respondents understood what was required from them.
- Step 6: Check whether responses could be interpreted in terms of



information that was needed for the study.

* Step 7: Check if the participants could answer all questions and revisit the questions that were not answered as per expectations. If errors were found in the researcher's instrument, the modification was done before the main research was conducted.

1.10.7 Plan for Data Collection

1.10.7.1 Recruiting the Participants

The researcher applied for ethics approval from the University of Venda Research Ethics Committee (Annexure 1) and obtained permission to access villages from ward councillors or chiefs of the selected communities in both provinces (Annexures 2 to 4) After permission was granted, the researcher asked the home-based care workers to identify traditional healers and faith-based within the communities. Through their assistance, the researcher was able to reach the aim of the study. All participants qualifying were informed about the process that was followed and that they could withdraw if they felt like it (Annexures 5 and 6) The researcher explained the benefit of the research and the process using the participant's language (Annexure 5).

1.10.7.2 Data Collection Method

Data collection describes different approaches to research questions answered by the participants (Maree, 2016). Individual face-to-face interviews and semi-structured interviews were used to collect data. The researcher asked a specific number of questions: for the traditional and faith-based healers, the question was: "Can you share how you manage epilepsy traditionally." The question was followed by probing. Participants were made comfortable and asked to read the consent form (Annexure 6). For participants who could not read, the researcher would read for them before commencing with the interview. The researcher asked the participants about the



indigenous practices used to manage epilepsy in their communities. The questions were asked differently per the grouped characteristics.

The demographic details and research questions from the study objective were created per the participants' characteristics. Each interview lasted for 30 to 45 minutes. A voice-recorder was used to capture data. Interviews were conducted using the participants' home language. During the interview, if there were misconceptions or misunderstandings, the researcher directed the participants by probing questions on the information needed for the study. The purpose of probing was to deepen the response to a question and increase the richness of the collected data. The probing method used was described by De Vos et al. (2011).

1.10.7.3 Contradicting

The researcher modelled further comments by giving a different response from what the participant was saying. For example, they denied the truth to get more information from the participants.

1.10.7.4 Linking

The researcher linked the participant's comments with the information the researcher needed to know for the study by asking questions such as: "Were you saying traditional healers do not disclose what they used to treat epilepsy?"

1.10.7.5 Encouraging

The researcher complemented the participants to give the information wanted in the study, such as praising them for their excellent job in managing PLWE.

1.10.7.6 Showing Understanding and Allowing Time for Elaboration

The researcher complimented the participants that their comments were well





understood and valued and gave them time to elaborate further by saying: "I never thought that way about the condition."

1.10.7.7 Acknowledging

The researcher repeated the participant's answer using different words to indicate that the researcher was paying attention to what had been said.

1.10.7.8 Direct Questions

The researcher kept on asking the participant more questions to get more information needed for the study; the question either came from the interview guide or the participant's response.

1.10.8 Trustworthiness

According to Brink et al. (2018), trustworthiness refers to the employment of procedures to ensure the accuracy of the findings. The methods that the researcher employed to ensure trustworthiness were as follows:

1.10.8.1 Credibility

Brink et al. (2018) alluded that this is a process of meaningful interpretation and truth from the collected data; hence, credibility is measured through the following techniques.

- * Prolonged engagement: the researcher stayed in the community conducting interviews until data saturation was reached.
- ★ Persistent observation: the researcher observed what influenced the participants to seek health from indigenous practices instead of sticking to Western medicines.





- * Triangulation: the researcher ensured credibility by using different data collection methods, which were semi-structured interviews and direct observations.
- * Peer debriefing: data were collected with a colleague who was not involved in the study, but understood the study and could debate each step or the research process with the researcher.
- * Member checks: this was done by going back to each participant to verify data collected from them was not misinterpreted.

1.10.8.2 Transferability

The study's findings could be transferable only if a similar study was done in a population whose geographical background and characteristics were the same as the population under study (Brink et al., 2018). The findings of this study could be transferable, but future researchers have to decide whether they want to apply the findings of the study to other contexts.

1.10.8.3 Confirmability

Confirmability refers to the ability of data to speak what the respondents mean rather than the perceptions of the researcher (Brink et al., 2018). In this study, an experienced supervisor who did not form part of data collection ensured conformability by allowing auditing to be done. The supervisors evaluated the data's accuracy, confirmed the findings, interpretation, and conclusion, and provided feedback on whether additional data needed to be collected.

1.10.8.4 Dependability

Dependability refers to the provision of evidence such that if the study was to be





repeated with similar participants in a similar context, its findings would be similar (Brink et al., 2018). In this study, dependability was ensured by allowing the auditor to review the study's methodology to check if it was adequately presented. The auditor was given the transcribed data for review and verified if any data were not analyzed.

1.10.9 Data Analysis

This is the process of taking raw data and making it significant components of thinking, inductive reasoning and theorizing (De Vos et al., 2011). A thematic analysis was used in this study to assist the researcher in identifying, analyzing, organizing, describing and reporting themes found from the collected data. Creswell (2014) identified six steps to be followed in qualitative data analysis. This study adopted Creswell's (2014) six-step data analysis method:

Step 1: Organize and prepare the data for analysis

The researcher listened to the recorded interview from the audiotape, transcribed, and arranged data from audiotape with the written data.

Step 2: Read or look at data holistically

The data were looked at and read by the researcher entirely, who then made sense out of the gathered evidence, and its meaning was in the form of writing notes or recording general thoughts about the data.

Step 3: Start coding all the data

Coding is the process of organizing data by bracketing chunks thereof and writing a word representing a category in the margins (Rossman and Rallis, 2012). Coding was done using eight steps provided by Tesch (1991) as follows:

1. Make sense of the idea





The researcher read the transcriptions and then wrote their meanings as they appeared in the researcher's mind.

2. Pick one interview

The researcher looked at one interview with stimulating information and read it completely. While reading, the researcher asked herself about the meaning of each of the responses in the interview.

3. Cluster together similar topics

After going through all the interviews and coming up with the meaning of the responses and themes, the researcher put together responses with the same meaning under the same theme.

4. Make a list of themes

A list of themes was made by the author of the research, referred to the transcribed interviews and allocated abbreviations of each code.

5. Find the most descriptive item

The researcher found a descriptive word that appeared in most topics and then organized it in order. This was done to reduce the list of themes.

6. Make a final decision

The researcher made a final decision regarding the abbreviations for every category by coding them alphabetically and arranging the data belonging to the same category. The researcher started to analyze data collected belonging to the same category.

7. Record data

The researcher recorded the analyzed data.





8. Recode data

The researcher recoded the analyzed data, where necessary.

Step 4: Generate a description and themes

The researcher used the coding process to generate a description of the people and the categories or themes for analysis. The researcher wrote information about the setting and the participants under the major themes.

Step 5: Representing the description and theme

The researcher wrote information under the significant themes about what the theme entails, the study's findings and support data by quoting the participants' responses from the interviews.

Step 6: Interpretation of the findings

The researcher wrote about the lessons learned from the study, compared the findings with the information from the literature review, and indicated whether the findings were the same with those of the past research conducted under the same phenomenon.

1.10.10 Ethical Considerations

Ethics refers to moral standards (De Vos et al., 2011). Ethical concerns need to be considered in all research methods and at each research design stage. The following ethical principles were considered throughout the study to ensure the protection of the ethical rights of the participants.

1.10.10.1 Approval to Conduct the Study

Ethical clearance was obtained from the University of Venda Human and Clinical Trials Research Ethics Committee (HCTREC) (Annexure 1) and Mpumalanga and Limpopo Provincial Departments of Health (Annexures 3 and 4). Permission to access villages





was obtained from the Chief, Induna, or Ward counsellors. Participants were provided with Study Information Sheet (Annexure 5) before they signed the Consent Form to indicate their approval to participate in the study (Annexure 6). Ethical clearance protected the researcher and the participants from any harm and exploitation.

1.10.10.2 Informed Consent

The UNIVEN consent form was used (Annexure 6) The information included aspects such as the purpose of the study, potential benefits, voluntary participation, and withdrawal from the study whenever they wanted to do so (Brink et al., 2012). The researcher read the consent form to each participant to enable them to make informed decisions. After the researcher ensured that participants understood the content of the form, the researcher allowed the participants to sign the consent form.

1.10.10.3 Freedom of Choice

According to this principle, a participant has the right to participate in a research study without any form of coercion (Brink et al., 2012). The researcher ensured the freedom of choice of participants by informing them that their participation was voluntary and that they were free to drop out of the study any time they wished to do so.

1.10.10.4 Privacy

It refers to the freedom to determine the time, extent, and general circumstances under which private information is shared with or withheld from others (Burns and Grove, 2011). The interviews were held at a secure location so that respondents were given a choice to withhold any information, which seemed to be too private to share. However, group interviews were affected.

1.10.10.5 Anonymity

In this study, the researcher ensured that the names of participants did not appear in





the research records during the collection of data or the research report (Brink et al., 2012).

1.10.10.6 Freedom from Harm

A participant's has the right to be protected from whatever harm—psychological, social, or physical (Brink et al., 2012). The researcher carefully protected participants from harm by formulating questions so that participants would not be experiencing any form of discomfort and observed the participants during interviews for signs of distress. If signs of distress were observed amongst the participants, the researcher provided time to ask for clarification or complaint.

1.10.10.7 Confidentiality

According to Brink et al., (2012), confidentiality prevents all the data collected during the study from making it accessible to unauthorized people. The researcher ensured confidentiality by keeping all information gathered during the study secret and keeping research documents inaccessible to people who were not involved in the study. No names were written on the analyzed data.

1.10.11 Delimitation

The researcher carried out an analysis of indigenous practices for the management of epilepsy in two provinces, Mpumalanga and Limpopo. The researcher was only allowed to collect data from traditional healers and faith-based healers from 18 years above in the selected communities.

1.10.12 Plan for Dissemination

The researcher disseminated the information by submitting the manuscript for publication in the accredited journal and the library, media such as radio, and presentation at workshops and national and international conferences.





1.11 References

- 1. Ba-Diop, A., Marin, B. and Druet-Cabanac, M. 2014. Epidemiology, Causes, and Treatment of Epilepsy in Sub-Saharan Africa. *Lancet Neurology* 13,1029-44.
- 2. Baker, G.A. 2002. The psychosocial burden of epilepsy: *Epilepsia* 43(6), 26-30.
- 3. Becker, M.H. 1974. The health belief model and personal health behavior. *Health Education Monographs* 2, 324-473.
- 4. Brink, H.I., Van Rensburg, G. and Van der Walt, C. 2012. Fundamentals of research methodology for health care professionals, 3rd edition. Juta and Company (Ltd).
- Brink, H.I, Van Rensburg, G. and Van der Walt, C. 2018. Fundamentals of Research Methodology for Health Care Professionals. 4th edition. Juta and Company (Ltd).
- 6. Burn, N. and Grove, S.K. 2011. Understanding Nursing Research, 5th edition, Philadelphia: Saunders.
- 7. Creswell, J.W. 2014. Research design: Qualitative, quantitative and mixed methods approaches, 4th edition, Thousand Oaks, CA: Sage Publications.
- 8. Creswell, J.W. and Creswell, J.D. 2018. Research design, International student edition, 5th edition, Sage Publications.
- 9. Depoy, E. and Gilson, S. 2008. Evaluation practice: how-to do-good evaluation research in work settings, London, Routledge Taylor and Francis Group.
- De Vos, A.S, Strydom, H, Fouche, C.B. and Delport, C.S.L. 2011. The Research at Grass Roots, for the social sciences and human service professions, 4th edition, Pretoria: Van Schalk.
- Dewa, W. 2012. Non-Attendance of Treatment Review Visits among Epileptic patient in Gokwe South District: Midlands Province Zimbabwe, Harare: College of Health Sciences, Department of Community Medicine, University of Zimbabwe.
- 12. Diop, A.G., De Boer, H.H., Mandlhate, C., Prilipko, L. and Meinardi, H. 2003. The global campaign against epilepsy in Africa. *Acta Tropica* 2003, 87(1), 149-159.
- 13. Glanz, K., Rimer, B.K., and Viswanath, K. 2008. Health Behaviour and Health Education: Theory, Research and Practice (fourth edition), San Francisco: Jossey-Bass.
- 14. Gray, D.E. 2009. Doing research in the real world, 2nd edition, UCT Press.
- 15. Hochbaum, G. 1958. Public Participation in Medical Screening Programs: Sociopsychological. Washington, DC, Government Printing Office.
- International League against Epilepsy/International Bureau for Epilepsy/World Health.
 Organization. 1999. Out of the shadows: Global campaign against epilepsy, ILAE/WHO





- Annual Report, Geneva: WHO.
- 17. Janz, N.K. and Becker, M.H. 1984. The health belief model: A decade later. *Health Education Quaterly* 11(1), 1-47.
- 18. Keikelema, M.J., Hills, R.M., Naidu, C., De Sa, A., and Z Weigenthal, V. 2012. General Practitioners Perceptions on Management of Epilepsy in Primary Care Settings in Cape Town, South Africa. *Epilepsy and Behaviour* 25, 105-109.
- 19. Keikelema, M.J. and Swartz, L., 2016. Perspectives on Epilepsy on the Part of Patients and Cares in a South African Urban Township: Department of Psychology, Stellenbosch University.
- 20. Kija, E. 2015. Traditional healers and the treatment of epilepsy: an African perspective.

 International League Against Epilepsy Newsletter 17(1).
- 21. Kumar, R., 2005, Research methodology: A Step-by-step Guide for Beginners, 2nd ed., Singapore: Pearson Education.
- 22. Laikhen, H.and Mash, R., 2015. Multimorbidity in non-communicable diseases in South African primary healthcare. *South African Medical Journal* 105(2), 134-138.
- 23. Mayosi, B. M. and Benatar, S. R. 2014. Health and health care in South Africa—20 years after Mandela. *New England Journal of Medicine* 371(14), 1344-1353.
- 24. Maree, J.G. 2016. First step in research ,2nd edition., Pretoria: Van Schaik Publisher.
- 25. McQueen, A.H. and Swartz, L. 1995. Reports of the experience of epilepsy in a rural South African village. *Social Science and Medicine* 40(6), 859-865.
- 26. Moselhy, H. 2011. Psychosocial and Cultural Aspects of Epilepsy, Crotia: INTECH.
- 27. Mpofu, E. 2003. Conduct disorder in children: Presentation, treatment options and cultural efficacy in an African setting. *International Journal of Disability, Community and Rehabilitation* 2(1), 44-49.
- 28. Mugumbate, J. and Nyanguru, A. 2013. Measuring the challenges of people with epilepsy in Harare, Zimbabwe. *Neurology Asia* 18(1), 29-33.
- 29. Mutanana, N. 2018. Indigenous Practices for Sustainable Management of Epilepsy in Zimbabwe: A case of epilepsy support foundation Zimbabwe, Chinhoyi University of Technology.
- 30. Newman, P., 2011, Epilepsy in South Sudan, South Sudan Journal 4(4), 86-89.
- 31. Polit, D.F. and Beck, C.T. 2017. Nursing Research: Generating and Assessing Evidence for Nursing Practice, 10th edition. Philadelphia: Lippincott Williams and Wilkins.
- 32. Preux P-M, Druet-Cabanac, M. 2005. Epidemiology and aetiology of epilepsy in sub-Saharan Africa. *Lancet Neurology* 4, 21-31.





- 33. Quintas, R., Raggi, A., Giovannetti, A.M., Pagani, M., Sabariego, C., Cieza, A. and Leonardi, M. 2012. Psychosocial difficulties in people with epilepsy: a systematic review of literature from 2005 until 2010. *Epilepsy and Behavior* 25(1), 60-67.
- 34. Rosenstock, I.M. 1974. Historical origins of the health belief model. *Health Education Monographs* 2(4), 328-335.
- 35. Rossman, G.B., and Rallis, S.F. 2012. Learning in the field: An introduction to qualitative research, 3th edition, Thousand Oaks, CA: Sage.
- 36. Stafford, G.I., Pedersen, M.E., van Staden, J. and Jäger, A.K. 2008. Review on plants with CNS-effects used in traditional South African medicine against mental diseases. *Journal of Ethnopharmacology* 119(3), 513-537.
- 37. Tesch, R. 1990. Qualitative Research: Analysis Types and Software Tools, New York, Falmer Press.
- 38. WHO. 2004. Epilepsy in the WHO Africa Region, Bridging the gap: the global campaign against epilepsy, out of shadows. Geneva: WHO Press.
- 39. Wolf, P. 2010. Sociocultural history of epilepsy, In C.P. Panayiotopoulos (Ed), Atlas of Epilepsies (pp.35-43). London: Springer-Verlag London Limited.
- 40. Zeneden, A.V. 2014. Visualizing the most neglected disease: Mental illness. https://www.humanosphere.org/science/2014/11/visualizing-neglected-diseasemental-illness/.



SECTION 2

MANUSCRIPT 1

2.1 Title: Management of Epilepsy Through Traditional and Western Approaches in Africa: A Systematic Review. Health SA Gesondheid (Under Review)

2.2 Authors and Affiliations

Chabangu Q.¹, Maputle M.S.¹, Lebese R.T.² and Makhado L.³

¹University of Venda, Department of Advanced Nursing Science, Private Bag X5050, Thohoyandou, 0950. Telephone: 015 962 8125, Email: *sonto.maputle@univen.ac.za

²University of Venda, School of Health Research Office, Private Bag X5050, Thohoyandou, 0950. Telephone: 015 962 8125, Email: rachel.lebese@univen.ac.za

³University of Venda, Department of Public Health, Private Bag X5050, Thohoyandou, 0950. Telephone: 015 962 8005, Email: lufuno.makhado@univen.ac.za

Corresponding author: *sonto.maputle@univen.ac.za

2.3 Abstract

Background: The reaction to epilepsy management has been described as moulded by traditional beliefs, despite the reported progress on anti-epilepsy medication. In Africa, traditional healers are perceived to play an essential role in caring for people living with epilepsy (PLWE), yet little is known about their epilepsy care. This work aims to systematically review the various traditional and Western methods of epilepsy management and their effectiveness in Africa.

Design: Qualitative synthesis





Method: A literature search of both qualitative and quantitative studies conducted from year 2000 to date was conducted from PubMed, ScienceDirect, and Google Scholar sites that studied traditional and Western methods of epilepsy management in Africa. The search strategy combined sets of keywords using AND/OR terms which are as follows: traditional methods, Western methods, spiritual healers, traditional healers, epilepsy management, effectiveness, and Africa.

Results: Epilepsy in Africa is managed using two methods: Western and traditional. Most people firmly believe that epilepsy is caused by witchcraft and evil spirits. The only treatment to conquer the evil spirit is through traditional and faith-based healing. Anti-epileptic medications were used, but the perceptions towards epilepsy and inaccessibility make PLWE lose interest in taking medication. African people agree that traditional and spiritual treatments are effective in epilepsy management.

Conclusion: Traditional and faith-based healers are perceived to provide frontline care for PLWE with considerable delays in seeking anti-epilepsy medication initiation. Indigenous and medical practitioners should collaborate in managing epilepsy, and the community should be aware of the availability of both practices.

Keywords: Africa, effectiveness, epilepsy, spiritual healers, traditional healers, traditional epilepsy management, Western epilepsy management

2.4 Introduction

Epilepsy is one of the prevalent non-communicable neurological conditions estimated to affect more than 60 million people worldwide (Dewa, 2012). From a medical perspective, epilepsy is defined as an illness of the brain which is characterized by an event of unpredictable disturbance of the normal function called epileptic seizures (World Health Organization, 2012). However, one should have one or more unprovoked seizures to be diagnosed as epileptic. For many Africans, the response to



epilepsy is made by indigenous beliefs amazingly related to each other one way or the other (Bhalla, Tchalla, Martin, et al., 2014). Africa is a diverse continent that symbolizes people from different cultural backgrounds. Therefore, there is a prevalent belief that epilepsy is a supernatural cause and not correctable with biomedical methods (Bhalla et al., 2014). The author looked at countries such as the Republic of Congo, Zimbabwe, Zambia, Namibia, Gambia, Uganda, Kenya, Tanzania, and South Africa, where epilepsy is believed to be caused by witchcraft, evil spirits, disobeying ancestors, punishment from God, and African magic (Osakwe, Otte and Alo, 2014). It is also thought that epilepsy is a contagious disease that can be transmitted through saliva, urine, blood, and faeces. In India and Nepal, the epilepsy landscape is also shaped by indigenous practices. In management the condition, PLWE end up consulting priests, some wear amulets to ward off evil spirits and some organize special prayers in the hope of a cure, casting anti-spell water for patients to drink and herbal medicine (Khwaya, Signh and Chaudhry, 2007).

However, in Africa, Western anti-epilepsy medications, prayers and herbal medications are commonly used for the management of epilepsy (World Health Organization, 2012). Furthermore, in South Africa, efforts are taken to assist people with epilepsy at government hospitals, clinics, and private hospitals. Despite the *Bring Epilepsy Out of the Shadow Campaign* by World Health Organization and other organizations, studies show fewer uptake of anti-epilepsy drugs (Dewa, 2012). Nevertheless, it has been reported that about 86% of PLWE are not on anti-epilepsy medicine (Epilepsy Support Foundation Zimbabwe, 2016).

Many Africans prefer to use the traditional and spiritual methods to manage epilepsy as they are groomed under certain beliefs (Dewa, 2012). It is further documented that many people firmly believe that epilepsy is linked to a spiritual cause, and about 70.5% of people consult traditional healers and their pastors first (Mohammed and Babikir,



2013). However, PLWE consult biomedical practitioners for assistance at a later stage of the disease, and this causes more complications and delays in managing the condition (Bhalla et al., 2014). The objectives of this review were to explore the different systems of epilepsy management and their effectiveness in Africa.

2.5 Methods

2.5.1 Search Strategy

The authors conducted an electronic search of all published studies regarding the management of epilepsy from different engines. Three electronic databases, namely, PubMed, ScienceDirect, and Google Scholar, was systematically searched to identify relevant studies from the year 2000 to date. Literature was searched by title, abstract, and keywords. The search was done using the following keywords: traditional methods, Western methods, spiritual healers, traditional healers, epilepsy, management, effectiveness, and Africa.

2.5.2 Inclusion and Exclusion Criteria

The authors included studies that documented the management of epilepsy in Africa. All published studies dating 20 years back up to present and focusing on the management of epilepsy in Africa, and written in English with full text are available were included as were both qualitative and quantitative studies. Studies older than 20 years with abstract only, duplications, and unpublished articles were excluded. Manuscripts written in languages other than English were also excluded.

2.5.3 Study Selection

The authors reviewed studies done in Africa from the year 2000 to date by using title and abstract before going through the article. Duplicates and studies that consisted of abstracts only were removed. The overall search yielded 17 927 studies, of which those irrelevant by title, and duplicates were removed. Articles found from Google





Scholar was 17 800, PubMed 20, and ScienceDirect 107. All relevant studies were 31 screened for abstract; 12 studies are excluded after reading their abstracts, and 7 were excluded after a full-text screening. Finally, 12 studies met the criteria and were used (Figure 2.1).

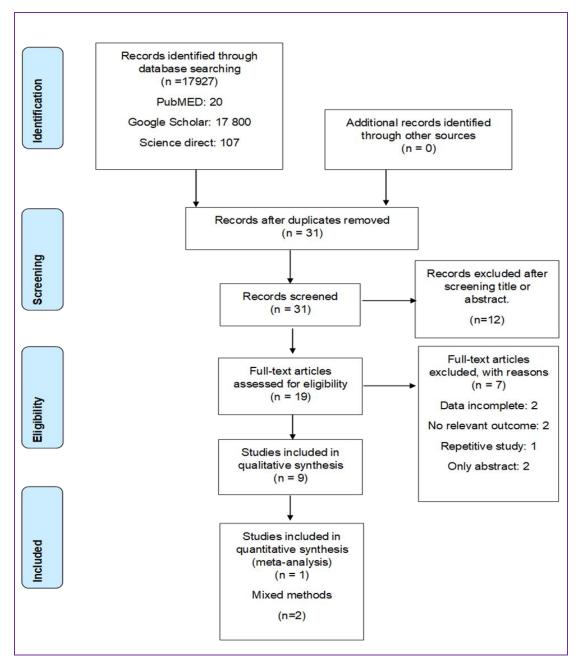


Figure 2.1: PRISMA 2009 flow diagram



2.5.4 Study Appraisal

The current appraisal was done through CASP (Critical Appraisal Skills Programme), a designed checklist that allows the author to check the methodological quality of the study against a fixed set of criteria. The author used the CASP to identify and appraise the included studies (Table 2.1). The skills programme consisted of 10 questions. For each study, the following questions were asked:

- 1. Was there a clear statement of the aims of the study?
- 2. Is a qualitative or quantitative methodology appropriate?
- Were the research designs appropriate to address the aims of the research?
- 4. Was the recruitment strategy appropriate to the aims of the research?
- 5. Was the data collected in a way that addressed the research issue?
- 6. Has the relationship between researcher and participants been adequately considered?
- 7. Have ethical issues been taken into consideration?
- 8. Was the data analysis sufficiently rigorous?
- 9. Is there a clear statement of findings?
- 10. How valuable is the research?

Table 2.2 summarizes the characteristics of the included studies. According to the authors, when the percentages are 80% and above, the study validity is higher. When 70% to 50%, the studies are considered average, and from 49% downward, they are not valuable to be included.





Table 2.1: CASP study appraisal

Author	Title	Designs	%
Anand et al.	Epilepsy and traditional healers in the Republic of Guinea	Qualitative	90%
Keikelema et al.	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	Qualitative	78%
Dolo et al.	Community perceptions of epilepsy and its treatment in an Onchocerciass endemic region in the Ituri Republic of Congo	Qualitative	85%
Mutanana	Indigenous practices for suitable management of epilepsy in Zimbabwe	Mixed method study	92%
Mutanana et al.	Challenges associated with anti-epilepsy medication and use of complementary or alternative medicine among people with epilepsy in rural communities of Zimbabwe	Qualitative	88%
Winker et al.	Attitude towards African traditional medicine and Christian spiritual healing regarding the treatment of epilepsy in a rural community of northern Tanzania	Qualitative	90%
Kendall-Taylor et al.	Comparing characteristics of epilepsy treatment provider on the coast: implication for treatment-seeking and intervention.	Qualitative	87%
Mohammed and Babikir	Traditional and spiritual medicine among Sudanese children with epilepsy	Quantitative	88%
Rutebemberwa et al.	Biomedical drugs and traditional treatment in care- seeking pathways for adults with epilepsy in Masindi District, Western Uganda: A household survey	Qualitative	92%
Coleman et al.	The treatment gap and primary health care for people with epilepsy in rural Gambia	Mixed method	96%
De Toit and Pretorias	Seizure in Namibia: A study of the traditional health practitioner	Qualitative	86%
Baskind and Birbeck	Epilepsy care in Zambia: A study of a traditional healer	Qualitative	78%



Table 2.2: Characteristics of the included studies

Author, Country, Year	Purpose	Design	Sample	Findings	Limitation
Anand et al. Guinea 2019	To characterize the reason, extent, and impact of traditional medicine use among people with epilepsy in the republic of Guinea.	Qualitative	132 people living with epilepsy and caregivers.	Most people in Guinea consult traditional healers as their frontline care for people with epilepsy and seek medical care later in failure of traditional attempts.	No limitation was indicated in the study.
Keikelema and Swartz South Africa 2016	To explore patients' experiences regarding their treatment and care in Cape Town.	Qualitative	Twelve people living with epilepsy were interviewed. Snowball and purposive sampling were used.	Anti-epilepsy drugs are commonly used; however, the health care practitioner's behaviour results in patients losing interest in taking medication.	The study sample was from a small area and cannot be generalized.
Dolo et al. Congo 2018	Investigate the perceptions and experiences regarding epilepsy and its treatment amongst community leaders, PWE, and their families, traditional healers, and health professionals.	Qualitative	A total of 14 focus group discussions involving 60 community leaders. 35 PLWE and their family, six traditional healers, and 39 semi-structured interviews with PLWE, family members, and health professionals.	Epilepsy is treated using anti-epileptic medication (AEM) and traditional treatment using sprays (in the churches), plants (mainly one plant called dodo), incantations (to chase away evil spirits), and bathing in the river.	No limitation.
Mutanana Zimbabwe 2017	Analyze challenges associated with anti-epilepsy medication and use of complementary medicines among people with epilepsy in rural communities in Zimbabwe.	Qualitative	Target populations are people living with epilepsy and their caregivers. Snowball sampling was used to sample 15 people living with epilepsy and 5 caregivers. Purposive sampling was used to sample 2 traditional healers, 2 faith-based healers, and 2 psychiatric nurses.	They consult traditional and faith healers because they are accessible. Participants agree that traditional and spiritual medicines are effective in epilepsy management. They were satisfied with the service received offered by traditional and spiritual healers in the communities of Zimbabwe.	The study suffered from methodological limitations in the sample size. It only focuses on one community.

37



Continued/...

 Table 2.2:
 Characteristics of the included studies (continued)

Author, Country, Year	Purpose	Design	Sample	Findings	Limitation
Zimbabwe Zimbabwe. management of epilepsy in Zimbabwe. methods ide str. Do psi usi tra		A sample of 150 family members, 170 PLWE were identified using proportional stratified random sampling. Doctors, nurses, and psychologists were identified using purposive sampling, and traditional healers, herbalists; Christian healers were identified using snowball sampling.	The findings revealed that people with epilepsy are not on anti-epilepsy treatment and they strongly believe that epilepsy is caused by witchcraft and evil spirit. They think biomedication does not help treat the disease however people with epilepsy have resorted to indigenous practices of epilepsy management. Indigenous practices are very effective in epilepsy management. And biomedication is not helpful.	The study focused on people living with epilepsy who are on treatment and residing in Zimbabwe getting counselling and help from Epilepsy Support Foundation Zimbabwe.	
Winker et al. Tanzania 2009	The prevailing attitude towards traditional medicine for the treatment of epilepsy in a rural area of Northern Tanzania.	Qualitative	167 people were interviewed 59 PLWE, 62 relatives, and 46 villagers.	Many people were convinced that traditional healing methods may successfully cure epilepsy while some thought prayer would cure or treat the causes and symptoms of it.	No limitation was indicated in the study.
Kendall-Taylor et al. Kenya 2009	Examine how treatment seeking may be facilitated or deterred by the characteristic of available treatment options.	Qualitative	8 traditional healers and 12 biomedical health workers were interviewed used convenience and snowball sampling.	Traditional healers were found to be having more influence in the treatment of epilepsy and their medicine differs from the one in the facilities by causation, social role, referral practices, and system of payment.	Lack of data from the individual decision-maker.
Coleman and Wairaven Gambia 2002	To study primary level management for people with epilepsy in rural Gambia using a community survey.	Mixed methods	69 people were surveyed.	According to the study, in Gambia, treatment for epilepsy is very expensive. Therefore, the patient goes for what they afford during a seizure.	No limitation was indicated in the study.

Continued/...



 Table 2.2:
 Characteristics of the included studies (continued)

Author, Country, Year	Purpose	Design	Sample	Findings	Limitation
DuToit and Pretorius Namibia 2018	To gain an understanding of traditional health practitioners, perception, and experience in the delivery seizure in Namibia.	Qualitative	11 traditional health practitioners were interviewed. Thematic was used.	Treatment is based on the causes of the illness rituals, and herbal are prepared through the guidance of the spirit, making the treatment unique to each individual.	With a small sample size of the study, the purpose was to generate depth rather than breadth. The study focused on generating information-rich findings on the perceptions and experiences of THPs in the management of seizures.
Baskind and Birbeck Zambia 2005	To better understand the epilepsy care delivered by traditional healers in Zambia.	Qualitative	Focus group discussion with 10 traditional healers. 4 Physicians and 8 traditional healers were interviewed one on one.	Epilepsy is treated with an antidote comprising the same ingredients used to bewitch the patient, failure to identify the causes lead to treatment failure.	The qualitative method does not seek to find a representative sample of informants.
Rutebemberwa et al Uganda 2020	Identify the health care provider where patients with epilepsy sought care and what treatment they received.	Qualitative	305 households with people living with epilepsy were surveyed using a questionnaire.	The patient seeks treatment from multiple providers, with the public sector attending to the biggest proportion of patients.	No limitations.
Mohammed and Babikir Sudan 2013	To study the impact of spirituality on the explanation of epilepsy aetiology and traditional medicine used in the management of epilepsy in Sudan.	Quantitative	180 caregivers which include 165 mothers, 10 fathers, 2 grandmothers, and 3 relatives.	The population in Sudan uses traditional and spiritual medicine to meet their primary health care because it is accessible and affordable and is part of their belief system.	No limitations.



2.6 Findings

The study aimed to systematically review the various traditional and Western methods of epilepsy management and their effectiveness in Africa. The results were based on the study findings conducted in the Republic of Congo, Zimbabwe, Zambia, Namibia, Gambia, Uganda, Kenya, Tanzania, and South Africa. The management and perception of epilepsy have been found to differ through cultures in Africa. Although the origin and causes of epilepsy remain unknown, an evil spirit is thought to cause epilepsy, still influencing people's perception of epilepsy management (Siriba, 2014). However, the management of epilepsy in public health sectors is affected by several factors such as lack of trained staff in epilepsy, beliefs about epilepsy, unavailability of drugs, and poverty (Eastman, 2005; Williams, Nefdt and Wilmshurst, 2015). In addition, a study in South Africa by Keikelema and Swart (2016) shows that some of the people with epilepsy combine Western and traditional to manage epilepsy. The following themes were identified from raw data: traditional methods of epilepsy management and Western methods of epilepsy management.

2.6.1 Theme 1: Traditional Methods of Epilepsy Management

In this study, a traditional health practitioner is recognized in the community. They provide health care through animals, plants, and other methods that are based on cultural, religious, and social. Traditional methods are diverse, including prayers, herbalists, spiritualists, and diviners (Newton and Garcia, 2012). Traditional health practitioners play an essential role in managing epilepsy in many low and middle-income countries. However, in Africa, traditional healers are one of the primary sources of health care (Newton and Garcia, 2012).

2.6.1.1 Sub-Theme 1.1: Christian Healers

The findings reveal that in Africa, many Christians manage epilepsy by praying as prayer warriors at churches and trying to do away with the demons or evil spirits





(Mutanana, 2018). However, prayers are made unique in African countries, and they are on an emerging indigenous understanding of Christians which is based on the emergent African Pentecostal movement (Mutanana, 2018). Furthermore, Christian healers believe their healing power comes from God and sometimes is a combination of both ancestral and Christian Holy Spirit (Karim, Ziqubu-Page, and Arendse, 1994). Services offered by Christian healers are diagnostic and curative (Truter, 2007). The Christian healers show that they are capable of healing epilepsy, and they have assisted many people through prayers, prophets, and prayed water (Dolo, Mandro, WonyaRossi et al., 2018).

In the West and East Africa, the findings show that the use of religion, prayer, magic, charms, or taboos, and ceremonies to take away spirit is effective. Still, one has to believe in their God (Allah) and follow the procedure and guidelines from Quran (Abdoulie, Kahwa, Abdelgadir et al., 2020). However, the standard spiritual techniques used to manage epilepsy by Sudanese are incantations, spitting curses, and ritual incensing. About 42.5% started consulting Christian healers before seeking medical attention (Mohammed and Babikir, 2013; Abdoulie et al., 2020). Furthermore, results show that PLWE in Zimbabwe seek divine intervention at the churches led by prophet Makandiwa and Magaya (Mutanana, 2018). Some PLWE strongly believe their prophets are healing them, while some suggest that these are hallucinations. Since this disease has been associated with evil spirits, they have no options but to take traditional methods to manage the condition (Mutanana, 2018).

2.6.1.2 Sub-Theme 1.2: Traditional Healers

The findings show that traditional indigenous practices shape epilepsy; these provide frontline care for PLWE (Mutanana, 2017). However, results show that epilepsy can be cured only if the patient has never had fire burns before, while some participants show it is not curable (Mutanana, 2017; Baskind and Birbeck, 2005). Traditional



healers are accessible in Africa; at least one traditional healer in each community compared with only four neurologists for the whole of each country (Pria, Guelngar, Foksouna et al., 2019). According to these findings, people seek help that can be easily accessible; however, there is a shortage of medication in clinics and hospitals. That is why anti-epilepsy drugs are not used by many people (Anand et al., 2019).

In Africa, the management of seizures is unique to each person and is always led by what the spirits tell about the person and the cause of the illness. Each traditional health practitioner employs different ceremonies and herbal preparations during treatment as instructed by the spirit. Other practices include using plant materials, insects, healing prayers, and laying hands. Another type of herbal medicine belongs to the supernatural realm and is only known to traditional healers. Since epilepsy is caused by witchcraft, it is assumed that epilepsy requires some antidote against the poison of witches (De Toit and Pretorias, 2018).

Witchcraft-induced seizures can be cured by treatment with an antidote comprising the same ingredients used in the original witchcraft (Baskind, and Birbeck, 2005). Treatment failures occur when the healer cannot identify and obtain the right ingredients (Baskind, and Birbeck, 2005). Only traditional healers can detect the poison and find the herbal antidote (De Toit and Pretorias, 2018; Winkler, Mayer, Ombay et al., 2010). These herbs grow in specific places and come from immune to evil powers (De Toit and Pretorias, 2018; Winkler et al., 2010). Treatment with these plants is much more expensive compared to ordinary herbal medicine.

In Tanzania, the healer produces powder from roots, barks, and leaves of trees and plants, which are unknown to the receiver, but usually are available at the market for the management of epilepsy (Winkler et al., 2010). Some people described that it is added to porridge or tea, while others reported a topical application, sometimes into



skin lacerations set just for this purpose (Winkler et al., 2010). The healer makes small cuts into the skin of body parts (scarification) that are affected by seizures (Winkler et al., 2010). These cuts are sometimes used as a depot for herbal medicine; in other cases, the scarification itself represents the treatment. Traditional healers explained that bleeding was the cause of epilepsy and whatever nature would leave the patient's body. In most cases, the cuts are set on the head and face but may be found all over the body (Winkler et al., 2010).

Traditional healing in Guinea is classified into two categories: treatment administration during the seizure and preventing and curing epilepsy (Anand et al., 2019). During seizures, traditional healers put garlic, orange, alcohol, or a paste made of grains into the nose or mouth of the seizing person and read Koranic scriptures to end seizures (Anand et al., 2019). Traditional curative healers use the application of talisman (French), gris-gris (malinke) or sebe (susu), and Koranic scripture by rubbing over the body and giving it as a drink to people with epilepsy (Coleman, Loppy and Walraven, 2002). The treatment in Gambia includes reading from the Koran, sometimes written down and sewn into cloth or leather amulets that had to be worn (Coleman, Loppy and Walraven, 2002).

The findings in Zimbabwe indicate that herbalists use herbs known as Mupingangozi (the herbs are found in Mozambique) to manage epilepsy. The herbs are mixed with a cup of boiled water given to people with epilepsy then the seizure will commence releasing the foam. Therefore, the foam has been given to a pigeon which will take the foam and fly away, which will be the end of epilepsy (Mutanana, 2018). Studies revealed that another way herbalists manage epilepsy is that the herbalist wakes in the morning before anyone and takes the grass on the road mixed with cold water then give the patient biting the spoon by the time the spoon is removed, epilepsy will be cured (Mutanana, 2018). Furthermore, Zimbabweans reveal that many communities



believe in traditional practices and consequently resort to traditional and spiritual medicines (Mutanana, 2017). Some studies reported availability and proved that traditional and religious practices are useful in managing epilepsy (Keikelema, and Swart, 2016). Many people in the community showed that they were satisfied with the services offered by traditional healers and religious healers (Keikelema, and Swart, 2016).

Nevertheless, the management by traditional healers has been reported effectively by the communities, and people have a positive attitude towards African epilepsy management because it has to do with their beliefs on epilepsy (Mutanana, 2017). All the healers claimed that seizures are completely healed once they treat a person. Success is measured by the complete absence of seizures as reported by the person (De Toit and Pretorias, 2018). Most people consult traditional healers as their frontline care for patients with epilepsy and delay seeking medical care and anti-epilepsy drug initiation (Anand et al., 2019.

2.6.2 Theme 2: Western Methods of Epilepsy Management

2.6.2.1 Anti-Epilepsy Medication

There are more than 20 prescriptions of anti-epilepsy drugs available in Africa. One option depends on lifestyle, type of seizure, age, and how often the person has a seizure (Federation of Disability Organizations in Mlawi, FEDOMA, 2011). Drug treatment is also given according to the individual's characteristics and the patient's type of seizure (Tuan, 2010). Phenytoin and phenobarbital are the most used anti-epilepsy drugs. Phenobarbital was offered more secure in the country's primary care system (Tuan, 2010). In Africa, phenytoin and phenobarbital are the cheapest, prescribed in 65% to 85% of patients, and considered most effective. However, other anti-epileptic drugs including carbamazepine, valproic acid are also accessible, but are very expensive (World Health Organization, 2012). All medication is widely dispensed



at the pharmacy and health care facilities in Africa.

The anti-epileptic drug has about 60% to 70% efficacy in terms of living freely from seizures (Keikelema and Swartz, 2016). The Patient Education Institution supports anti-epileptic medication that is effective, and about 80% of patients with epilepsy can have seizures controlled with medication. Anti-epilepsy drugs are recommended as less harmful because they are scientifically proven, unlike indigenous practices (Anand, Othon, Sakadi et al., 2019). The African beliefs in the treatment of epilepsy and the side effects of drugs result in the underutilization of anti-epileptic medication. Many people consult African healers first; when African medication fail, they seek health care from Western medicine (Dolo et al., 2018). A study showed that some people with epilepsy use anti-epilepsy medication and indigenous practices, however, some leave anti-epilepsy medication completely for indigenous practices (Mutanana, 2018).

In South Africa, there are efforts to assist PLWE at the government hospitals, clinics, and NGOs such as the Zimbabwe Epilepsy Foundation. However, instead of this effort, there is still low uptake of anti-epilepsy medication (Kendall-Taylor, Kathoni, Rimba and Newton, 2009; Rutebemberwa, Ssemugabo, Tweheyo et al., 2020). Traditional medicine can have an essential role in treating epilepsy when used together with modern approaches.

2.7 Discussion

In Africa, two anti-epilepsy approaches are used, namely, traditional and Western. The traditional approach includes traditional healers, herbalists, pastors, and prophets. Traditional healers are embedded within communities and are instrumental in defining and disseminating beliefs and attitudes regarding illness (Puckree, Mkhize, Mgobhozi and Lin, 2002). The traditional healers are usually more geographically accessible than



Western medical providers (Puckree et al., 2002), and they can communicate more readily with patients and families than the Western medical providers (Baskind and Birbeck, 2005). Regarding epilepsy management, traditional healers use plants and or animals to treat epilepsy while pastors and prophets use oil, holy water, prayers, and sprays to take away the evil spirit. In contrast, Western medical health care practitioners, including nurses and doctors, provide a Western approach. They prescribe anti-epilepsy medication, namely: phenobarbital, phenytoin, carbamazepine, valproic acid, and diazepam, to manage epilepsy. Anti-epilepsy medications are underutilized because of the cost, and they are not easily accessible other communities. It is proven that anti-epilepsy medicines can control seizures. However, there is no proof of evidence on traditional medicine, even though many people still consult traditional healers and Christian healers to manage epilepsy.

There seems limited community health literacy about epilepsy medications and their side effects, as evidenced by defaulting of treatment and consultation of traditional healers for management, especially after noticing the side effects of the medicines. People with epilepsy seek medical health assistance after traditional and Christian healers fail to manage their condition. Even when PLWE can access medical care, they may simultaneously or first seek care from traditional healers.

2.8 Conclusion

PLWE strongly believe that epilepsy is a spiritual issue and treatment should be done through herbs, prayers and many people show that they are more satisfied with the service offered by traditional and spiritual healers. Anti-epilepsy treatment is less used in Africa due to people's perceptions and beliefs have about epilepsy. Before seeking medical care, many consult traditional spiritual healers for epilepsy management.



2.9 Recommendations

Medical practitioners must undergo training in epilepsy management and work hand-in-hand with the indigenous practitioner. Medical practitioners also need to understand the importance of indigenous religious beliefs in epilepsy management. They should consider safe indigenous medicine instead of convincing people to take modern medicine. The traditional practitioner must be trained on biomedication; this will allow indigenous practitioners to understand epilepsy management from the Western perspective, its strength and weakness, and the medical practitioner will understand the strength and weaknesses of the indigenous practitioner. They should tolerate biomedication in epilepsy management instead of convincing people to take indigenous medicine.

2.10 Acknowledgments

The researchers would like to acknowledge all traditional and faith-based healers who participated in this study from Mpumalanga and Limpopo rural villages, and the village headmen who granted permission to conduct the study.

2.11 Authors' Contributions

Q.C. conducted the study and drafting of this manuscript. R.T.L was the co-supervisor and conducted the literature review. M.S.M was the supervisor and edited of the article and L.M who is the project leader, contributed in the finalization of the article.

2.12 Funding

Special thanks for the financial support from the GladAfrica team, GladAfrica Epilepsy Foundation and Research, and Publication Committee of University of Venda.

2.13 Conflict of Interest Statement

The authors declare that they had no financial or personal relationship(s) which may





have inappropriately influenced them in writing this article.

2.14 References

- 1. Abdoulie, E.M., Kahwa, I., Abdelgadir, A.A., Thomas, A. and Ogwang, D.E. (2020). Traditional approach and medical plants in treatment of epilepsy in West and East Africa. *Neuropharmacy Journal* (5); 121-130. DOI:10.37881/1521.
- 2. Anand, P., Othon, G.C., Sakadi, F., Tassiou, N. R., Hamani, A., Bah, A. K., Allaramadji, B.T., Barry, D.N., Vogel, A., Cisse, F.A., Mateen, F.J., and Guinea Epilepsy Project. (2019). Epilepsy and traditional healers in the Republic of Guinea: A mixed methods study. *Epilepsy and Behavior* 92, 276-282.
- 3. Baskind, R. and Birbeck, G. (2005). Epilepsy care in Zambia: A study of traditional healers. *Epilepsia* 46(1): 1121-1126.
- 4. Bhalla, D., Tchalla, A.E., Martin, B., Ngoungou, B.E., Tan, C.T and Preux, P. (2014). Epilepsy: Asia vs. Africa. *Epilepsia* 55(9), 1317-1321.
- 5. Coleman, R., Loppy, L. and Walraven, G. (2002). The treatment gap and primary health care for people with epilepsy in rural Gambia. *World Health Organization* 80, 378-383.
- 6. Dewa, W. (2012). Non-Attendance of Treatment Review Visits among Epileptic Patients in Gokwe South District: Mildrads Province Zimbabwe. Harare: College of Health Sciences, Department of Community Medicine, University of Zimbabwe.
- 7. Dolo, H., Mandro, M., Wonya'Rossi, D., Ngave, F., Fraeyman, J., Siewe, J.N., Suykerbuyk, P. & Colebunders, R. 2018. Community perceptions of epilepsy and its treatment in an onchocerciasis endemic region in Ituri, Democratic Republic of Congo. *Infectious Diseases of Poverty* 7(1), 1-9.
- 8. Du Toit, A. and Pretorias, C. (2018). Seizures in Namibia: A study of traditional health practitioners. *Epilepsia Open* 3(3), 374-382.
- Eastman, R. (2005). Epilepsy in South Africa. Acta Neurological Scandinavica 112(18),
 8-11. https://doi.org/10.1111/j.1600-0404.2005.00501.x
- 10. Epilepsy Support Foundation Zimbabwe (2016). Available from www.esf.org.zw/help.html. Accessed on the 20 September 2021.
- 11. Federation of Disability Organizations in Mlawi (FEDOMA). (2011). The Discourse of Disability, Gowa, Malawi: Fredrick Douglas Institute Prize.
- 12. Karim, A.S.S., Ziqubu-Page., T.T., and Arendse, R. (1994). Bridging the gap: Potential for health care partnership between South Africa Traditional Leaders and biomedical personnel in South. Report of the South Africa Medical Research Council. South Africa Medical.





- Keikelema, M.J. and Swartz, L. (2016). Perspectives on Epilepsy on the Part of Patients and Cares in a South African Urban Township: Department of psychology, (Masters Dissertation). Stellenbosch University.
- Keikelame, M.J. (2015). A thing full of stories: Traditional healers' explanations of epilepsy and perspectives on collaboration with biomedical care in Cape Town. *Transcultural Psychiatry*, 52(5), 659-680.
- 15. Kendall-Taylor, N.H., Kathoni, C., Rimba, K. and Newton, C.R, (2009). 'Comparing characteristics of epilepsy treatment provider on the Kenyan coast: implication for treatment-seeking and intervention.' *Rural and Remote Health* 9:1253 http://www.rrh.org.au.
- 16. Khwaya, G.A., Signh G., and Chaudhry, N. (2007). Epilepsy and religion. *Annals of Indian Academy of Neurology* 10, 165-168.
- 17. Mohammed, I.N. and Babikir, H.E. (2013). Traditional and spiritual medicine among Sudanese children with epilepsy. *Sudanese Journal of Paediatrics* 13(1), 31-37.
- 18. Mutanana, N. (2017). Challenges associated with anti-epilepsy medication and use of complementary or alternative medicines among people with epilepsy in rural communities of Zimbabwe. *Malaysian Journal of Medical and Biological Research* 4(2), 53-60.
- 19. Mutanana, N. (2018). Indigenous Practices for Sustainable Management of Epilepsy in Zimbabwe: A case of epilepsy support foundation Zimbabwe. (Thesis for Doctor of Philosophy Degree in Development Studies). Chinhoyi University of Technology.
- 20. Newton, C.R, and Garcia, H.H. (2012). Epilepsy in poor regions of the world. *Lancet Neurology* 380, 1193-1201.
- 21. Osakwe, C., Otte, M.V. and Alo. C. (2014). Epilepsy prevalence, potential causes, and social beliefs in Ebonyi State and Benue State, Nigeria. *Epilepsy Research* 108, 316-326.
- 22. Puckree, T., Mkhize, M., Mgobhozi, Z. & Lin, J. 2002. African traditional healers: what health care professionals need to know. *International Journal of Rehabilitation Research* 25(4), 247-251.
- 23. Rutebemberwa, E., Ssemugabo, C., Tweheyo, R. et al. (2020). Biomedical drugs and traditional treatment in care-seeking pathways for adults with epilepsy in Masindi district, Western Uganda: a household survey. *BMC Health Service Research* 20, 17. https://doi.org/10.1186/s12913-019-4879-2
- 24. Siriba, R.M. (2014). The experience of people living with epilepsy in Nzhelele, Limpopo. (Masters Dissertation). University of Limpopo. URI: http://hdl.handle.net/10386/1306
- 25. Truter, I. (2007). African traditional healers: Cultural and religious beliefs interwined in





- a holistic way. South African Pharmaceutical Journal 74(08), 12-18.
- Tuan. N. (2010). Epidemiology and Care of Epilepsy in Vietnam. (Masters dissertation).
 Stockholm: Karolinska Institutet.
- 27. Williams, N., Nefdt, W. M., Wilmshurst, J.M. (2015). Epilepsy South Africa: Turning obstacles into true potential. Epilepsy South Africa Western Cape, Cape Town, South Africa. *Epilepsia* 56(2), 184-7. doi: 10.1111/epi.12641
- 28. Winkler, A.S., Mayer, M., Ombay, M., Mathias, B., Schmutzhard, E., and Jilet-Aall, L. (2010), 'Attitudes towards African traditional medicine and Christian spiritual healing regarding treatment of epilepsy in a rural community of Northern Tanzania' *African Journal of Traditional Complementary and Alternative Medicines* 7(2), 162-170.
- 29. World Health Organization (2012). Epilepsy. USA: Fact Sheet Number 999.



SECTION 3

MANUSCRIPT 2

3.1 Title: Exploring Indigenous Practices for Management of Epilepsy by Traditional Healers at Rural Villages of Limpopo and Mpumalanga Provinces

3.2 Authors and Affiliations

Chabangu Q¹, Maputle MS¹ and Lebese RT²

¹University of Venda, Department of Advanced Nursing Science, Private Bag X5050, Thohoyandou, 0950. Telephone: 015 962 8125

²University of Venda, School of Health Research Office, Private Bag X5050, Thohoyandou, 0950. Telephone: 015 962 8125

Corresponding author: Ms Qolile Chabangu, email: chabanguq24@gmail.com

3.3 Abstract

Background: Indigenous approaches to the management of epilepsy were explored amongst the Mpumalanga and Limpopo communities. The purpose of the study was to determine the indigenous practices that were used to manage epilepsy.

Methods: The researchers used a qualitative, ethnographic technique that was exploratory and descriptive. Purposive and snowball sampling were used to select a group of 17 traditional healers for in-depth interviews at their homes. The data were analyzed using Creswell's six processes [1], as well as Tesch's eight phases for creating code [2].





Results: The findings demonstrated that traditional healers have different perspectives on the origins of epilepsy, and their treatment plans are based on their knowledge of the disease. Traditional healers use plants and alternative measures to treat epilepsy, even though Western medicine is still used.

Conclusion: Traditional healers and primary health care providers must work collaboratively to educate communities on the importance of integrating biomedicine and indigenous practices, as traditional healers are a strong inspiration to their communities. Future research should look at the effectiveness of plants and alternative measures used for the treatment of epilepsy.

Keywords: epilepsy, indigenous, management, practices, traditional healers

3.4 Introduction

Epilepsy is a brain illness marked by a recurring and unpredictable interruption of normal function known as an epileptic seizure [3]. To be diagnosed as epileptic, a person must have two or more unprovoked seizures prior to the assessment. The Epilepsy Foundation [4], on the other hand, claims that epilepsy causes the brain to produce aberrant messages, which results in seizures, which can occur because of illness or a head injury. Epilepsy is not regarded a congenital condition in this traditional group, and people with epilepsy are seen as people who practice magic or witchcraft in their communities.

The belief of epilepsy in Central America differs from that of other African cultures [5]. Mexico is a very traditional Central American society, and their religion has not yet been touched by Western culture. Although there is no cure for this illness, it can be helped by utilizing a combination of herbs [5]. Epilepsy is also said to be witchcraft in Spain, as it enters through the nose and head as a wing and lodges in the bones and muscles. It can be managed by eating winged-ants, pigeons, and butterflies that arrive



on rainy days [5]. While, in Brazil, all issues affecting the neurological system, including epilepsy, are claimed to be caused by the spirit of an animal slain by a hunter, no one in this origin hunts animals. However, this ailment can be managed with the use of two plants dissolved in water [5].

On the study of the effects of herbal medicine on epilepsy, Carod Artal and Vazquez-Cabrera [5] found that herbal medical traditions are informed in China, Iran, Europe, and America. Even though herbal medications are radically different from one another, the quality of epilepsy herbs in Chinese traditional herbal medicine is unrivalled in the world of herbalism. While traditional medicine is widely acknowledged and widely utilized in anti-epileptic treatment, there is a lack of proof for its efficacy and toxicity in most cases [6]. When people in Africa aren't feeling well, it's estimated that 80 percent of the population consult traditional healers [7]. Mpumalanga and Limpopo are rural provinces in South Africa, where traditional indigenous methods are used as part of epilepsy treatment, and the majority of epilepsy patients rely on cultural traditions to manage their disease [8].

This study explores traditional healers' indigenous techniques in the care of epilepsy in selected communities in Mpumalanga and Limpopo. Most individuals in these provinces are poor and unable to pay for their medical bills, and the public health system is unable to satisfy all the health needs of persons with epilepsy [9]. The use of indigenous plants and alternative measures for medical reasons has a long history in South Africa. Over the past few years, the public health system has deteriorated, and the lack of a robust biomedical system has necessitated the development of traditional epilepsy therapy. Traditional medication, according to Mayosi [9], is still the most economical and accessible source of epilepsy management for the poor in South Africa's primary health care system.



Furthermore, Mayosi [9] observed that indigenous practices are not adequately documented, and the plants and other alternative measures used to manage epilepsy are not shown. This study explored plants and other alternative measures used for epilepsy management in the selected communities of Mpumalanga and Limpopo provinces to conserve the plants used.

3.5 Materials and Methods

3.5.1 Methods

The researchers employed a descriptive and exploratory qualitative ethnographic research approach to answer the question: "What practices do you use as a traditional healer to diagnose and manage epilepsy?" This design was suited for gathering data in a natural context because it enables the researchers to gain information on the cultural context of the participants [10]. It also allowed participants to discuss their opinions in a secure and private environment [11].

3.5.2 Study Setting

The researchers chose two provinces, namely, Mpumalanga and Limpopo, because of the scant literature available on traditional epilepsy management in these areas. Mpumalanga is in the far east of South Africa, bordered on the north by Limpopo, the east by Mozambique and Swaziland, the west by Gauteng and the Free State, and the south by KwaZulu-Natal. The most widely spoken languages in Mpumalanga are Ndebele, Zulu, Northern-Sotho, Swati, and Tsonga. The following areas were purposely chosen for the research: Acornhoek in Bushbuckridge Municipality, Ehlanzeni District, Clara is in the Bohlabela District of Bushbuckridge Municipality and Jerusalema is in the Ehlanzeni District of Mbombela Local Municipality. Limpopo is a province of South Africa in the far north, bordering Zimbabwe, Botswana, and Mozambique. Limpopo's population comprises primarily rural blacks of the Pedi, Tsonga, and Venda tribes, with a small minority of Afrikaans-speaking whites. Limpopo



is also one of the country's most fertile agricultural regions. The research was conducted in the rural communities of Bochum, Blouberg Local Municipality under Capricorn District, Mtititi Village of Collins Chabane Municipality, Malavuwe, and Nweli of Thulamela Municipality under the Vhembe District. In addition, even fewer studies have been conducted in these locations, even though they do not focus on indigenous traditions for epilepsy healing.

3.5.3 Population and Sampling

The study was conducted in the selected communities of Mpumalanga and Limpopo on traditional healers aged 18 years and above. People less than 18 years of age were excluded from the study. There were around 30 traditional healers practising in the study setting. The sample size was 17 traditional healers who were purposefully recruited. Snowball sampling was also utilized to enlist the help of study participants in locating more potential participants, especially when access to the population was limited for the researcher. From the 30 identified traditional healers included in the sample, some declined, while others younger than 18 didn't meet the inclusion criteria and others were no longer interested in participating.

3.5.4 Ethical Considerations

Ethical standards were ensured by obtaining ethical clearance (Ref: SHS/20/PDC/45/2710) from the University of Venda Ethics Committee. Permission to access the village was gained after receiving ethical clearance from the Chief, Induna, or Ward counsellors, and participants signed consent forms to express approval. The researcher and the participants were safeguarded from injury and exploitation by ethical clearance. Participants gave verbal and written informed consent, and were informed of their right to withdraw from the study without any penalty. Adherence to ethical principles of fairness, privacy, confidentiality, anonymity as well as participants' rights to voluntarily participate was ensured.



3.5.5 Data Collection

The language practitioner created a semi-structured interview guide in English and translated it into the participants' home language. The interview guides were structured from an African traditional point of view: what are contributory causes, diagnosis, and management of epilepsy? The interview guide was used to gather information from 17 traditional healers, which was regarded as an acceptable sample size for in-depth qualitative interviews [12]. The interviews were conducted in the participants' homes as well as telephonically (video calling) and lasted 30 to 60 minutes.

The researchers found no differences between those interviewed at home and those through video call because the researcher was able to sense the participants' emotions, even on the video. The interview responses were convincing and managed to address traditional healers' indigenous practices of epilepsy's origins, diagnosis, management as well as their attitude toward sharing information. All 17 traditional healers were given the opportunity to ask questions at the end of the interview. At the conclusion of each interview, field notes were written.

3.5.6 Data Analysis

The language practitioner transcribed the audio recorded data from the interviews from the participants' native language to English. The first author double-checked each completed transcript for correctness by reading it and listening to the recording. Themes relating to participants' explanations of the causes, diagnostic measures, and treatment and care were identified using thematic analysis. The themes and subthemes were tabulated and categorized into appropriate meanings, and similarities and differences were compared. This study developed four main themes, each with sub-themes.



3.5.7 Trustworthiness

The criteria for ensuring trustworthiness outlined in Guba and Lincoln [13] as cited in Polit and Beck [14] were adhered to. Credibility was ensured through prolonged engagement during data collection. The researcher contacted the participants to make an appointment and to establish rapport before the actual visit for data collection. The researcher spent time with the participants listening and observing them as they were interviewed. The participants were interviewed to the point at which there was data saturation. A member check was also conducted to validate the truth and to confirm the findings. A voice recorder was used to capture data to ensure credibility. Transferability was ensured by thick descriptions of the research methodology. The recorded interviews were transcribed verbatim and the nonverbal cues (for example, silence, sighs, frowns, and leaning back) were included in brackets of the transcripts to ensure authenticity.

3.6 Results and Data Presentation

The demographic profile of the sample for this study comprised of 17 traditional healers. Data were collected from the 17 traditional healers in the selected communities of Limpopo and Mpumalanga. The ages of the traditional healers ranged from 24 to 70 years. Participants were interviewed using their native languages. A traditional healer is a person recognized in the community in which s/he lives as capable of rendering health care using animal, mineral substances, vegetables and several other methods based on social, cultural, and religious backgrounds [8].

In this context, traditional healers are herbalists (they know medications, but did not undergo formal training) and diviners (they are trained). Traditional healers have been regarded to be more significant in the African society in epilepsy management compared to Western-trained psychiatrists. It was thus important to find out their management of epilepsy. The researcher shows how traditional healers manage



epilepsy and their perception about the condition based on the data collected in the selected communities of Mpumalanga and Limpopo. Table 3.1 presents the demographic characteristic of traditional healers.

 Table 3.1:
 Demographic characteristics of traditional healers

Participant	Gender	Marital status	Highest standard	Age	Year started practicing	Qualified traditional health practitioner
1	F	Not married	Grade 5	57	2000	No
2	F	Not married	Grade 2	36	2007	Yes
3	F	Married	Grade 3	61	Just know medication	No
4	F	Married	Grade 7	58	2005	Yes
5	F	Not married	Grade 5	38	2014	Yes
6	F	Not married	Grade 5	45	2001	Yes
7	F	Not married	Grade 4	62	2011	Yes
8	F	Not married	Grade 6	55	2004	Yes
9	F	Not married	Grade 6	67	2007	Yes
10	F	Not married	Grade 3	35	2013	Yes
11	F	Married	Grade 12	47	2009	No
12	F	Married	Grade 5	45	2012	Yes
13	М	Not married	Grade 2	70	Don't remember	No
14	F	Not married	Grade 12	24	2018	Yes
15	М	Married	Grade 5	65	Don't remember	Yes
16	М	Not married	Never attended school	67	2000	Yes
17	F	Married	Grade 3	56	Don't remember	Yes

Presentation of data is done according to themes that are discussed separately.

Table 3.2 illustrates the themes and sub-themes in the context of traditional healers.



Table 3.2: Themes and sub-themes reflecting traditional healers' indigenous practices of managing epilepsy

Themes		Sub-Themes				
1.	Participants' perceptions on the contributory causes of epilepsy	1.1. Physical and environmental factors1.2. Traditional beliefs associated with the occurrence of seizure				
2.	Participants' description of how they diagnose a person with epilepsy	2.1. Observation of occurrence of epileptic seizures2.2. Family history of epileptic condition				
3.	Participants' descriptions of indigenous practices of managing the seizures	3.1. Use of alternative indigenous measures3.2. Working collaboratively with primary health care professionals				
4.	Participants' expression of how they felt about sharing on how they manage the condition information	4.1. Positive attitudes towards sharing treatment information4.2. Negative attitudes towards sharing of treatment information				

3.6.1 Theme 1: Participants' Perceptions on the Contributory Causes of Epilepsy

3.6.1.1 Sub-Theme 1.1: Physical and Environmental Factors

Most traditional healers cited that sharing of equipment such as plates, cups, mats and sharing food at home with someone with epilepsy may result in one contracting the disease. Furthermore, traditional healers claimed that as they heal clients on the road, epilepsy is being left in that place where rituals were performed. Therefore, people passing by the place where rituals are being performed can contract epilepsy. The following quotations depict how the traditional healers view contagious spread as one of the causes of epilepsy.

Epilepsy can be caused by using same cup and plates that are used by epileptic client. P12. Male, 45.

Epilepsy can be caused by many things, firstly staying in a large mat (ecansini) of a person with epilepsy because it's contagious and eating food that was left by person suffering from epilepsy. P11. Female, 47.



Some they passed by a place where they once healed someone with epilepsy then they contract the disease because some remove foam in the mouth when the person was fitting then throw it in the road and they know someone will pass get it. P11. Female, 47.

Findings showed that healers believed that epilepsy is a condition that comes from nowhere and can be generational, that is, one can inherit the condition from the family or great grandparent. It is a condition that is around the family and once it's in the family it cannot be treated. Participants indicated that epilepsy can be passed from mother to offspring during pregnancy and birth, meaning the child can acquire epilepsy via transmission from the mother.

Can be hereditary from one generation to another. P12. Female, 45.

So, with epilepsy, it also depends on whether the person who gave birth to the patient also suffers from epilepsy because if you have epilepsy, you might give birth to a child who suffers from epilepsy. It is just like other illnesses; epilepsy can be inherited. P17. Male, 65.

That illness just comes from nowhere, but in most people its generational. In some it isn't generational, but just the illness itself. There are families that have epilepsy, with those ones; even if we run and do this and that, you can't heal them. P15. Male, 65.

Substance use has been considered to be the causes of epilepsy because it triggers some neurons in the brain that may result in shaking of the body and the management of epilepsy that was caused by substance abuse is through medical treatment traditionally cannot be treated. However, traditional healers mentioned that if they found out that it is substance-triggered epilepsy, then patient is referred to hospital for further management.

I advise the patient to seek treatment from hospital because the body





is used to having drugs. Parents should check if their children are using substances before consulting because it affects the brain we take history regarding substance abuse because it also causes epilepsy. P17. Male, 65.

3.6.1.2 Sub-Theme 1.2: Traditional Beliefs Associated with the Occurrence of Seizure

In this study, participants believed that when someone is suffering from epilepsy, there is a snake in the stomach around the umbilical cord. It is believed that the snake rotates with the moon whereby when the moon is full, seizure occurs. This is perceived as evidence that epilepsy is influenced by the new or full moon.

As you know that seizure comes when there is full moon, there is a snake in the stomach around the umbilical rotate. Ooooh ohk, there is a snake in there when the snake looks down the person doesn't fall when the moon start clocking like a watch the snake awaken and look up then it coughs out a form that comes out when fitting. P12. Female, 45.

I explain again that we must monitor because that thing (meaning seizures) comes when there is a full moon, for others when the full moon has ended. I'd explain again that they must monitor and not just assume it's healed. I'd ask when the person has seizure. Then I'd tell them to monitor then and they would come to me that it's true, there's nothing, I feel nothing. This will mean that the person is healed. P 12. Female, 45.

Participants articulated that epilepsy, even if the history was known, is caused by evil people meaning it was caused by a human being. However, traditional healers indicated that as they can see things of the spirit, they are able to identify whether the condition is caused by evil doing of people or by other factors. Findings showed that healers take history of how epilepsy has started to determine the causes and management of epilepsy is based on how the condition occurred to the patient.



Yes, because even in the past epilepsy and mental illness are caused by evil people. As traditional healers, we can distinguish between epilepsy caused by evil people and one that is not caused by evil people. We take history regarding substance abuse because it also causes epilepsy. P17. Male, 65.

3.6.2 Theme 2: Participants' Description of How They Diagnose a Person with Epilepsy

3.6.2.1 Sub-Theme 2.1: Observation of Occurrence of Epileptic Seizures

Participants reported to have evidenced clients with epilepsy falling and having body stiffness and have proved that even though the client was a child s/he couldn't lift the client up due to stiffness associated with epilepsy. Other participants indicated that they diagnosed epilepsy by seeing the client's rolling eyes change into red and complaining of headache then fall down and sometimes vomit—something that look like a snake. Furthermore, participants saw an epileptic client by falling each and every month more than once resulting in biting of the teeth and foaming at the mouth. Participants expressed how they diagnosed epilepsy in an individual:

The person will fall and become stiff; I was unable to pick him up although he was four years. P1. Female, 57.

A person with epilepsy, you see her fall every month some fall twice, biting teeth, and excreting foam that's when we say this person is suffering from epilepsy. P15. Male, 65.

The person becomes red, have headache, falls down and vomit something that look like a snake. P16. Male, 65.

3.6.2.2 Sub-Theme 2.2: Family History of Epileptic Condition

In the findings, participants reported that in the family epilepsy is a well-known





condition whereby everyone is aware of it and can diagnosed it without any surprises because it is generational. A participant communicated that her child was also suffering from epilepsy, however, a female traditional healer was responsible for healing her child and she taught her how to use the medication and reported good results. As she is a traditional healer as well, she continued with the knowledge provided while seeking help for her child now others are benefiting from the knowledge acquired. This is what the participant said:

My child had a seizure when he was four, now he is 22 years. I went to church and clinic it did not help. My friend told me that her husband was helped by medication from Tzaneen which he started to use. I also went to Tzaneen and started harvesting this medicine. I'm not a traditional healer, I just know this medication and it helps. I treat people as far as Swaziland and my son has never fitted since then. P3. Female, 61.

At home we have this condition in almost all our households. My child was diagnosed by an old lady and gave her the medication to drink. When the old lady died, I started using this medication on others and it helped. I've since graduated as a traditional healer and I'm helping a lot of people. P5. Female, 38.

3.6.3 Theme 3: Participants' Descriptions of Indigenous Practices of Managing the Seizures

3.6.3.1 Sub-Theme 3.1: Use of Alternative Indigenous Measures

Participants pointed out that if the client was brought to them while fitting there are medications (herbs) used to stop fits. The herbs are mixed in a clay pot and the client is urged to inhale it, then the seizure would stop. During seizures, some insert an object that won't be harmful to the client to prevent biting injuries while others mentioned that instead of putting any flat and hard object, they place a table spoon inside the mouth. This is what traditional healers said about the management of epilepsy during seizure:



During seizure, I put ball point in the mouth so that the client does not bite self during the seizure. P6. Female, 45.

Ok ... there are those who come having seizure we start by mixing our medicine in a clay pot for the client to inhale. P14. Female, 24.

When I say its severe, I mean epilepsy can kill the patient at any time because during seizures, there must be someone nearby so that the patient doesn't bite the tongue. P17. Female, 56.

From this analysis, the local people in Limpopo and Mpumalanga have a long history of using indigenous plants for medicinal purpose. Traditional medicine has remained one of the most affordable and accessible sources in the communities. Results clearly showed that participants trusted indigenous medicines even though indigenous knowledge is not adequate. Participants quoted the following:

I give them herbs that I get from the river. I take the roots of 'RINKA' which I grind and soak in water. I give them half a glass of this solution twice a day. Before I give my client, I normally test on myself to ensure that the medication is not harmful. I grind this medicine and if it's a small child I mix with yogurt, for infants I mix with soft porridge and adults I give the one teaspoon three times a day, I also give them this powder to take home. P1. Female, 57.

I use a tree called (**msinsi**) many people don't know it I will show you, it can be found in the forest some they have it in their yard, but they don't know it heals epilepsy. It's a tree with flowers I cut the roots and grate it and boil it until the water changes to yellow, it is taken with soft porridge. P12. Female, 45.

When we treat epilepsy, we prepare steaming using **Tsemo** (traditional herbs). Tsemo is a mixture of different trees. When we prepare steaming, it depends on how the traditional healer treats epilepsy. We make fire until it produces a lot of ashes, then we take



tshidongo and put those ashes together with the herbs. The patient is then covered and then steamed. P17. Female, 56.

We also give **muoluso** for the patient to leak. It's a tree that we use to treat epilepsy, we just burn it then it changes its colour to black. P17. Female, 56.

Participants further cited that management of epilepsy is done procedural wherein armpit hair and nails are cut off and mixed with 'ilihlanga' from the river together with animal product for the client to inhale. Participants refused to provide the name due to some reason. Participants claimed that the entire product is burnt with firewood inside the clay pot and the client inhale the fumes. For the procedure to be success a virgin girl or boy should perform the procedure not everyone qualifies to do so.

The participant has a strong believe that epilepsy is carried in the urine, and travel from the body to the brain causing epileptic seizure. Participants use chicken, urine and water to treat epilepsy because with urine all the waste in the body is excreted through urination. However, it can be noted that participants manage epilepsy by injecting blood from the chicken and human being mixed with urine and water, therefore, the mixture is injected back both into the chicken the human-being. Furthermore, the chicken is also given the mixture by mouth. Proceeding, the chicken is given to someone to throw it away in the forest and never look back on his or her way of coming back because failure to do so, the patient won't be healed.

As a healer I remove the hair (head) armpit hair, pubic hair and nails and mix with animal products that I have which I won't mention and (lihlanga) in the river for the patient to use it to inhale. I will make firewood put my entire product in a clay pot then put on fire let it burn then the client inhale. After inhaling we take (lihlanga) and take the entire product place inside it and close then we look for a child who has not started dating or menstruation and go to the forest to dig a



whole then closed it we instruct the child that after that he/she must go home and not look back. P12. Female, 45.

So, when I treat epilepsy, I use white chicken, we inject the chicken with the patient's blood; we also use his or her urine and mix it with water. The urine carries epilepsy, so we mix herbs and use a razor to inject it to the chicken and the patient. It means that we transfer the patient's illness to the chicken. After that we take the urine and herbs then feed the chicken. It means that the illness is now transferred to the chicken. P17. Female, 56.

Participants associated epilepsy with 'Gonono,' an insect that is found in the bushes because it rolls people feaces and lies in the back making sounds just like when someone is having epileptic seizure.

Yes, sometimes a person who has epilepsy gets ill like **Gonono** (Fly), Sometimes it rolls people's feaces in the bushes. It lies on its back and makes a sound 'Hwiiiiiii...'. So, most healers treat patients with that **gonono** then the patient becomes healed. The gonono is burnt and crushed. Meaning if the traditional healer uses it for treatment, s/he will inject it to the patient so that the patient must not lie on the back like the gonono and we also use it for steaming. P17. Female, 56.

3.6.3.2 Sub-Theme 3.2: Working Collaboratively with Primary Health Care Professionals

Most participants showed interest of working collaboratively with primary health care professionals to manage epilepsy. Hence, the results showed that they refer clients to primary health care first before proceeding with management.

Before starting with treatment, I request that my client go to the clinic to be checked things like blood pressure and sugar. This is to ensure that I don't give my medication on a weak person. P4. Female, 58.



I always advise them not to stop taking treatment from the clinic. P6. Female, 45.

I don't mix with medication from the clinic. P9. Female, 67.

Participants pointed out that they advised those who use traditional medicine for epilepsy to avoid taking liquor, and eat pork and fish because these foods can trigger seizures. At the clinic, health professionals build capacity on risks settings like near fire to avoid burning or near pool to avoid drowning.

A person with epilepsy should not drink liquor, eat pork and fish. P1. Female, 57.

No, I don't know any other methods besides those that I shared. What I know about epilepsy is that the patient should never get burned because when we treat the patient, he or she will not heal. The patient should not sit next to a fire or go to the river because if seizures start while the patient is inside the water he or she will drown and die inside the river. P17. Female, 56.

3.6.4 Theme 4: Participants' Expression of How They Felt About Sharing on How They Manage the Condition Information

3.6.4.1 Sub-Theme 4.1: Positive Attitudes Towards Sharing Treatment Information

Participants didn't see a problem with disclosing the herbs they are using to heal epilepsy with the belief that there are many people who need help out there. Some traditional healers were willing to show the places where the trees are found. That indicates a good attitude toward sharing the knowledge they have. However, the last participant was so confident with the management she uses to treat epilepsy and was not too difficult when sharing the information.

I use RINKA and its working I don't have a problem with sharing





information there are lots of patients to cure. P1. Female, 57.

We don't stay with medicine in the house when you want I can go with you to show you the tree that we use to heal epilepsy. P12. Female, 45.

I use **MSINSI** to treat epilepsy and its working; so far, I have healed 4 clients with the same tree I can go and show you. P12. Female. 45.

3.6.4.2 Sub-Theme 4.2: Negative Attitudes Towards Sharing Treatment Information

Many participants showed negative attitudes when it comes to sharing of treatment. Some mentioned that others will take their customers if they tell them about the tree. Some claimed that the ancestors will get angry when they share information without putting money down.

I can't share my treatment plan and practices with anyone; they are going to steal from me and become more powerful than me. P1. Female, 57.

Medication is always there we know the tree, but we cannot tell anyone unless the client is at the training of becoming a 'sangoma' (traditional healer) because the ancestors would get angry at me if I disclosed such information. P11. Female, 47.

3.7 Discussion

This study's findings were based on an analysis of data gathered from traditional healers. Traditional healers have cited several misconceptions concerning epilepsy, which may impact epilepsy treatment decisions. These misunderstandings are the result of lack of accurate health knowledge and epilepsy training. The participants' perceptions on the contributory causes of epilepsy were physical and environmental



factors and traditional beliefs associated with the occurrence of seizures. Physical and environmental factors included contagious spread, heredity and substance abuse while traditional beliefs include snakes in the stomach that is controlled by the moon and evil spirit, but the majority believe that epilepsy is communicable. As a result, people with epilepsy seek assistance from traditional healers who believed that sharing equipment at home with someone who has the ailment can cause seizures.

Mutanana et al. [8] and Mohammed and Babikir [15] revealed that in some cultures, epilepsy is thought to be contagious or caused by supernatural forces, causing people with epilepsy to be disliked and feared by others, as well as having embarrassment and fear within themselves. Yet the majority believed that epilepsy is also contagious, and it can be spread by saliva, urine, faeces, and blood [16; 17]. The World Health Organization [17] argued that epilepsy is communicable and proves that the causes of the disease are unknown. Yet, structural, genetic, viral, metabolic, and immunological factors all have a role in the condition's onset.

Epilepsy is a condition that occurs when the brain cells are triggered, and enough oxygen cannot reach the brain. Traditional healers often equate heredity with blood-to-blood contact; however, epilepsy could be passed down through the family even if neither parent has suffered from it. Mutanana et al. [18] reported that traditional healers attributed epilepsy to genetics. Inheritance was also mentioned as a source of epilepsy, implying that there are families who suffer from this ailment and cannot be treated since it runs in the family.

According to Mutanana et al. [18], epilepsy can be passed down through the generations via the ancestral spirit, and this can occur because of unfulfilled desires. Not only that, epilepsy is a condition that is passed down from parents to offspring and is caused by blood transmission. If you inherit wealth from someone who has epilepsy,



you will also have it [17]. There are other mental illnesses, like schizophrenia, that can be triggered by substance abuse. As a result, epilepsy is similar to other mental illnesses in that it starts in the brain and goes off-centre where massages are sent into the brain, resulting in seizures. Some traditional healers associate epilepsy with a snake that is controlled by the moon, however, a snake is a reptile that is not designed to live in the stomach, so it is unbelievable that others believe that it can live in someone's stomach.

Anderson [19] supported that epilepsy is thought to be induced by an insect travelling about inside the stomach. According to Jilek [20], a link between the phase of the midday and convulsive episodes has been made since ancient times, and it is still believed. Epilepsy is also thought to be caused by a bad spirit, and the only way to treat it is to consult traditional healers, who are thought to be doctors who can detect things from the spirit through their ancestors, as supported by Deegbe [21], De Graft, Aikins et al. [22] and Osakwe, Otte and Alo [22]. The study findings discovered that the majority of participants strongly believe epilepsy is linked to a spiritual cause. An evil spirit can be created by a jealous person, but in some cases, it is claimed that the patient has a calling to be a traditional healer, and the consequence is a seizure to make the calling known.

Most patients had epilepsy seizures, as evidenced by their falling, rolling eyes, trembling, and excreting foam from the mouth. Traditional healers' associate epilepsy with the insect called 'gonono,' — in Tshivenda culture a bush bug that rolls human feces. The perceptions of symptoms were similar to the Western presentation. According to Keikelema [24], epilepsy is a 'thing' that occurs inside the body and is characterized by jerking of the body, turning of the eyes, foaming from the mouth, stiffness of the fingers, urination, and loss of consciousness. Nonetheless, Mutanana [8] claim that epilepsy is characterized by a sudden fall, limb movement, and saliva



ejection from the mouth. Furthermore, epilepsy is referred to as a falling or fitting condition since patients with epilepsy shake and fall [25]. Moreover, the most serious attack occurs when one collapses to the ground like a corpse [5]. Most traditional healers feel that the insect 'gonono' is the proper insect for curing epilepsy. However, the usage of 'gonono' may be risky because it is not documented or established, but traditional healers have a lot of faith in it and have a lot of influence in the communities. It is apparent that the communities of Mpumalanga and Limpopo are adopting these methods to manage epilepsy.

While a patient is having a seizure, placing a flat artifact like a spoon in the patient's mouth has been identified as one of the most often used ways for supporting the patient in seizure management. These non-pharmacological strategies for assistance during seizures should be taught to the public. People should be informed and empowered with strategies to prevent patient injury because epilepsy can strike at any time, thus having knowledge makes it easier for people to adjust to the disease and decreases the risk of stigma. Anand et al. [26] explained other management approaches by traditional healers, for example, to insert garlic, orange, wine, or a paste formed of grains into the seizuring person's nose or mouth and read Koranic text to stop seizures.

Plants have been found to be the most employed by traditional healers in Mpumalanga and Limpopo to treat epilepsy. The researchers identified plants like *Rinka, msinsi, tsemo, and muoluso* used in epilepsy care, but its effectiveness still need to be determined. In the study, traditional healers claimed to be using the roots of '*Rinka*' which is ground and soaked with water, then half a cup is drunk twice a day. In the case of a child, the medication is given with yoghurt to stimulate a pleasant taste. Nevertheless, other participants indicated that they use '*msinsi*' (traditional herbs) as their medication it is grated and boiled until it changes colour to yellow. Participants



indicated that they use 'tsemo', a traditional herb used by the Venda tribe, a mixture of various trees. The herbs are used for steaming. However, results showed that steaming depends on traditional healers used to manage epilepsy. Fire is made and ashes produces are placed in a clay pot called tshidogo, and together, all the product and the patient are covered with blanket and steamed. The traditional healer claimed to use 'muoluso' a burnt tree, and it changes its colour to black. Therefore, the patient leaks the medication.

The plants are blended with water or burnt to inhale the fumes, depending on how the traditional healer employs them. The most difficult aspect of treating epilepsy with traditional healers is that the plants are only known by them. They do not share this information because they are discreet, assuming that they will do their job and make more money. Carod Artal et al. [5] reported the usage of two plants in combination to cure epilepsy. The plants are dried and worn grains and the seeds of both plants are mixed and diluted in cold water every day for two weeks. In Brazil, epilepsy is managed with two plants whose roots are crushed and diluted with cold water for four hours before being put into the client's eyes many times for three days [5].

Chicken has been the most widely utilized livestock in conjunction with the body's excretion, which is urine, in the treatment of epilepsy. Using the same product to inject chicken and human bodies may be harmful because the chicken is thrown away afterwards, and others may take the chicken and eat it, increasing the risk of infection. However, the process has the potential to infect humans. People with epilepsy have a small possibility of being healed because the procedure appears to be challenging to follow as described. Traditional healers cited situations to avoid when having epilepsy; fire burns, lengthy walks on the road alone, playing near the river, fish, and pork are all things that put persons with epilepsy at risk. During the therapy period, the client is not allowed to eat monkeys or any form of fish; only after he has been treated is he



allowed to eat these forbidden foods [5]. Furthermore, animal spirits can cause seizures; however, depending on the person's societal or religious beliefs, these animals can be a jaguar, a puma, or a sparrow hawk, among other creatures [5].

Collaboration with health professionals is valued. Some ttaditional healers work well with the primary health care system because they send patients to the hospital for screening and confirmation of other diseases before starting therapy, while others are confident in their treatment and believe they can manage the condition without it. Traditional healers who believe they don't need help have a high risk of misdiagnosing because persons with high fevers can have seizures if they aren't treated. Traditional healers should be involved in the management of epilepsy so that knowledge about the cause of epilepsy can be shared and misconceptions reduced, as they are the community's main influence.

According to Keikelema [25], most traditional healers supported collaboration with primary health care providers and gave techniques for doing so. Traditional healers, he continued, are eager to initiate recommendations between the two systems, but this hasn't been possible due to a lack of acknowledgement. However, numerous obstacles remain in the way of collaboration in the health care system, such as the fact that traditional healers' sick certificates are not accepted [27]. On the other hand, it underlines the importance of formal agreements that include freedom of expression and respect for traditional healers' and primary health care professionals' knowledge [25; 28]. Peltzer [28] observed that few patients are referred to traditional healers from the primary health care system even in circumstances where traditional medicines have benefits. According to Yang [29], indigenous practices can be developed and integrated. Findings show that only a few traditional healers have a positive attitude toward sharing their information, evidenced by when they mentioned plants that can be used to treat epilepsy. In contrast, the majority has a negative attitude toward



sharing information because they do not want their information to be used by medical practitioners.

3.8 Conclusion

In both provinces, plants and alternative measures such as livestock and insects are used to treat PLWE. Their perceptions and misconceptions about epilepsy are similar in both provinces. Nevertheless, many collaborate well with primary health professionals, yet few do not believe in in-hospital treatment. Traditional healers indicated that even though biomedical practitioners are not cooperating, they are willing to work with them. Indigenous practices should be taken into the consideration by the health system as well.

3.9 Conflict of Interest

The authors declare no conflict of interest.

3.10 Acknowledgements

To all participants, thanks for their valuable contribution to this study. GladAfrica Epilepsy Research Project (GERP) generously funded the study. Thanks to the person who helped translate the interview question into the participants' native language.

3.11 References

- 1. Creswell, J.W. 2014. Research design: Qualitative, quantitative and mixed methods approaches, 4th edition, Thousand Oaks, CA: Sage Publications.
- 2. Tesch, R. 1990. Qualitative Research: Analysis Types and Software Tools, New York, Falmer Press.
- 3. World Health Organization. Epilepsy. USA: Fact Sheet Number 999.
- 4. Epilepsy Foundation. *Revised classification of seizures*. Retrieved march 2017 from www.epilepsy.com.
- 5. Carod-Artal FJ, Vázquez-Cabrera CB. An anthropological study about epilepsy in native tribes from Central and South America. *Epilepsia*. 2007 May;48(5):886-93.





- 6. Liu W, Ge T, Pan Z, Leng Y, Lv J, Li B. The effects of herbal medicine on epilepsy. Oncotarget. 2017 Jul 18;8(29):48385.
- 7. Stafford GI, Pedersen ME, van Staden J, Jäger AK. Review on plants with CNS-effects used in traditional South African medicine against mental diseases. *Journal of Ethnopharmacology*. 2008 Oct 28;119(3):513-37.
- 8. Mutanana N. Indigenous Practices for Sustainable Management of Epilepsy in Zimbabwe: A Case of Epilepsy Support Foundation Zimbabwe (Doctoral dissertation, Chinhoyi University of Technology).
- 9. Mayosi BM, Benatar SR. Health and health care in South Africa—20 years after Mandela. *New England Journal of Medicine*. 2014 Oct 2;371(14):1344-53.
- 10. De Vos AS. Research at grass roots: For the social science and human service professions. Pretoria: Van Schaik. Denzin, NK and Lincoln, YS (2011).
- 11. Gray, D.E., Doing research in the real world, 2nd edition, UCT press. 2009.
- 12. Silverman D. Doing qualitative research: A practical handbook. Sage; 2013 Apr 22.
- 13. Lincoln, Y.S. & Guba, E.G. Naturalistic inquiry, 1985. Newbury Park: CA, Sage Publications.
- 14. Polit, D.F. and Beck, C.T. Nursing Research: Generating and Assessing Evidence for Nursing Practice, 2017. 10th edition. Philadelphia: Lippincott Williams and Wilkins.
- 15. Mohammed IN, Babikir HE. Traditional and spiritual medicine among Sudanese children with epilepsy. *Sudanese Journal of Paediatrics*. 2013;13(1):31.
- 16. Ekeh BC, Ekrikpo UE. The knowledge, attitude, and perception towards epilepsy amongst medical students in Uyo, Southern Nigeria. *Advances in Medicine*. 2015 Mar 31;2015.
- 17. World Health Organization. World Health Organization annual report 2019 WHO Country Office Lebanon: health for all.
- 18. Mutanana N. Challenges associated with anti-epilepsy medication and use of complementary or alternative medicines among people with epilepsy in rural communities of Zimbabwe. Malaysian Journal of Medical and Biological Research. 2019 Dec 31;6(2):77-84.
- 19. Anderson J, Hamandi K. Understanding juvenile myoclonic epilepsy: contributions from neuroimaging. *Epilepsy Research*. 2011 May 1;94(3):127-37.
- 20. Jilek WG, Jilek-Aall LM. The problem of epilepsy in a rural Tanzanian tribe. *The African Journal of Medical Sciences*. 1970 Jul 1;1(3):305-7.
- 21. Deegbe DA. Experiences of people living with epilepsy in the Accra Metropolis (Doctoral dissertation, University of Ghana).





- 22. de Graft Aikins A, Anum A, Agyemang C, Addo J, Ogedegbe O. Lay representations of chronic diseases in Ghana: implications for primary prevention. *Ghana Medical Journal*. 2012;46(2):59-68.
- 23. Osakwe C, Otte WM, Alo C. Epilepsy prevalence, potential causes and social beliefs in Ebonyi State and Benue State, Nigeria. *Epilepsy Research*. 2014 Feb 1;108(2):316-26.
- 24. Keikelame MJ, Swartz L. 'A thing full of stories': Traditional healers' explanations of epilepsy and perspectives on collaboration with biomedical health care in Cape Town. *Transcultural Psychiatry.* 2015 Oct;52(5):659-80.
- 25. Keikelame MJ, Swartz L. Lost opportunities to improve health literacy: observations in a chronic illness clinic providing care for patients with epilepsy in Cape Town South Africa. *Epilepsy and Behavior*. 2013 Jan 1;26(1):36-41.
- 26. Anand P, Othon GC, Sakadi F, Tassiou NR, Hamani AB, Bah AK, Allaramadji BT, Barry DN, Vogel A, Cisse FA, Mateen FJ. Epilepsy and traditional healers in the Republic of Guinea: A mixed methods study. *Epilepsy and Behavior*. 2019 Mar 1;92:276-82.
- 27. Janse Van Rensburg K, Taylor A, Hodgson T, Benattayallah A. Acute exercise modulates cigarette cravings and brain activation in response to smoking-related images: an fMRI study. *Psychopharmacology*. 2009 Apr;203(3):589-98.
- 28. Peltzer K. Perceptions of epilepsy among black students at a university in South Africa. *Curationis*. 2001 Sep 28;24(2):62-7.
- Yang KS. Monocultural and cross-cultural indigenous approaches: The royal road to the development of a balanced global psychology. Asian Journal of Social Psychology. 2000 Dec;3(3):241-63.



SECTION 4

MANUSCRIPT 3

4.1 Title: Faith-Based Healers' Understanding of Epilepsy Management in Rural Villages of South Africa

4.2 Authors and Affiliations

Chabangu Q.1, Maputle M.S.1 and Lebese R.T.2

¹University of Venda, Department of Advanced Nursing Science, Private Bag X5050, Thohoyandou, 0950, Telephone: 015 962 8125

²University of Venda, School of Health Research Office, Private Bag X5050, Thohoyandou, 0950. Telephone: 015 962 8125

4.3 Abstract

Background: The purpose of the study was to explore faith-based healers' understanding of epilepsy management in rural villages of South Africa. t

Objective: Explore the indigenous practices that faith-based healers use to manage epilepsy in the selected villages of Mpumalanga and Limpopo provinces of South Africa.

Methods: The researcher used a qualitative, ethnographic approach that was explorative and descriptive. For in-depth interviews, purposive and snowball sampling were used to identify faith-based healers. The data were analyzed using Cresswell's six processes and Tesch's eight-phases of qualitative data analysis for generating codes.





Results: The findings revealed that faith-based healers in the selected villages of Mpumalanga and Limpopo provinces make use of prayer and light ultramel tea to manage epilepsy; however, collaboration with biomedication is considered by most, but few primary health care providers collaborate with traditional healers.

Conclusion: Faith-based healers, traditional healers and primary health care providers must be educated on the importance of integrating prayer, the use of herbal medicine and biomedication for them to refer from one to another in case one treatment proves ineffective for the client.

Keywords: epilepsy, indigenous practices, management, faith-based healers

4.4 Introduction

Epilepsy is a brain disorder categorized by a recurrence of unpredictable disturbances of normal function, known as epileptic seizures, treated with anti-epilepsy drugs [1, 2, 3]. It is a major public health issue that affects approximately 50 million people worldwide, with 80% of those affected living in resource-poor countries. The condition is regarded by Western health care providers as a mental illness. However, in the traditional African perspective, it is related to spirituality [4, 5, 6]. People's attitudes, knowledge about the illness and treatment are affected by a combination of factors, including culture and religion [7].

Religious beliefs can have a favourable impact on health when they serve as a source of inspiration, or they can have a negative impact when they are associated with guilt and punishment [7]. In India, epilepsy is influenced by religious beliefs, such as the perception that epilepsy is caused by spirit possession. As a result, some people seek the advice of a priest, some wear amulets to ward off evil spirits, and others organize specific prayers in the hopes of finding a cure [8]. Traditional epilepsy care is practised by all Hindu and Buddhist castes in Nepal [9] who do house calls to treat patents.



Furthermore, in African countries such as Nigeria, Sudan, Ghana, and South Africa, there is a strong belief in African medicine and that epilepsy is linked to spiritual causes and witchcraft [6, 10]. There is a grave social stigma attached to epilepsy, with some people believing that it is a contagious disease transmitted by insects, saliva and touching someone living with epilepsy [3, 11]. Although biomedication is available, spiritual medicines are preferred in these countries. According to a study conducted by Mutanana [12] in Zimbabwe, anti-epilepsy drugs are associated with several challenges in rural communities. People are not educated about the drugs' side effects, so people with epilepsy use spiritual medicine.

According to Bhala [13], the African epilepsy treatment rationale is influenced by indigenous beliefs. Some studies have reported that modern treatment is sometimes unavailable and that there is a widespread indication that epilepsy is spiritual, but not treatable by anti-epilepsy drugs. People with epilepsy have resorted to indigenous practices for epilepsy management, and faith-based healing plays an essential role in epilepsy globally. They do, however, use a variety of indigenous practices, such as prayers, pastors, and prophets. Furthermore, despite these differences in traditional practices, faith-based healers are the most commonly employed method among patients with epilepsy, followed by prayers [14]. According to Mutanana and Dolo [11,14], some people use indigenous methods to supplement biomedicine.

According to Mohammed and Babikir [15], in Mpumalanga and Limpopo, people believe epilepsy is a contagious and untreatable disorder. People living with epilepsy use spiritual healing to manage their condition, whereas few use it as anti-epilepsy medication. According to Mohammed and Babikir [15], in South Africa, people first attempted spirituality before turning to biomedical approaches; others believed spiritual management was effective in treating epilepsy. Little is known about how faith-based healers manage epilepsy in rural villages of the selected provinces. The study aimed



to explore the indigenous practices used by faith-based healers to diagnose and manage epilepsy in the selected communities of Mpumalanga and Limpopo provices.

4.5 Material and Methods

4.5.1 Study Setting

The researcher chose rural villages in two provinces, Mpumalanga and Limpopo, as there was little literature available about religious or spiritual epilepsy management in these areas. Mpumalanga is in the far east of South Africa, bordered on the north by Limpopo, the east by Mozambique and Swaziland, the west by Gauteng and the Free State, and the south by KwaZulu-Natal. The most widely spoken languages in Mpumalanga are Ndebele, Zulu, Northern-Sotho, Swati, and Tsonga. The following areas were purposely chosen for the research: Acornhoek in Bushbuckridge Municipality, Ehlanzeni District, Clara is in the Bohlabela District of Bushbuckridge Municipality, and Jerusalem is in the Ehlanzeni District of Mbombela Local Municipality.

Limpopo is a province of South Africa in the far north, bordering Zimbabwe, Botswana, and Mozambique. Limpopo's population is primarily rural blacks of the Pedi, Tsonga, and Venda tribes, with a small minority of white Afrikaans speakers. Limpopo is also one of the country's most fertile agricultural regions. The research was conducted in the rural communities of Bochum, Blouberg Local Municipality, and Capricon District, Thulamela, Malavuwe Vhembe District, Local Municipality, Vhembe District Mtititi Thulamela Local Municipality. In addition, fewer studies were conducted in these locations, even though they do not focus on indigenous traditions for epilepsy healing.

4.5.2 Methods

The researchers employed a descriptive and exploratory qualitative ethnographic research approach to answer the question: "What practices do you use as faith-based





healers to diagnose and manage epilepsy?" This design was suited for gathering data in a natural context because it enables the researcher to gain information on the cultural context of the participants [16]. It also allowed participants to discuss their opinions in a secure and private environment [17].

4.5.3 Population and Sampling

The population comprised of faith-based healers who were providing spiritual care. Thirty faith-based healers were practising in the study setting. Purposive non-probability snowball sampling was utilized to sample study participants. Inclusion criteria included that participants must be 18 years and above and have agreed to participate in the study. Those younger than 18 years of age were excluded. The number of participants who agreed to participate was seven (7). This was regarded an acceptable sample size for in-depth qualitative interviews [18].

4.5.4 Ethical Considerations

Ethical standards were ensured by obtaining the ethical clearance (Ref: SHS/20/PDC/45/2710), from the University of Venda Ethics Committee. Permission to access the village was gained after receiving ethical clearance from the Chief, Induna, or Ward counsellors, and participants signed consent forms to express approval. Ethical clearance safeguarded the researcher and the participants from injury and exploitation. Participants gave verbal and written informed consent and were informed of their right to withdraw from the study without any penalty. Adherence to ethical principles of fairness, privacy, confidentiality, anonymity as well as participants' rights to voluntarily participate was ensured.

4.5.5 Data Collection

The interview guide was used to gather information from 7 faith-based healers. The language practitioner created a semi-structured interview guide in English and



translated it into the participants' language. The interview guides were "faith-based healers' points of view" with a focus on "What are contributory causes, diagnosis, and management of epilepsy?". The interviews were conducted in the participants' homes and lasted 30 to 45 minutes. The interview responses were convincing and managed to address faith-based healers' indigenous practices of epilepsy's origins and diagnosis, management, and attitude toward sharing information. All seven traditional healers were allowed to ask questions at the end of the interview. After each interview, field notes were written. Data saturation was reached with the sixth participant, but the researchers interviewed the seventh participant as well.

4.5.6 Data Analysis

The language practitioner transcribed the audio-recorded data from the participants' native language to English. The first author double-checked each completed transcript for correctness by reading it and listening to the recording. The participants' explanations of the contributory causes, diagnostic measures, and management were identified. Three themes that emanated from the qualitative data analysis were categorized into appropriate meanings, and similarities and differences compared.

4.5.7 Trustworthiness

As outlined in Guba and Lincoln cited in Polit and Beck [19], the criteria for ensuring trustworthiness were adhered to. Credibility was ensured through prolonged engagement during data collection. The researcher contacted the participant to make an appointment and to establish rapport before the actual visit for data collection. During the interviews, the researcher spent time with the participants listening and observing them as they were interviewed. The participants were interviewed to the point at which there was data saturation. A member check was also conducted to validate the truth and to confirm the findings. A voice recorder was used to capture data to ensure credibility. Thick descriptions of research methodology ensured



transferability. The recorded interviews were transcribed verbatim, and the nonverbal cues (for example, silence, sighs, frowns, and leaning back) were included in brackets of the transcripts to ensure authenticity.

4.6 Results and Data Presentation

There were seven people in this study's demographic profile (Table 4.1). Data were gathered from seven pastors in Limpopo and Mpumalanga communities. The participants ranged in age from 30 to 70 years old. Participants were interviewed in their original language.

 Table 4.1:
 Demographic characteristic of faith-based healers

Participants	Gender	Highest standard passed	Marital status	Age in Years	Year started being a pastor	Qualified faith- based healer	Churches
1	М	Grade 12	Married	42	2010	Yes	Nazarene Church
2	М	Grade 12	Married	70	1998	Yes	Lutherine Church
3	М	Grade 12	Married	42	1999	Yes	Royal Grace
4	F	Grade 12	Divorced	32	2017	No	Faith Devine Ministry
5	F	Grade 12	Married	55	2007	No	Zion Christian Church
6	М	Grade 12	Married	42	2012	Yes	Assemblies of God
7	M	Grade 8	Married	45	2010	Yes	New Life Gospel

Data are presented using themes that emerged, namely: perceived contributory causes, the practices to diagnose and the indigenous management of epilepsy.



4.6.1 Theme 1: Participants' Perceptions of the Cause of Epilepsy

In the individual interviews, participants were asked: "What do you think are the contributory causes of epilepsy?" According to the participants, the aetiology of epilepsy was explained culturally and medically. Some participants thought that epilepsy is caused by an evil spirit bewitchment, witchcraft, or black magic. Nevertheless, as a result of the information they have received about the ailment, some have accepted Western perspectives on the origins of epilepsy, which include faulty electrical connections in the brain or it is not an inborn disorder, but rather develops over time as the patient grows.

Participants' thoughts on the evil spirit as a cause of epilepsy were as follows:

According to my understanding, this condition looks like a spiritual attack, because a person is born normal and suddenly develops fits and parents would see their child grow but unfortunately cannot detect it at early age. Participant 1. Male, 42.

Epilepsy is just a spirit that the devil uses to people or is when the person is bewitched due to jealousy. Types of a spirit I believe those spirit are hereditary, taking it from ancestors and it is passed on from one generation to another. Participant 2. Male, 70.

According to the study results, the participants were aware of no exact perceived causes of epilepsy. Still, some perceived that epilepsy is a condition produced by an imbalance of muscles in the spinal cord that leads to a failure of communication between the brain and body, resulting in falls and shaking of the body. The participants cited:

I have no research on the causes of epilepsy, but according to me, it has to do with the muscles that balance the spinal and when communication with the brain and body disappear that may cause



one to lose balance then fall. Participant 2. Male, 70.

Some of them it's due to accident ... he did bang his brain and the leakage goes in his brain. It's where the nerve started to shake. Participant 3, Male, 42.

There is a bubble in the lungs that produces dizziness and fits, which is known as epilepsy. As a result, fresh milk enters the lungs, collects everything, and then travels to the brain, where the individual vomits the bubble, which is visible. Participant 5. Female, 55.

4.6.2 Theme 2: Participants' Description of How They Diagnosed Epilepsy

One participant had a deceased sibling who had been diagnosed with epilepsy and had died as a result of the ailment, which doctors at the hospital confirmed. Since birth, he had been caring for him until he developed epilepsy at the age of four when he learned about the ailment. This is what the client had to say:

According to my judgement, epilepsy is a chronic condition even the hospital failed to heal it completely. I had a brother who died of this condition we tried all the ways to get help but it couldn't work. Participant 1. Male, 70.

History from the patient guides the diagnosis. Participants explained certain warning signals prior to a seizure that their patients reported. This seemed to refer to an aura. Some patients experience "funny feeling in the stomach", "a sharp, throbbing headache", "dizziness" or "an ugly cry".

You see ... this thing is full of stories because sometimes while the patient is sitting like this ... enjoying him/herself then suddenly s/he falls. Patient 6. Male, 42.





4.6.3 Theme 3: Participants' Descriptions of the Different Ways of Managing Seizures

Based on data obtained in selected villages in Mpumalanga and Limpopo, the researchers deduced different perspectives on the condition and management of epilepsy. Participants stated that their clients had arrived at their consultations in a stable state, but if they started to fit, they put an object in their mouth to prevent injuries. As a result, the management of epilepsy during seizures is similar; the differences begin when others use herbs or holy water. Participants have the following to say on seizure management:

When PLWE falls, I her/him in a safe position so that he or she doesn't bite the tongue. if possible, I put something in the mouth to avoid injuries. Participant 5. Female, 55.

We [faith-based healers] have different ways of helping since it comes in different ways you must first search ... How did it enter and how did you get it? Is there a certain foreign body disturbing him/her that is going up his back or it's in the brain or he was fed something inside? You must try and get that thing out by making a person vomit. When that thing is out, he will be able to live and become right ... We give him holly water and pray that will make a patient powerful ... We stretch his muscles ... We then refer to the doctor so that he can check this thing in the brain what is it ... Participant 2. Male, 70.

Participants were affiliated to different churches, explaining why they suggested praying, fasting, and referring to biblical scripture as a cure for epilepsy. One participant claimed that he heals epilepsy by praying and fasting and begging God to heal the client, using the Bible verse Luke 1:37, for nothing is impossible with God. On the other hand, participants did not discourage clients from getting medical assistance from physicians and nurses; they encouraged them to do so, stating that the wisdom doctors possess in controlling epilepsy was given by God to serve his people. The



following quotations illustrate the participants' views.

I just pray for them nothing special and do fasting and prayer. The other thing is that as pastors we need to do counselling and tell the client how God works for him to; answer your prayers. Participant 4. Female, 32; Participant 1. Male, 42.

We first do counselling, read the word of God for the client and some you find that they are not born again we feed them with the word and tell them that God is able to do so that he/she can have faith if not born again accept Jesus Christ as the Lord and saviour. The person who need healing must accept Jesus first after we pray with them if it need spiritual deliverance will have the session for that, our duty is to make them reach the point of accepting Christ. Participant 4. Female, 32.

As we believe that it is a spiritual thing. We pray with the client because the bible says the evil spirit won't go away without prayer and fasting and support. Some spirit doesn't go away by praying. Only we need to fast for days. Participant 2. Male, 70.

What we have to do is to have faith in God even when the person is sick. Only God can cure all illnesses, not that we don't believe in doctors. We pray for the persons then we advise them to seek medical treatment. Participant 1. Female, 42.

Because epilepsy affects the lungs, a Zion Christian Church (ZCC) participant stated that drinking a lot of water and light tea mixed with fresh milk can help heal epilepsy. According to him, there is a bubble in the lungs that produces dizziness and fits, known as epilepsy.

A person with epilepsy should drink a lot of water. From there, that person drinks light tea and fresh milk for three days. After drinking fresh milk, PLWE starts vomiting several times then the bubble





comes out, and it is visible. Participant 5. Female, 55.

Even though participants believed that praying and fasting will heal epilepsy, the medication from the hospital should not be stopped because it prevents seizures from occurring frequently. However, the participant works effectively with the medical practitioner. Although other participants mentioned using tea and inducing vomiting to manage epilepsy, these methods have no bearing on medical treatment and should not be used simultaneously.

No, medical treatment is taken daily. Tea doesn't prohibit PLWE from taking treatment because both treatments work together. Participant 5. Female, 55.

4.7 Discussion

Although faith-based healers have unique perspectives on epilepsy, they are an important sociocultural cornerstone of epilepsy management around the world. According to Seneviratne [20], most people have sought religious and spiritual healing to manage epilepsy. In this study, faith-based healers believed that epilepsy is a condition caused by an evil spirit and bewitchment, while others cite Western factors such as inadequate brain connectivity due to knowledge gained at school, government clinics, and radio or through book reading. [10; 21]. Ismail et al. [7] supported that epilepsy is a spiritual disease that is caused by an evil spirit, witchcraft, and it could be a punishment from God due to the evil doing committed by our forefathers.

Furthermore, in rural areas, it is generally believed that epilepsy is due to possession of spirit [22]. On the other hand, others believe it is a lung disease caused by a bubble in the lung, the cause of the bubble is unknown. According to accounts, epilepsy is thought to be a form of witchcraft that enters the nose and head as wind and remains inside the bones, muscles, and occasionally within the head [23].



However, medically, epilepsy is a brain disease marked by one or more spontaneous seizures, which some associate with the lungs, especially when the client has trouble breathing. Petterson [24] argued that epilepsy may be recognized as a medical condition because there is a widely held belief that evil spirits cause seizure disorders and that epilepsy is contagious. Anderson [25] maintained that epilepsy is triggered by referring evil animals and spirits into the body, shaking the body. The participants' understanding of the bubble in the lungs arises when the patient has difficulties breathing. Newman [26], Pandey [27] and Robinson [28] blamed cultural beliefs for the treatment gap in epilepsy because people seek help from what they believe in.

Findings show that faith-based healers are less likely to encounter patients experiencing epilepsy because most of their patients arrive for consultation in a stable state. However, in an incident, an individual is assisted by putting a client in a safe position and placing a flat hard object in the patient's mouth to prevent injuries, which is common among many people. Anand et al. [29] explained another management during a seizure: insert garlic, orange, wine, or a paste formed of grains into the seizuring person's nose or mouth and read Koranic text to stop seizures. Placing an object in the patient's mouth is a relatively safe way to keep them from biting their tongue, but waking the client, in my opinion, may impact blood flow to the brain, potentially complicating the problem [30]. However, when a client has a seizure, all that must be done is a monitor how long the episode lasted [32].

Faith-based healers have faith in God that He could heal any type of disease. However, they strongly believe that God is able to do all things. However, Rajbhadhari [9] supported that Muslims also believe that prayer has the power to cure a variety of ailments, including epilepsy. Many people living with epilepsy (PLWE), especially those who believe in Christianity, firstly consult faith-based healers for management, yet even those who do not believe in God, after they have tried many ways to treat



their condition, also consult pastors as their last option. Management of epilepsy by faith-based healers is through faith, prayer, fasting and the use of tea. Therefore, healing is determined by how much faith one has in God. Dolo [11] emphasized that epilepsy is treated using anti-epilepsy medication and traditional treatment using sprays (in the churches), incantations (to chase away evil spirits) and bathing in the river. For those who have little faith in God, pastors offer counselling before starting with management.

Faith-healers use light tea mixed with fresh milk for three days drank with enough water. However, it can also be used to induce vomiting to excrete the bubble in the lung. Still, then injection of medication and steaming is prohibited by pastors due to unknown factors, including cutting of the body using a razor that can precipitate a seizure. However, the clients have to avoid burns because it makes it difficult for healing. Akhtar, Ahmad, Ahan, Fahud Khurram and Haq [32] supported that due to poor orientation to time, place, and person during a seizure, such burn injuries may deepen and lead to more difficult management. Surprisingly, even pastors have believed that traditional healers can cure epilepsy. Some have consulted them before for management. Madhibha [33] corroborated that some believe in traditional religions while others believe in Christianity and Islam.

Faith-based healers collaborate well with primary health care professionals. Many prefer hospital treatment because at the hospital there is a better understanding of the causes of epilepsy so the condition can be explained well. During the health care seeking, PLWE use modern medicine, traditional herbs and prayers interchangeably [34]. Some pastors strongly disagree to merge with the traditional healer in the management because of their different beliefs. Dolo [11] showed that people from the Christian religion did not accept traditional treatment, which could put them in conflict with their religious beliefs. However, the health-seeking behaviours of families depend



on their financial possibilities and their experiences with the efficacy of the chosen treatment option.

4.8 Limitation

The study was conducted in rural villages in Mpumalanga and Limpopo provinces. The findings may not be representative of other villages of other provinces. This qualitative study looks at depth and richness of data, which was not attained since several people agreed to attend, but then changed their minds on the scheduled date.

4.9 Conclusion

Faith-based healers in Mpumalanga believed in prayer and fasting for the management of epilepsy, and they strongly believe that prayer is the only therapy to all diseases. However, Limpopo's findings revealed that people from Zion Christian Church use the light tea and prayer. The tea is used to induce vomiting and excrete the foam in the lung; therefore, epilepsy is assumed to be completely healed. Findings revealed that faith-based healers have solid working relationships with primary health providers. There are no contraindications for their therapy. Their understanding of the aetiology of epilepsy differs slightly depending on their church or religious affiliation. Faith-based healers use anti-epilepsy to control seizures even though they have their own traditional management medication that is still useful.

4.10 Conflict of Interest

The authors declare no conflict of interest.

4.11 Acknowledgement

A thank you is due to everyone who took part in this study for their helpful input. Glad Africa Epilepsy Research Project (GERP) supported the research. The authors are grateful to the language translator for assistance with the interview question.





4.12 References

- 1. World Health Organization. Epilepsy. USA: Fact Sheet Number 999.
- 2. Cherney, K. Epilepsy and Seizure Medicines List. Retrieved March 22, 2017, from www.healthline.com.
- 3. Epilepsy foundation. Revised classification of seizures. Retrieved March 2017 from www.epilepsy.com.
- 4. Munthali A, Braathen SH, Grut L, Kamaleri Y, Ingstad B. Seeking care for epilepsy and its impacts on households in a rural district in southern Malawi. *African Journal of Disability*. 2013 Jan 1;2(1):1-8.
- 5. Diop AG, de Boer HM, Mandlhate C, Prilipko L, Meinardi H. The global campaign against epilepsy in Africa. *Acta Tropica*. 2003 Jun 1;87(1):149-59.
- Ismail H, Wright J, Rhodes P, Small N, Jacoby A. South Asians and epilepsy: exploring health experiences, needs and beliefs of communities in the north of England. Seizure. 2005 Oct 1;14(7):497-503.7
- 8. Khwaja GA, Singh G, Chaudhry N. Epilepsy and religion. *Annals of Indian Academy of Neurology*. 2007 Jul 1;10(3):165.
- Rajbhandari KC. Epilepsy in Nepal. Canadian Journal of Neurological Sciences. 2004 May;31(2):257-60
- 10. Ekeh BC, Ekrikpo UE. The knowledge, attitude, and perception towards epilepsy amongst medical students in Uyo, Southern Nigeria. *Advances in Medicine*. 2015 Mar 31;2015.
- Dolo H, Mandro M, Wonya'Rossi D, Ngave F, Fraeyman J, Siewe JN, Suykerbuyk P, Colebunders R. Community perceptions of epilepsy and its treatment in an onchocerciasis endemic region in Ituri, Democratic Republic of Congo. *Infectious Diseases of Poverty*. 2018 Dec;7(1):1-9.
- Mutanana N. Indigenous Practices for Sustainable Management of Epilepsy in Zimbabwe: A Case of Epilepsy Support Foundation Zimbabwe (Doctoral dissertation, Chinhoyi University of Technology).
- 13. Bhalla D, Tchalla AE, Marin B, Ngoungou EB, Tan CT, Preux PM. Epilepsy: Asia versus Africa. *Epilepsia*. 2014 Sep;55(9):1317-21
- Mutanana N. Challenges associated with anti-epilepsy medication and use of complementary or alternative medicines among people with epilepsy in rural communities of Zimbabwe. *Malaysian Journal of Medical and Biological Research*. 2019 Dec 31;6(2):77-84.
- 15. Mohammed IN, Babikir HE. Traditional and spiritual medicine among Sudanese children with epilepsy. *Sudanese Journal of Paediatrics*. 2013;13(1):31.
- 16. De Vos AS. Research at grass roots: For the social science and human service





- professions. Pretoria: Van Schaik. Denzin, NK and Lincoln, YS (2011).
- 17. Gray, D.E., Doing research in the real world, 2nd edition, UCT press. 2009
- 18. Silverman D. Doing qualitative research: A practical handbook. Sage; 2013 Apr 22
- 19. Seneviratne U, Rajapakse P, Pathirana R, Seetha T. Knowledge, attitude, and practice of epilepsy in rural Sri Lanka. Seizure. 2002 Jan 1;11(1):40-3.
- Keikelame MJ, Swartz L. 'A thing full of stories': Traditional healers' explanations of epilepsy and perspectives on collaboration with biomedical health care in Cape Town. *Transcultural Psychiatry*. 2015 Oct;52(5):659-80.
- 21. World Health Organization. Global action plan for the prevention and control of noncommunicable diseases 2013-2020. World Health Organization; 2013.
- 22. Carod-Artal FJ, Vázquez-Cabrera CB. An anthropological study about epilepsy in native tribes from Central and South America. *Epilepsia*. 2007 May;48(5):886-93.
- 23. Patterson V. Telemedicine for epilepsy support in resource-poor settings. *Frontiers in Public Health*. 2014 Aug 21;2:120.
- 24. Anderson J, Hamandi K. Understanding juvenile myoclonic epilepsy: contributions from neuroimaging. *Epilepsy Research*. 2011 May 1;94(3):127-37.
- 25. Newman PK. Epilepsy in South Sudan. South Sudan Medical Journal. 2011;4(4):86-9.
- 26. Pandey S. Challenges in neurological practice in developing countries. *Indian Journal of Public Health.* 2012 Jul 1;56(3):227.
- 27. Robinson R. Managing epilepsy in South Sudan. South Sudan Medical Journal. 2016
 Nov 9;9(4):92-5.
- 28. Anand P, Othon GC, Sakadi F, Tassiou NR, Hamani AB, Bah AK, Allaramadji BT, Barry DN, Vogel A, Cisse FA, Mateen FJ. Epilepsy and traditional healers in the Republic of Guinea: A mixed methods study. *Epilepsy and Behavior*. 2019 Mar 1;92:276-82.
- 29. Moselhy HF. Psychosocial and cultural aspects of epilepsy. 2011. IntechOpen.
- 30. Rutebemberwa E, Semugabo C, Tweheyo R, Turyagaruka J, Pariyo GW. Biomedical drugs and traditional treatment in care seeking pathways for adults with epilepsy in Masindi district, Western Uganda: a household survey. *BMC Health Services Research*. 2020 Dec;20(1):1-3.





SECTION 5

GENERAL DISCUSSION, LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS

5.1 Summary of Key Findings

This thesis consists of five sections, which guided the indigenous practices for the management of epilepsy by traditional healers and faith-based healers in selected rural communities of Mpumalanga and Limpopo. Orientation of the study detailing the indigenous practice for the management of epilepsy in the selected communities of Mpumalanga and Limpopo provinces was presented in Section 1. The focus of the section was to describe the introduction and background to the problem, problem statement, research question, and purpose, objectives, the rationale of the study, a conceptual framework which was the health belief model (HBM) was discussed briefly as well as how it was adopted and integrated into the study and the significance thereof.

Section 1 also indicated that the research study adopted a qualitative ethnographic design, and described how data were collected and analyzed, discussed sample and sampling, measures to ensure trustworthiness and ethical consideration. Sections 2-4 present the three manuscripts prepared for publication in peer-reviewed journals. These are summarized in terms of the key findings in relation to the study's objectives. Section 5 provides a general discussion, limitations, recommendations and conclusions, aimed to serve as the cohesion of the study is brought together and discussed.



Furthermore, detailed recommendations and the limitations of the study's findings are presented and discussed. The study aimed to determine the indigenous practices for the management of epilepsy by traditional healers and faith-based healers in the selected rural communities of Mpumalanga and Limpopo provinces in South Africa. The following is the summary of the key findings in relation to the study's objectives.

Section 2—Manuscript 1: A systematic review analyzed the gaps regarding the management of epilepsy in Africa. This work aimed to systematically review the various traditional and Western methods of epilepsy management and their effectiveness. A literature search was conducted electronically starting from 2000 up to date. The study review included both qualitative and quantitative studies examining epilepsy management in Africa. The findings were that in Africa, two approaches were used: traditional and Western, whereby traditional refers to pastors, traditional healers, and Western are all medical practitioners. Traditional healers use plants and animals to manage epilepsy, while Western medical practitioners use anti-epilepsy medication. Findings revealed that people with epilepsy strongly believe that epilepsy is a spiritual phenomenon. Treatment should be done through the use of herbs and prayers. Many studies show that people are more satisfied with the service offered by traditional and spiritual healers. Anti-epilepsy treatment is used to a lesser extent in Africa due to people's indigenous beliefs and perceptions about epilepsy. Before seeking medical care, many people consult traditional and spiritual healers for epilepsy management.

Section 3—Manuscript 2: A group of 17 traditional healers were selected for in-depth interviews and the *Open Health Public Journal* guidelines were followed. The key findings suggested that in both provinces, traditional healers use plants and alternative measures such as livestock and insects as treatment to people living with epilepsy (PLWE). Their perceptions and misconceptions about epilepsy are similar in both provinces. Nevertheless, many collaborate well with primary health care professionals,



yet few do not believe in-hospital treatment. Traditional healers indicated that even though biomedical practitioners were not cooperating they would be willing to work with them. Indigenous practices should take into the consideration the health system as well.

Section 4—Manuscript 3: Seven faith-based healers were interviewed face-to-face, and findings suggested that many faith-based healers in Mpumalanga believe in Christianity, and they strongly believe that prayer is the only remedy to all diseases. However, the results in Limpopo revealed that people affiliated to the Zion Christian Church (ZCC) managed epilepsy using mild tea and prayer. Though they have solid working relationships with primary health care providers and there are no contraindications for their therapy, their understanding of the causes of epilepsy differs slightly depending on the church one is attending.

The studies presented in the manuscripts revealed that epilepsy can be managed in two ways: through traditional practices and biomedication. On the other hand, anti-epilepsy treatment is well-known and documented, even though it is not always available and may be too expensive. While faith healers solely know indigenous traditions, transmitting information from one to another is difficult due to client competition. Although a few records demonstrate indigenous traditions, it is not shown that they are effective. Traditional and religious healers work very well with hospital treatment for epilepsy management.

5.2 Limitations

There were limitations during data collection. The study sample of 30 traditional and faith-based healers was not reached as only 50 per cent of the anticipated sample participated. The current study included an electronic search from published work in English between 2000 to date in the systematic review of 12 databases. Other studies



could have been published outside the time frame, in other languages and databases that the researcher might have missed that would have impacted the findings of this study. The researcher is African, and while it may appear that she is using her experiences to support the use of traditional and religious practices in epilepsy management, she has made every effort to prevent bias by adhering to research ethics. Data were supposed to be collected over six months. Still, because travel between places was restricted due to the Covid-19 pandemic, the researcher had to develop an alternative approach, which was video conferencing. To get around this, the researcher had to rearrange the data collection schedule so that the study could take place on weekends and on days that were convenient for the participants. Because the investigation was confined to saturation, the results cannot provide an expansive view of epilepsy management practices by traditional and faith-based healers.

5.3 Recommendations

5.3.1 Recommendations for Biomedical Practitioners

All health care professionals must receive training in epilepsy origins, diagnosis and management elements. These include the community's epilepsy management knowledge, attitudes, and behaviours. Before commencing epilepsy medication, health care providers should educate people with epilepsy about the potential side effects of epilepsy medications. In addition, health care providers must acknowledge the importance of indigenous religious beliefs in epilepsy management. Apart from persuading people with epilepsy to take modern medicine, they should encourage primary and secondary health care workers to collaborate with indigenous practitioners. They should tolerate non-harmful indigenous medicines, but insist on continuing to use biomedicine.



5.3.2 Recommendations for Indigenous Practitioners

Biomedication must be taught to traditional practitioners. In Mpumalanga and Limpopo, the health organizations that support PLWE must insist on conducting seminars and workshops to train indigenous practitioners in epilepsy management. This would help them to comprehend epilepsy from a Western perspective. Both will be aware of the advantages and disadvantages of biomedication. Instead of persuading people with epilepsy to take indigenous medicine, indigenous practitioners should be encouraged to collaborate with main and secondary health care providers to manage the condition. People with epilepsy should be able to accept biomedicines in epilepsy therapy.

5.3.3 Recommendations for a Multi-Cultural Approach in Epilepsy Management

Because many people would consult an indigenous practitioner, a non-competitive partnership between health care practitioners and indigenous practitioners should be maintained, with both parties sharing knowledge and training to deepen the collaboration. Rather than opposing indigenous practitioners, medical practitioners should collaborate with them. As a result, it is suggested that epilepsy management be approached from a multicultural perspective. In order to effectively manage epilepsy, a team of local practitioners must be developed in rural and urban areas of Mpumalanga and Limpopo provinces. To manage epilepsy, both parties must be educated in indigenous practices and biomedication and must work together as a team.

5.3.4 Recommendations for Policymakers

Supportive legislation, similar to that which has supported the HIV/AIDS epidemic and cancer, is needed to support epilepsy management. The health care system needs to continue to educate people about how to treat epilepsy. It is necessary to provide training materials for various groups, including school teachers, PLWE, communities,



family members, caregivers, and the general public. To minimize the stigma associated with epilepsy, the community needs proper knowledge, and training materials and must emphasize that the condition is treatable. The training materials should address the public's perception of the condition and health practitioners' knowledge, attitudes, sociocultural context, and collaboration with traditional leaders. In Mpumalanga and Limpopo, policies to assist indigenous epilepsy management approaches are recommended.

5.3.5 Recommendations for Future Studies

Future research should investigate the effectiveness of the plants as well as alternative methods like prayers and the use of light tea in the treatment of epilepsy. This will allow researchers to see if traditional epilepsy management makes a difference in people's lives. A study is also needed to look into medical practitioners, indigenous practitioners, counsellors, psychologists, and social workers in supporting persons with epilepsy to live better lives.

5.4 Conclusion

The purpose of the study was to determine the indigenous practices for the management of epilepsy in the selected rural communities of Mpumalanga and Limpopo provinces. A systematic review was conducted and manuscripts on the findings were prepared. The findings suggested that anti-epilepsy drugs, plants, animals, light tea, prayer, and fasting are used to manage epilepsy in Africa. However, the use of plants, animals, prayers, and tea are poorly documented. Furthermore, the study confirmed that people in those areas also have some knowledge gaps and need to be taught about epilepsy to reduce the stigma about the condition. Traditional and faith-based healers are the communities' influence when it comes to treatment, and their knowledge on the condition is limited and fraught with misconceptions about the condition. Traditional healers, faith-based healers and medical practitioners need to be



supported by organizations that support epilepsy to provide training in both biomedication and traditional management of epilepsy. Also, emphasis should be placed on recommendations for the traditional healers, faith-based healers and medical practitioners. Future research should consider the effectiveness of the traditional management of epilepsy.



ETHICS APPROVAL CERTIFICATE FROM THE UNIVERSITY OF VENDA HUMAN AND CLINICAL TRIALS RESEARCH ETHICS **COMMITTEE (HCTREC)**

ETHICS APPROVAL CERTIFICATE

RESEARCH AND INNOVATION OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR: Ms Q Chabangu

STUDENT NO: 4005084

PROJECT TITLE: Indigenous practices for management of epilepsy by traditional and faith-based healers in the selected rural communities of Mpumalanga and Limpopo.

PROJECT NO: \$H\$/20/PDC/45/2710

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE	
Prof MS Maputle	University of Venda	Supervisor	
Prof RT Lebese	University of Venda	Co-Supervisor	
Ms. Q Chabangu	University of Venda	Investigator – Student	

Type: Masters Research

Risk: risk to humans, animals, environment, or a sensitive research area Approval Period: October 2020 - October 2022

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

Ceneral Conditions

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

In 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.

Annually (or as otherwise requested) on the progress of the project, and upon completion 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 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 the project protocol without the necessary approval of the project protocol without the necessary approval of the project protocol is 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.

ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE

Name of the HCTREC Chairperson of the Committee: Prof Pascal Bessong

Signature:





LETTER TO TRIBAL AUTHORITY REQUESTING PERMISSION TO CONDUCT RESEARCH

University of Venda Private Bag X5050 Thohoyandou 0950

Re: Tribal Authority

Request for Permission to Conduct Research Project

I, Chabangu Qolile, Master of Nursing student, am planning to conduct a research project in your community. My research topic that I am interested in researching in your community is as follows:

"Indigenous practices for the management of epilepsy by traditional healers and faith-based healers in the selected rural communities of Mpumalanga and Limpopo, South Africa".

The purpose of the study is to determine the indigenous practices for management of epilepsy by traditional and faith-based healers in the selected rural communities of Mpumalanga and Limpopo. The study will be interviewing traditional healers and faith-based healers and the information will help all people living with epilepsy to have choice regarding their care and make it easier for them to live with the condition.

I therefore require permission to conduct the research project.

Yours truthfully:

Chabangu Qolile (14005084)



PERMISSION FROM MPUMALANGA PROVINCE DEPARTMENT OF HEALTH TO CONDUCT RESEARCH





No.3, Government Boulevard, Riverside Park, Ext. 2, Mbombela, 1200, Mpumalanga Province Private Bag X11285, Mbombela, 1200, Mpumalanga Province Tel: +27 (13) 766 3429, Fax: +27 (13) 766 3429.

Litiko Letemphilo

Departement van Gesondheid

UmNyango WezeMaphilo

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:

PHASE 1 NEEDS ASSESSMENT

- 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 Moumalanda 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





with the Study	How many:		1
*	Nurses:		
	Doctors:		
	Other, please specify:		NC
5.2: Patients / Researchers' Records/Files	Yes		
5.3: Interviewing Patients/ participants at Facilities	Yes		
5.4: Interviewing Patients/ participants at Home	Yes		
5.5: Resource Flow (Are there	Yes		NC
benefits to Patients/community)	Please list: all potential remedial ideas emanated from research will be taken up for healthcare practice and policy		
5.6: Resource Flow (Are there	Yes		NO
benefits to Facility/District)	Please list: to promote epilepsy awareness through the production and supply of pamphlets, aminated visual awareness materials and other posters, provision of continuous community based epilepsy awareness		
6. Availability of Required Clearant	ce		
6.1: Ethical Clearance	Yes	Pending	NO
	Clearance Number:		
6.2: Clinical Trial	Yes	Pending	
	Clearance Number:		
6,3: Vaccine Trial	Yes	Pending	
	Clearance Number:		
6.4: Budget	Yes		NO
3	Source of fund: GladAfrica Foundation Trust		1
Declaration by Applicant: Mr/Ms/ <mark>Dr/</mark> Prof/Adv <u>Lufuno Makhado</u> : CEO/Institution/District.	agree to submit/present the result of thi	s study back to the	
	MPUMALANGA PROV. GOVERNMEN PUP EMLANZENI BISTRICT OFFICE PRIVATE BAG X. 11278 98 ANDERSON STREET NELSPRUIT 1200	ported / Not Supported	
Donald .	EMLANZENI DISTRICT OFFICE PRIVATE BAGX 11275 BB ANDERSON STREET NELSPRUIT 1200 Dele Reserve 2020 -07- 1 5	15/7/2020	
Final .	EMLANZENI DISTRICT OFFICE PRIVATE BAG X 11278 B6 ANDERSON STREET NELSPRUIT 1200		

Letter of Support Signed by Chief Director (CD)/CEO/District Manager (DM)/Programme Manager (PM)

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





Indwe Building, Government Boulevard, Riverside Park, Ext. 2, Mbombela, 1200, Mpumalanga Province Private Bag X11285, Mbombela, 1200, Mpumalanga Province Tell : +27 (13) 766 3429, Fix: +27 (13) 766 3458

Litiko Letemphil

Departement van Gesondheid

UmNyango WezeMaphilo

Enq:

013 766 3766/3511 MP_202006_009

Provincial Research Approval Letter

Dr Lufuno Makhado University of Venda, Health Sciences Research office Private Bag X5050 Thohoyandou, 0950

TITLE:

APPLICATION FOR RESEARCH APPROVAL: EPILEPSY INTERVENTION PROGRAMME IN RURAL COMMUNITIES OF LIMPOPO AND MPUMALANQA PROVINCES.

Dear Dr Makhado

The Provincial Department of Health Research Committee has approved your research proposal in the latest format you sent.

Approval Reference Number:

MP_202006_009

Data Collection Period:

15/08/2020 to 15/11/2020.

Approved Data Collection Facilities:

BUFFELSHOEK CLINIC; COTTONDALE CLINIC; HLUVUKANI CLINIC; JERUSALEM CLINIC; LUDLOW CLINIC; MURHOTSO CLINIC

Kindly ensure that conditions mentioned below are adhered to, and that the study is conducted with minimal disruption and impact on our staff, and also ensure that you provide us with a soft or hard copy of the report once your research project has been completed.

Condition

Please note that due to the Covid-19 pandemic, face to face interviews may not be permitted during lockdown

Kind regards

DR C NELSON MPUMALANGA PHRC CHAIRPERSON DATE: 03 August 2020

MPUMALANGA
THE PLACE OF THE RISING SUN

MRUMALANGA PROVINCE

MRUMALANGA PROVINCE

OFFARTMENT OF HEALTH

PRINCE SARUTT 2005

PRINCE SARUTT 2005



PERMISSION FROM LIMPOPO PROVINCE DEPARTMENT OF HEALTH TO CONDUCT RESEARCH



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.
 - 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

> Private Bag X9302 Polokwane Fidel Castro Ruz House, 18 College Street. Polokwane 0700. Tel: 015 293 6000/12. Fax: 015 293 6211. Website: http/www.limpopo.gov.za

The heartland of Southern Africa – Development is about people!



LETTER OF INFORMATION

RESEARCH ETHICS COMMITTEE

UNIVEN Informed Consent LETTER OF INFORMATION

Title of the Research Study: "Indigenous practices for management of epilepsy in selected rural communities of Mpumalanga and Limpopo

Principal Investigator/s/ researcher: Ms Qolile Chabangu, BCur

Co-Investigator/s/supervisor/s: Prof M.S. Maputle (DCur) and Prof R.T. Lebese, (DCur)

Brief Introduction and Purpose of the Study: This study will determine and explore how the local indigenous practices, traditions, and beliefs are taken into consideration in the management of epilepsy.

Outline of the Procedures: (Responsibilities of the participant, consultation/interview/survey details, venue details, inclusion/exclusion criteria, explanation of tools and measurement outcomes, any follow-ups, any placebo or no treatment, how much time required of participant, what is expected of participants, randomization/ group allocation). A qualitative, ethnographical approach will be used, where exploratory and descriptive designs will be followed. The target population will be people living with epilepsy, caregivers, traditional, and faith-based healers. Sampling will be identified using purposive sampling. However, the sample size will be determined by the data saturation in each community and within strata per selected community. Data will be collected by using semi-structured interviews in the selected communities of Mpumalanga and Limpopo. Data will be analyzed using six steps of data analysis as described by Cresswell (2014). In this study, trustworthiness will be ensured using four criteria which include dependability, confirm ability, transferability, and credibility

Risks or Discomforts to the Participant: (Description of foreseeable risks or discomforts to for participants if applicable e.g. Transient muscle pain, VBAI, post-needle soreness, other adverse reactions, etc.). No risks or discomforts are anticipated to participants

Benefits (To the participant and to the researcher/s e.g. Publications).

Please note that participation in this study is voluntary and there will be no direct benefits to anyone who participates. There will be no penalties if you want to withdraw from the study or if you do not want to answer some of the questions if they are violating your rights. The researcher will generate a publication from the data.





Reason/s why the Participant May Be Withdrawn from the Study: (Non-compliance, illness, adverse reactions, etc. Need to state that there will be no adverse consequences for the participant should they choose to withdraw).

Participants will be informed that participation is voluntary, they can withdraw their participation if they feel uncomfortable with no punishment.

Remuneration (Will the participant receive any monetary or other types of remuneration?)
No

Costs of the Study: (Will the participant be expected to cover any costs towards the study?). No

Confidentiality: (Description of the extent to which confidentiality will be maintained and how will this be maintained): No names will be used when transcribing the interviews. I undertake that all information provided by you will be used only for the study. Everything that you will say will be treated as private and confidential and no-one will know you answered the question apart from the researcher. The answers given by participants will be combined and analyzed per common themes and categories and the combined information will be in the form of a report.

Research-related Injury: (What will happen should there be a research-related injury or adverse reaction? Will there be any compensation?).

No research related injury is anticipated.

Persons to Contact in the Event of Any Problems or Queries:

(Supervisor and details) Please contact the researcher (0714035023 chabanguq24@gmail.com, my supervisor (0846022063 Sonto.Maputle@univen.ac.za) or the University Research Ethics Committee Secretariat on 015 962 9058. Complaints can be reported to the Director: Research and Innovation, Prof G.E. Ekosse on 015 962 8313 or Georges Ivo.Ekosse@univen.ac.za

General:

Potential participants must be assured that participation is voluntary and the approximate number of participants to be included should be disclosed. A copy of the information letter should be issued to participants. The information letter and consent form must be translated and provided in the primary spoken language of the research population



CONSENT FORM

Statement of A	greement to Participate in	n the Research Stu	idy:
I hereby confirm that I have been conduct, benefits and risks of this s I have also received, read and under	tudy - Research Ethics Cle	earance Number:	
regarding the study.			
I am aware that the results of the sinitials and diagnosis will be anonyr			sex, age, date of birth,
In view of the requirements of researin a computerized system by the re	-	ollected during this s	study can be processed
I may, at any stage, without prejudi	ce, withdraw my consent a	nd participation in th	ne study.
I have had sufficient opportunity to participate in the study.	ask questions and (of my	own free will) decl	are myself prepared to
I understand that significant new participation will be made available		g this research wh	ich may relate to my
Full Name of Participant	Date	Time	Signature
I, (Name of researcher) herewith	confirm that the above par	ticipant has been fu	ully Informed about the
nature, conduct and risks of the abo	ove study.		
Full Name of Researcher	Date	Time	Signature
Full Name of Witness	Date	Time	Signature
Full Name of Legal Guardian	Date	Time	Signature



Please note the following:

Research details must be provided in a clear, simple and culturally appropriate manner and prospective participants should be helped to arrive at an informed decision by use of appropriate language (grade 10 level- use Flesch Reading Ease Scores on Microsoft Word), selecting of a non-threatening environment for interaction and the availability of peer counselling (Department of Health, 2004)

If the potential participant is unable to read/illiterate, then a right thumb print is required and an impartial witness, who is literate and knows the participant e.g. parent, sibling, friend, pastor, etc. should verify in writing, duly signed that informed verbal consent was obtained (Department of Health, 2004).

If anyone makes a mistake completing this document e.g. a wrong date or spelling mistake, a new document should be completed. The incomplete original document should be kept in the participant's file and not thrown away, and copies thereof must be issued to the participant.

References:

Department of Health: 2004. Ethics in Health Research: Principles, Structures and Processes

http://www.doh.gov.za/docs/factsheets/guidelines/ethnics/

Department of Health. 2006. *South African Good Clinical Practice Guidelines*. 2nd Ed. Available at: http://www.nhrec.org.za/?page_id=14





CONFIRMATION BY LANGUAGE EDITOR

CONFIRMATION BY LANGUAGE EDITOR



Prof Donavon C. Hiss

Cell: 072 200 1086 | E-mail: hissdc@gmail.com or | dhiss@outlook.com

13 June 2022

To Whom It May Concern

This serves to confirm that I have edited the language, spelling, grammar and style of the Master of Nursing thesis by Chabangu Qolile, titled: "Indigenous Practices for the Management of Epilepsy by Traditional and Faith-Based Healers: A Case Study in Selected Rural Communities of Mpumalanga and Limpopo Provinces" The manuscript was also professionally typeset by me.

Sincerely Yours



Cert. Freelance Journalism, Dip. Creative Writing, MSc (Medicine), PhD