# Epilepsy Management in African Society

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Cambridge
Scholars
Publishing

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This book first published 2024

Cambridge Scholars Publishing

Lady Stephenson Library, Newcastle upon Tyne, NE6 2PA, UK

British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library



ISBN: 978-1-0364-0980-7
ISBN (Ebook): 978-1-0364-0981-4

A special dedication to all people who are living with epilepsy in Africa.

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# PREFACE

This book introduces the reader on the indigenous practices used by Africans in epilepsy management. Africans have their beliefs towards the causes of epilepsy, and resultantly some have chosen traditional modes of epilepsy management as compared to western bio-medication. This book is important to educate the Doctors, Psychologists and Counsellors on how they should handle cases of epilepsy, particularly if they are faced with clients who are antagonistic to western medications. Indigenous knowledge Systems (IKS) is also an interesting subject matter that has escalated, particularly with the issue of climate change. This book is unusual and worth reading as it covers issues of indigenous knowledge systems, particularly as they are related to epilepsy management.

Whilst the author was mainly focused in Africa, these are issues that have affected several countries at global level including the Asian countries as the author clearly shows the perceptions of Africans towards indigenous practices in sustainable management of epilepsy. The author reveals that the majority of people in Africa are not on anti-epilepsy medication because they strongly believe epilepsy is caused by witchcraft and evil spirits. They think bio-medication is not helpful in treating the disease. As such, people with epilepsy have resorted to indigenous practices of epilepsy management.

There are various modes of indigenous practices which they use and these include prayers, pastors/prophets, herbalists and the clergyman. From these different forms of traditional practices, traditional herbs have proved to be the most popular among people with epilepsy, followed by prayers. People with epilepsy are of the opinion that these indigenous practices are very effective in epilepsy management. Medical practitioners, on the other hand are not cooperating with indigenous practitioners in spite of the fact that the community has a positive perception towards these indigenous practices. To this end, the author recommends the community to be educated about bio-medication, and the effectiveness of anti-epilepsy medication in epilepsy management.

However, local traditions and beliefs should be taken into account in epilepsy management. Medical practitioners should incorporate indigenous practitioners rather than antagonising them. Primary and secondary health workers must go under training in all aspects of management of epilepsy. These people must be trained on the knowledge, attitudes and practices of indigenous practices in epilepsy management. Indigenous practitioners too, must be trained on bio-medication. They should work hand in hand with primary and secondary health workers. The involvement of family members, people with epilepsy and the community at large is important in order to maintain a momentum which will facilitate the sustainability of epilepsy management.

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# ACKNOWLEDGMENTS

It is not unusual in my *Shona* indigenous religion to appreciate and acknowledge the assistance that I received from other people during my study. This section is meant for the following people who have made this book a reality. These include my PhD Supervisors, Professor Tsvere and Dr Chiweshe. The African indigenous religion has become a reality to me through you. Thank you for all the guidance and moral support that you gave me during the challenging times of my studies. Epilepsy Support Foundation Zimbabwe also afforded me an opportunity to carry out this study at their institution. God bless you. Chinhoyi University of Technology; the Institute of Lifelong Learning and Development Studies (ILLDS) and the Graduate Research Studies Directorate (GRSD) in particular. I really appreciate your support guys. Participants who provided me with insightful information that helped me to shape this study. God bless you.

# ABBREVIATIONS AND ACRONYMS

| | |
|---|---|
| AED | Anti-Epilepsy Drugs |
| AIDS | Acquired Immune-Deficiency Syndrome |
| CAM | Complementary or Alternative Medicine |
| EEG | Electro Encephalon Gram |
| EITF | Epilepsy Implementation Taskforce |
| ESFZ | Epilepsy Support Foundation Zimbabwe |
| FEDOMA | Federation of Disability Organisations in Malawi |
| HBM | Health Belief Model |
| HHS | Health and Human Services |
| HIV | Human Immunodeficiency Virus |
| IK | Indigenous Knowledge |
| IOM | Institute of Medicine |
| IT | Information Technology |
| PEOU | Perceived Ease of Use |
| PU | Perceived Usefulness |
| PWE | People with Epilepsy |
| RCT | Randomised Controlled Trial |
| UN | United Nation |
| UNAIDS | United Nations Programme on HIV and AIDS |
| UNESCO | United Nations Educational, Scientific and Cultural Organisation |
| TAM | Technological Acceptance Model |
| TDM | Therapeutic Drug Monitoring |
| TRA | Theory Reasoned Action |
| WHO | World Health Organisation |
| ZNHS | Zimbabwe National Health Strategy |

# CHAPTER 1

# EPILEPSY FROM AN AFRICAN PERSPECTIVE

## Introduction

This book provides a nuanced analysis on the experiences of Zimbabweans towards anti-epilepsy bio-medication. Whilst the subject of epilepsy has been heavily contested (Mutanana, 2017) in the last decades, insignificant attention has been devoted to examining the health seeking behaviour of people living with epilepsy in developing countries such as Zimbabwe. The majority of Zimbabweans are poor and the public health systems are incapable of meeting all the health requirements of people who are living with epilepsy (Maroyi, 2013). The public health system has deteriorated over the past 20 years and the absence of a robust biomedical system of health necessitated the development of traditional knowledge sustainable management of epilepsy. Several studies also report major progress in the reduction of diseases like malaria, tuberculosis, polio and the spread of HIV and AIDS but not much has been done to eradicate mental health diseases, such as epilepsy (Mugumbate & Nyanguru, 2013; Maroyi, 2013; Munthaki, et al., 2013). What it means is that the mental health illness epidemic has been neglected within the development sphere. Zenden (2014) concurs with this observation and states that despite the massive toll and powerful impact the diseases of the brain can have on people's lives, they have not received the same amount of attention as other infectious disease outbreaks such as HIV and AIDS, malaria or even health problems like obesity. This book thus sought to bring mental health illness into the development arena.

## What is Epilepsy?

Epilepsy is one of the major brain disorders in Zimbabwe and thus a health priority (Dewa, 2012). Statistics by the Epilepsy Support Foundation Zimbabwe (2016) reveal that epilepsy contributes 56% of all conditions reported through the mental health surveillance system (psychiatric returns)

in Zimbabwe. Epilepsy Support Foundation Zimbabwe (2016) states that over 240000 people in Zimbabwe have been diagnosed with this disease. There are efforts to assist people with epilepsy at government hospitals, clinics and non-governmental organisations but in spite of these efforts, studies have shown that there is less uptake of anti- epilepsy medication. For instance, Dewa (2012) observes that a total of 209 patients in an epilepsy register under his study were not on follow-up treatment contrary to the 433 recorded incidences of epilepsy in Gokwe South Region. Mpofu (2001) believes that those who do not come for epilepsy medication make use of traditional healers and prophets.

From a biomedical perspective, epilepsy is described by WHO (2012) as a disorder of the brain which is characterized by a recurrence of unpredictable interruptions of the normal function called epileptic seizures. A person should have two or more unprovoked seizures prior to the date of assessment to be diagnosed as being epileptic. Epilepsy Scotland (2008), FEDOMA (2011), Cherney (2016) and Epilepsy Foundation (2017) argue that epilepsy causes the brain to send abnormal signals and this activity results in seizures. These seizures happen because of a number of reasons such as injury or sickness. Cherney (2016) and Epilepsy Foundation (2017) thus describe epilepsy as a condition that causes recurrent seizures and is treated with anti-epileptic drugs (AEDs). There are more than 20 prescriptions of AEDs available and one's option depends with age, lifestyle, and type of seizure and how often he or she has seizures (Epilepsy Scotland, 2008; FEDOMA, 2011; Cherney, 2016 and Epilepsy Foundation, 2017). In Zimbabwe, the commonly used drugs are Phenobarbital, Carbamazepine and Phenytoin. However, Epilepsy Support Foundation Zimbabwe (2016) reports that about 86% of people living with epilepsy are not on anti-epilepsy medication in Zimbabwe. Those who are on anti-epilepsy medication may still make use of traditional modes of epilepsy treatment to complement AEDs.

Epilepsy is attributed to spirituality in African Traditional Practices (Chilopola et al…, 1999; Birbeck, 2000; Munthali et al., 2013 and Diop et al., 2013; Mutanana & Mutara, 2015). Many people in African countries, Zimbabweans included believe in African indigenous practices and have consequently resorted to indigenous and spiritual forms of treatment

(Maroyi, 2013; Mutanana & Mutara, 2015). To this end, several studies have demonstrated that people with epilepsy make use of indigenous and spiritual medicine forms of treatment for epilepsy (Watts, 1989, WHO, 2002; Al-Safi, 2007; Luongo, 2008, Shizha & Charema, 2011; Mohammed & Babikir, 2013; Mutanana & Mutara, 2015). The indigenous healer or diviner occupies a central place in communities' participation in life events, including epilepsy (Mutswanga & Mafunga, 2009). In some cases, studies have suggested an inter-play between bio-medication and African indigenous medication. For instance, Asadi-Pooya & Emami (2013) concur that indigenous medicines may be used to complement bio-medication. What it shows is that indigenous medicines are dominant, but unlike anti-epilepsy medications they are not formalised (Maroyi, 2013).

Several studies have revealed indigenous medicines to be more advantageous over bio- medication because they are the most affordable and easily accessible sources of treatment in the primary health care system, especially to the poor rural communities (WHO, 2001; Maroyi, 2013 and Mutanana & Mutara, 2015). The lower uptake of anti-epilepsy medication has been attributed to the fact that many people with epilepsy who live in developing countries have limited access to health care facilities. In this context, it is widely believed that indigenous and spiritual forms of treatment, being easily accessible, play an important role in treating people with epilepsy. It is apparent that some people with epilepsy are relying heavily on traditional and spiritual medicines to sustain their livelihoods and these practices have reached a crucial stage of development in Zimbabwe. However, Maroyi (2013) contends that despite the increasing acceptance of traditional medicine in Zimbabwe, the rich knowledge of these indigenous medicines is not adequately documented, a knowledge gap which this study seeks to cover. Winkler et al., (2010) also report that in sub- Saharan Africa, studies on the attitude of people (both affected and not affected by epilepsy) towards traditional medicine for treatment of epilepsy are scarce, a knowledge gap which this study also sought to cover.

Throughout history epilepsy has been perceived as a mysterious and supernatural disorder (Mpofu, 2003). Studies have also shown that a widely held notion about epilepsy in Africa is that epilepsy is caused by evil spirits and witchcraft (Carod-Artal & Vazquez- Cabrera, 2007). Mutanana &

Mutara (2015) also argue that many communities in Zimbabwe still believe that epilepsy results from witchcraft or possession by evil spirits. There is a grave social stigma attached to epilepsy with some people believing that it is a contagious disease (Epilepsy Support Foundation, 2016). Thus Mpofu (2003) is of the opinion that traditional healers and prophets (faith healers) are crucial at community level and they are the first port of call and often the last resort too. Historically, epilepsy has been neglected, feared and misunderstood (Cure, 2013). As such, a veil of secrecy surrounding this disease has resulted in these myths, superstitions and general lack of knowledge. Cure (2013) believes this has impeded scientific progress towards finding answers to one of the oldest known neurological diseases leaving treatment and research efforts in dark ages.

According to Epilepsy Support Foundation Zimbabwe (2016), stigma and discrimination both at the workplace and school as well as lack of family care have had an influence on epilepsy management. Most people with this condition are living unproductive lives (Mugumbate & Nyanguru, 2013). Consequently, they are failing to acquire education, training and employment and this has had a negative impact on their social life. Meanwhile, shortages of medication, staff and equipment at public health centers is also a hindrance to compliance for many, whilst the cost at private centers is very prohibitive. Therefore, epilepsy is hindering their development psychologically, medically, educationally and economically. In consistency with a report by WHO (2012), epilepsy becomes an important subject matter in order to ensure the good health of people with epilepsy as this is essential to their welfare and to sustained economic and social development.

The United Nations (2013) states ensuring healthy lives and promoting the well-being for all ages is essential to sustainable development, yet Epilepsy Support Foundation Zimbabwe (2016) reports that about 75% of people with epilepsy are failing to meet their basic needs to treatment and rehabilitation. What it shows is that the government of Zimbabwe is failing to offer meaningful social assistance to people with epilepsy through these western practices. The result has been unmet medical and social needs of people with epilepsy which justifies the development of indigenous technologies for sustainable management of epilepsy. To promote the well-being of people with mental illness, Mpofu et al..., (2011), Tseng (1999)

and Shoko (2007) have strongly recommended the development of these indigenous healing practices.

## Conclusion

In conclusion, it can be noted that Africa has its own understanding on the causes and effects of epilepsy. This has explained why the author had so much interest on the issue of epilepsy. The application of western medications appears to be a problem in Africa because of the widely held beliefs on the causes of this disease. In the next chapter, the author begins with the concept of the Sustainable Livelihoods Framework on epilepsy management in Africa.

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# CHAPTER 2

# THE CONCEPT OF SUSTAINABLE LIVELIHOODS FRAMEWORK OF EPILEPSY MANAGEMENT IN AFRICA

## Introduction

Collier (2007) argues that when one is doing development work, an essential factor is to ensure the state is in a position to secure the support of development activities. Petersen & Pedersen (2010) concur with Collier and further posit that if the state is unable or uninterested in creating resources that support different development activities, then there is a little chance of activities to continue. In this study, it will be argued that the government of Zimbabwe should support the development of indigenous practices in sustainable management of epilepsy in Zimbabwe. The author therefore agrees with several researchers who have advocated for sustainable livelihoods in developing countries such as Zimbabwe.

## The Sustainable Livelihood Approach

According to DFID (2000), the sustainable livelihood approach is inspired by the work of Robert Chambers in the 1980s which was later developed by Chambers, Conway and others in the 1990s.This framework is a tool in development work because it highlights how to understand, describe and analyse the main factors that affect livelihoods of local people, such as people with epilepsy in Zimbabwe. DFID (2000) has described sustainable livelihood as a livelihood that is comprised of the capabilities, assets which include material and social resources and activities which are required as a means of living. To this end, a livelihood is sustainable when it copes with and recovers from shocks and stresses maintaining and enhancing capabilities and assets, while at the same time not undermining the natural resource base.

Researchers such as Chilopola et al..., (1999), Birbeck (2000), Munthali et al..., (2013), Diop et al.., (2013), Mutanana & Mutara (2015) have described epilepsy as a mental condition attributed to spirituality in African Traditional Practices. Many people in African countries, Zimbabweans included believe in African traditional practices and have consequently resorted to traditional and spiritual medicines (Maroyi, 2013 and Mutanana & Mutara, 2015). To this end, several studies have demonstrated that people with epilepsy make use of traditional and spiritual medicines as treatment for epilepsy (Watts, 1989, WHO, 2002; Al- Safi, 2007; Luongo, 2008, Shizha and Charema, 2011; Mohammed and Babikir, 2013 and Mutanana & Mutara, 2015). The indigenous healer or diviner occupies a central place in communities' participation in life events, including epilepsy (Mutswanga & Mafunga, 2009).

In some cases, studies have suggested an inter-play between bio-medication and indigenous medication. For instance, Asadi-Pooya (2014) agree that indigenous medicines may be used to complement bio-medication. What it shows is that indigenous medicines are dominant, but unlike modern medicines they are not formalised. Simply put, people with epilepsy are coping and recovering from shocks and stresses using traditional resources thus maintaining and enhancing capabilities or assets. However, advocates of sustainable livelihood have argued that there should not be undermining of the natural resource base.

Chambers & Conway (1992) have posited that the Sustainable Livelihoods Framework is a way of understanding the livelihoods of local people, such as people with epilepsy in Zimbabwe. The approach was found to be suitable in this study because it places people with epilepsy and indigenous medicines at the centre of development agenda. This approach also draws its influence from Chambers & Conway (1992) who have suggested that a livelihood is comprised of assets, capabilities and activities that are required as a means of living. These researchers believed a livelihood was sustainable if it coped with and recovered from stress and shocks. A sustainable livelihood also provides livelihood for future generations. This approach is people centred; it is holistic and dynamic in nature. The theory also provides a framework for analysing indigenous practices in sustainable management of epilepsy in community development.

Petersen & Pedersen (2010) argue that this framework best describes what development dedicated to reduction of poverty should be focused on in order to create livelihoods for the local people, such as people with epilepsy. The first basic principle identified by Petersen & Pedersen (2010) is that the development work has to focus on the people. The study will focus on people with epilepsy and the community, the majority of who are poor. What it means is that we need to focus on what matters to people with epilepsy, and as individuals or communities differ in their cultures and how this affects the way in which they understand epilepsy treatment. Another principle identified by Petersen & Pedersen (2010) is that the poor themselves must be key actors in identifying important aspects of their own livelihoods. This study therefore seeks to find out from the community on its perceptions towards both bio-medication and traditional medication. The community knows what matters to itself such as the government, community based organisations and non-governmental organisations that handle issues of people with epilepsy. Petersen & Pedersen (2010) argue it is a principle for donors such as Epilepsy Support Foundation to be process facilitators that help people with epilepsy to be aware of their priorities and to analyse their own surroundings for resources such as traditional medicines. What it means is that participation and partnership between the community and service providers becomes essential factors in development of indigenous practices of epilepsy management. People with epilepsy are thus empowered instead of being dependant on the outside world for epilepsy management all the time. There are different components within the sustainable livelihood theory. These are vulnerability context, assets, transforming structure and process, livelihood strategies and livelihood outcomes.

## The Vulnerable Context

DFID (2000) supported by Petersen & Pedersen (2010) explain the vulnerability context as an external environment in which poor people lives in. It includes critical trends like technological and population trends. Petersen & Pedersen (2010) further argue the vulnerability context includes shocks such as the natural disasters and economic inflation as well as seasonality which describe the way prices and employment opportunities shift for various reasons. All these factors, according to DFID (2000) affect

assets that people have and therefore the sustainability of their livelihoods. In this study, it will be argued people with epilepsy are vulnerable to technological trends in the world. Indigenous technologies, for instance, the much publicised '*spiritual papa movement'* by Prophet Magaya and Prophet Makandiwa in Zimbabwe on the social media can influence people with epilepsy. Economically, people with epilepsy may not also be vulnerable because they may not have money to buy bio-medication.

## *Assets*

The sustainable livelihoods framework is also centred on the belief that people are in need of assets in order to achieve positive livelihoods outcomes (DFID, 2000). Human beings have different kinds of assets which are combined in order to achieve to livelihoods which they seek. According to Petersen & Pedersen (2010) *human capital* is one of these assets. It refers to knowledge, skills, ability to good health and labour that enables people to achieve their desired livelihoods. There are people who are knowledgeable about indigenous practices of epilepsy treatment, skills on handing epileptic people, and have the ability and good health to manage people with epilepsy.

The human capital, according to DFID (2000) is essential in order to use in the other kinds of capitals in existence. We also have *social capital*, described by Petersen & Pedersen (2010) as the social resources that people with epilepsy can get help from so that they can achieve their livelihoods. This can be done through networking, or membership of formalised groups or trust between people that make them help each other. For instance, people with epilepsy can network with indigenous doctors and medical doctors to get help. They can as well be formalised groups, like the Epilepsy Support Foundation Zimbabwe. Petersen & Pedersen (2010) also identifies *natural capital* which is understood in a very broad manner because it covers tangible factors such as natural resources like trees, land *et cetera* and more intangible products like atmosphere and biodiversity. In this study, the researcher wants to examine tangible factors such as traditional herbs and intangible products such as spirituality. Then we have *physical capital* which describes basic infrastructure and producer goods needed in order to support livelihoods that people seek. The *financial capital* is finally the

financial resources which people can use in order to achieve livelihoods that they strive for.

## The Transforming Structure and Process Component

DFID (2000) supported by Petersen & Pedersen (2010) identify the transforming structure and process component that includes institutions, policies and organisations that frame livelihoods for the poor. These are found at all levels, which are from the household to the international level. Petersen & Pedersen (2010) explain that these processes and structures are the ones that determine and access that human beings have different kind of assets, thus the importance cannot be over emphasised. Some examples of these processes include international agreements, laws and ownership rights to secure rights of people. Structures might be in existence within ministries, self-help groups in local community and banks that give credit. Subsequently, this means that these indigenous practices need to be supported with laws and international agreements to secure the rights of African people who are suffering from epilepsy.

## Livelihood Strategy

Petersen & Pedersen (2010) identify another component, livelihood strategies, a way that people act so that they can achieve their desired livelihood. According to DFID (2000), access that people have to different kinds of assets affect strategies which they employ and that structures and processes within a given society create possibilities and constraints on strategies which people are able to use. If one believes in indigenous practices of epilepsy management, it affects the ways [they] employ in managing the condition.

## Livelihood Outcome

Finally, Petersen & Pedersen (2010) claims livelihood outcomes are achievements of people's strategies of livelihood. Outcomes are described by the local people themselves, in this case, people with epilepsy since they include more than the income. Petersen & Pedersen (2010) believes for outsiders it is difficult to understand what the people are seeking and why