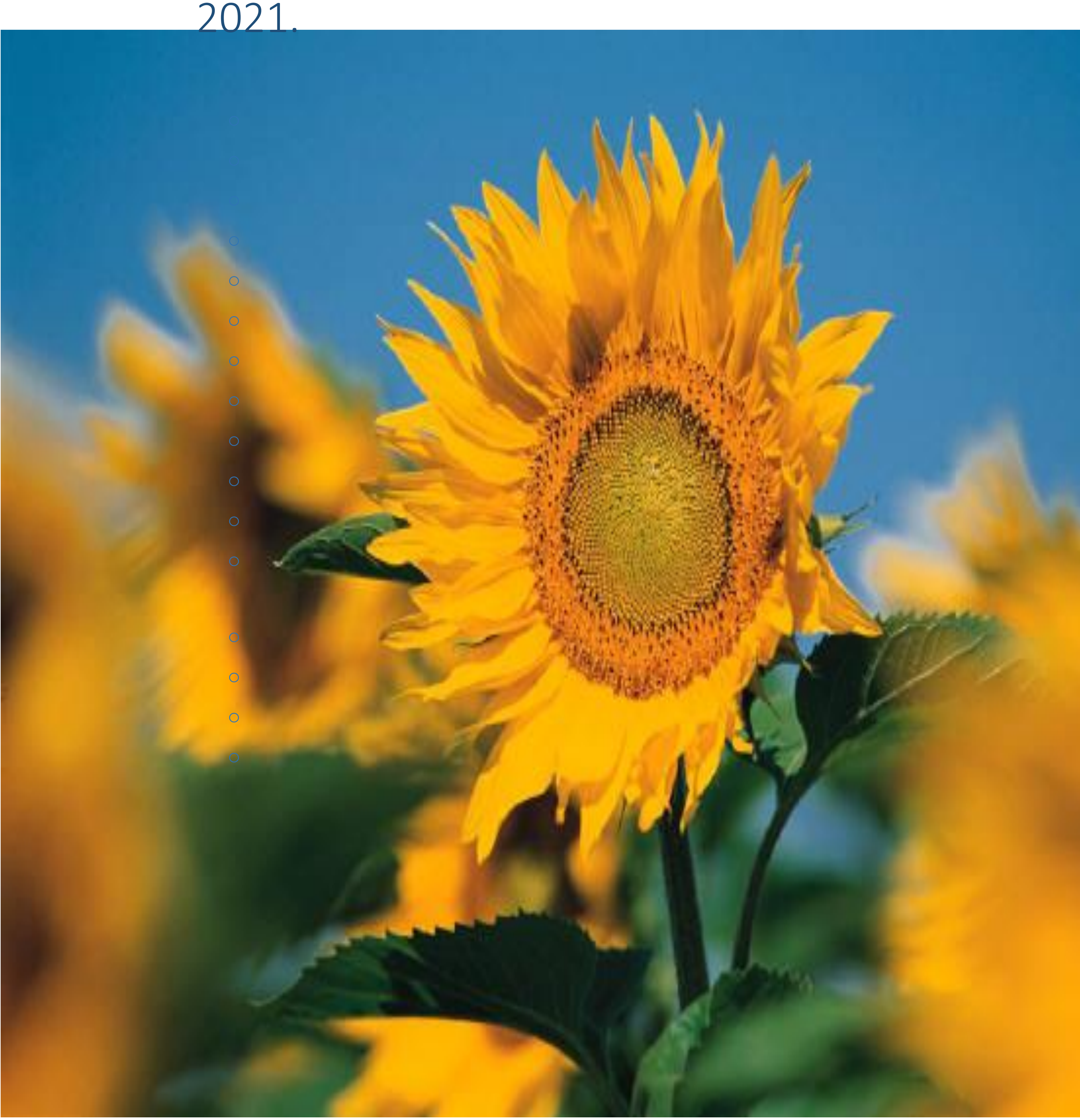
➢ EPILEPSY SIYANCOBA PROJECT 2020-2021.



Epilepsy Siyancoba Project Report-Dvokodvweni Assessment.

27 July 2021-3rd December 2021

➢ Foreword

- This project was undertaken in the Dvokodvweni constituency as there was an identified need for such a comprehensive study. This is for a few reasons. Firstly, the community of Dvokodvweni is found in the Lubombo region of Eswatini. This area (Lubombo) is characterized by a very hot and humid climate which is a factor in the occurrence of seizures. Moreover, Dvokodvweni is situated in one of the most poverty stricken areas of the country, most people living with epilepsy are common found in poverty stricken communities. The area is also situated where there is high traffic and car accident; vehicle accidents are usually accompanied by head injuries. Head injuries often eventually lead to epilepsy.

➢ Acknowledgements

This dissertation could have not been a success without the support of different stakeholders and people from the various walks of life. Firstly, EEO would like to thank God Almighty who gave us the strength, wisdom and courage to stand and be alive to accomplish this study in the midst of all the challenges that the country and the world at large is subjected to which feeds from the blows that COVID-19 pandemic served us with. The organization would like to extend sincere thanks to the following international bodies; Band Foundation and International Bureau of Epilepsy (IBE) - Africa Region, pumped coffers to cater for the financial requirements of the project from the starting point to the final mark of the Siyancoba Project.

Also, EEO would like to appreciate and heap praises to ESEPARC for providing professional criticisms, guidance and insights during this study. Indeed their input was of utmost importance in ensuring that the organization fishes the right information which are in line with the research ethical standards and they proved to be a useful tool for this piece of writing.

Lastly, we can not leave behind the respondents who sacrificed their time and attended well and fully to the questionnaires. Not forgetting all other stakeholders which comprise all the units of the Ministry of Health, Ministry of Social Welfare and the councils of Dvokodvweni constituency representing the six chiefdoms which were engulfed by the study, who through their direct and indirect efforts made this study a dream come true.

- Collaboration partners

1. International Bureau of Epilepsy Africa Region
2. Band Foundation
3. Mpaka clinic
4. The Ministry of Health
5. Deputy Prime Ministers office-Social Welfare Department
6. Dvokodvweni Constituency

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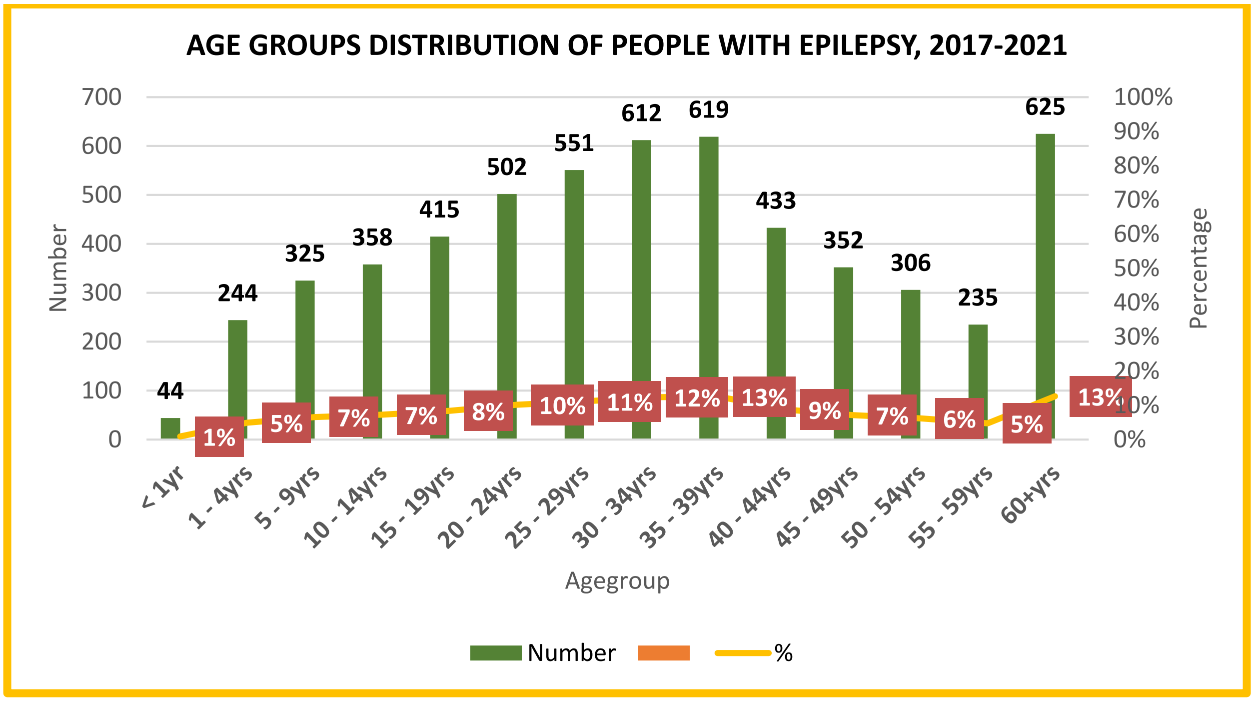
Contents


AGE GROUPS DISTRIBUTION OF PEOPLE WITH EPILEPSY, 2017-2021
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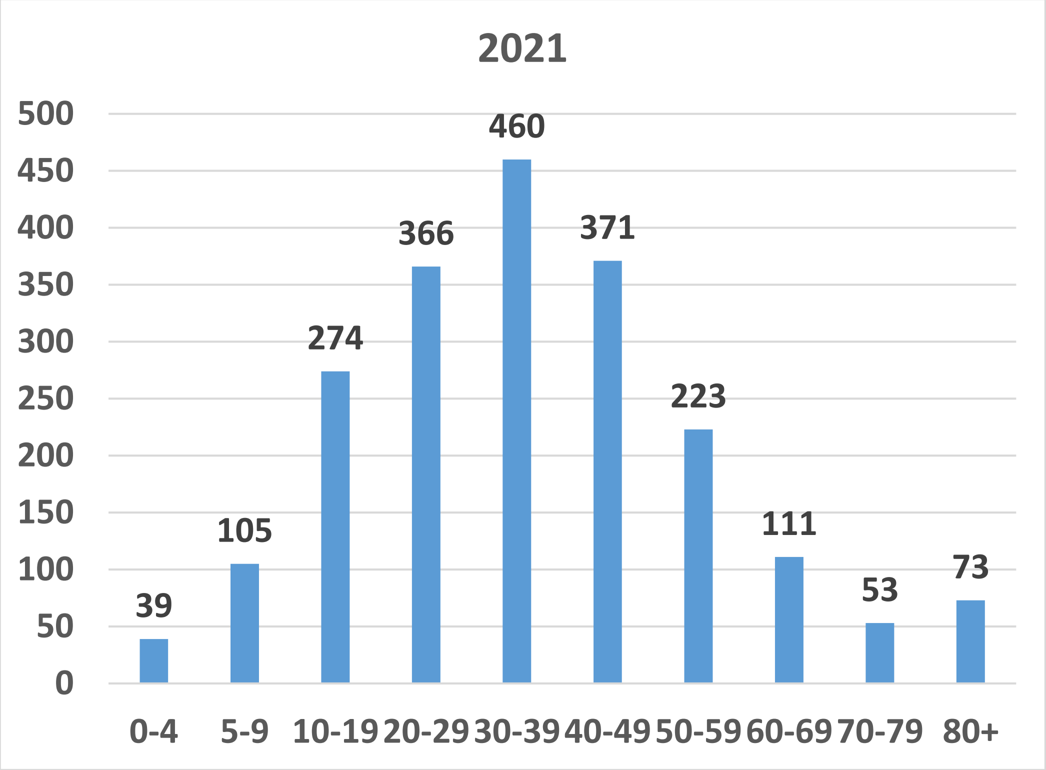
2021
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274
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73
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10-19
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30-39
40-49
50-59
60-69
70-79
80+

➢

Glossary of terms

Epilepsy - is a non-communicable, chronic brain condition, that affects people of all ages

Adults - in this Assessment refers to persons 15 and older

Constituency - in this assessment it refers the Dvokodvweni and its citizens

WHA 68.20(2015) - Sixty-eighth **World Health Assembly** A68.

WHA 73.10 (2020) - The Seventy-third **World Health Assembly** (**WHA**) adopted resolution **WHA 73.10** on Global actions on epilepsy and other neurological disorders

IBE-Africa - The International Bureau for Epilepsy in the African continent

Intersectoral Global Action Plan - The intersect oral global action plan on epilepsy and other neurological disorders 2022–2031 is a milestone document and is a major accomplishment in the collaboration between the WHO, the Member States and non-State actors – WFN, ILAE, IBE and others.

Children - in this Assessment refers to individuals 10 years and under

Persons with Epilepsy - in this assessment refers to a person diagnosed with epilepsy.

Disability- Physical or mental condition that limits a person's movements, senses, or activities.

People with Epilepsy and Disability- in this assessment refers to people who have disabilities caused by epilepsy

Human Immunodeficiency Virus - A virus that attacks cells that help the body fight infection, making a person more vulnerable to infections

HIV prevalence - Percentage of People Living with HIV.

Informed consent - The purpose of the research is explained to, including role and how the trial will work.

Informed assent - is a term used to express willingness to participate in research by persons who are by definition too young to give informed consent but an older guardian consent on their behalf

Tuberculosis - a bacterial infection spread through inhaling tiny droplets from the coughs or sneezes of an infected person.

Stigma - a mark of disgrace associated with a particular circumstance, quality, or person

Discrimination - The unjust or prejudicial treatment of different categories of people or things, especially on the grounds of race, age, or sex.

Knowledge gap - A disparity in access to information

Seizures - a sudden, uncontrolled electrical disturbance in the brain.

Rural health motivators - community rural health advocators

Comorbidities - disease or medical condition that is simultaneously present with another or others in a patient.

Advocacy - Actions that attempts to influence policymakers and stakeholders by increasing both public attention and private pressure/incentives on a certain issue

Awareness - Action taken to inform or educate people about a topic or issue but not necessarily aimed at specific behavioral or policy change

HIV incidence - The estimated number of persons newly infected with HIV during a specified time period

➢ Abbreviations of terms

EEO - Eswatini Epilepsy Organization

PWED - Persons with epilepsy and Disabilities

IGAP - Intersectoral Global Action Plan

WHA - World Health Assembly

RHM - Rural Health Motivators

SDG - Sustainable Development Goals

WHO - World Health Organization

IBE - International Bureau of Epilepsy

PWE - Persons with Epilepsy

DALYS - Disability Adjusted life years

NCDs - Non-Communicable Diseases

TB - Tuberculosis

MDR - MultiDrug Resistant

HIV - Human Immune Virus

ASD - Autism Spectrum Disorder

EDUC - Epidemiology and Disease Control Unit

TWG - Technical Working Group

PLHIV - People Living with HIV

HMIS - Health Management Information System

CMIS - Client Management Information System

OVC - Orphan and Vulnerable Children

MEHPRI - Making Epilepsy a Health Priority in Africa

SHIMS - Swaziland HIV Incidence Measurement Survey

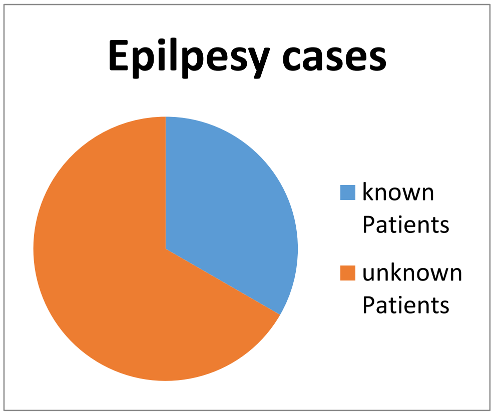
1. Summary of key findings

The major findings from the assessment will be presented in various themes and subthemes.

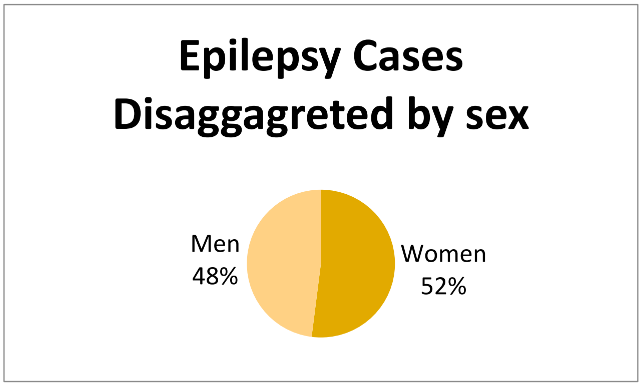
1.1 The Extent of Epilepsy in the constituency

○

It was accentuated from the results that Epilepsy comes third among non-communicable diseases recorded in the Dvokodvweni Inkhundla, the magnitude or rough estimate of the population being treated for epilepsy was gathered through the sampled population out of the 100 PWE sampled at the Dvokodvweni Inkhundla, it was found the 60% of those were known patients the remaining 40 were still unknown and not found in any databases Statistics of PWE and other neurological disorder.



1.2 Statistics of PWE and other neurological disorder



Results from the Data of the number of PWE gathered from Mpaka clinic highlighted that there were more women (52%) than men (48%) who came to seek assistance in health care facilities pertaining to epilepsy.

- The data also highlighted the alarming rise in the number of HIV cases mainly in women and young PWE mainly 80% of women with epilepsy have been diagnosed with HIV.
- The findings also postulated that very little proportion of the PWE are deaf and mute, while a majority presented with physical disabilities which were caused by the condition.
- It was established that most of the women with epilepsy were living with chronic diseases like HIV, TB which subject the PWE to mental health disorders Stress related disorders, depression and anxiety disorders.

1.3 Perceptions in relations to PWE

1.3.1 Witchcraft

- One family highlighted that the epilepsy came as a result of witchcraft practice which the PWE was subjected to at a tender age, since the person started portraying signs and symptoms of epilepsy as early as three years of age.
- The findings revealed that a large magnitude of PWE uses traditional interventions to help combat and cure the condition, since they believe the cause is traditional.

1.3.2 Head Trauma

- Another perception that was prevalent from the assessment was that of head trauma where by the PWE stated that they were assaulted and suffered head injuries which they believed marked the onset of epilepsy in their lives because it was after that experience that they started having seizure eruptions. This was more dominant with the older people (mostly male)
- 4 out of the 15 males that were subjects of the study brought forth that they experienced the head injury while they were under the bracket of the working class which according to them later caused epilepsy.

1.3.3 Ancestral Calling

- One PWE verbalized that the cause of epilepsy in his life, was because of an ancestral calling that he had, and the ancestors were punishing him for not answering the call.

1.3.4 Unknown Causes

- About 45% of the total study sample clearly stated that they were not aware of what could be the cause of the epilepsy that they were diagnosed with. Among these PWE, were the 5 patients who showed signs of mental instability?
- This proved that epilepsy was just a tip of an iceberg in their dysfunctional well-being, there is a need for engaging other social service likes the therapeutic intervention, and administering of psychiatric medication on top of the anti-epilepsy treatment

1.3.5 Severe headaches

- One PWE stated that epilepsy came as a result of suffering severe headache for quite an extended period of time.

1.4 THE SOCIAL SETTING:

1.4.1 The social environment in the school

- The study has proved that most of the people with epilepsy we engaged with at community level were school drop-outs.
- The findings from the results also revealed that most children with epilepsy are slow learners and those who were intellectually gifted in their earlier stages of learning gradually lost their academic competency.
- The study reflected the lack of first aid equipment and knowledge from teachers and other students on seizure management resulting in an unfavorable learning environments

1.4.2 Family setting

- The study established that a majority of the PWE at the Dvokodvweni Inkhundla are from families living below the poverty line.
- The study revealed most of the PWE are dependent population who are chronically ill and children of very tender age.
- The findings highlighted The majority of the PWE are being stigmatized, discriminated and suppressed due to the condition
- The PWE are mostly perceived by their family and community members as “good for nothing “this in-turn negatively affects their self-esteem.
- Most PWE have comorbid conditions, HIV/AIDS being the most prevalent among PWE , Management of the comorbid conditions is poor ,Awareness levels are very low leading to poor adherence on epilepsy medication, ART, and others

- There is burnout on the caregivers especially RHMs and family level caregivers due to lack in knowledge and resources such as basic PPE including the epilepsy treatment medication

1.4.3 Health facilities

- It was accentuated from the findings that there is still lack of primary health care services in the community, these has resulted to lack of medication available in the local clinics staff shortages due availability of clinics, professional staff to deal with these condition e.g. occupational therapist

1.4.4 Community

- Drawing from the empirical data it was highlighted that neither one of the chiefdom situated under Dvokodvweni Constituency provide services at the community level, specially dedicated to address the needs of the people with epilepsy, with an aim to optimize clients functioning in the society.
- Available support systems of the likes of umphakatsi and Nearest Care Point (NCPs) provide no social services to people with epilepsy.
- From the findings it was revealed that the Rural Health Motivators (Bagcugcuteli) are not capacitated in handling epilepsy cases as they had little to no knowledge on epilepsy first aid guide and management,
- Observations from the assessment also highlighted that PWED only receives partial psychotherapy in local clinics.

1.5 REASONS FOR POOR ADHERENCE

1.5.1 Scarcity of medication

- From the findings it was ascertained the scarcity of medication in the hospitals was one of the major reasons of poor adherence to medication by persons with epilepsy, That has resulted in them changing medication several times because of its unavailability and scarcity in the hospitals.

- It was reported that the PWE would be given any anti-epilepsy drug that is available at that particular time; this was caused by the unavailability of epilepsy drugs in the hospital.
- The findings highlighted that PWE have to travel to hospitals in Manzini and Siteki or even Mbabane and Sidvokodvo (the Luke Commission) due to unavailability of medicine in the nearby Mpaka clinic. This puts financial pressure to the already financially incapacitated PWE

1.5.2 Lack of food

- According to the assessment done, the people with epilepsy are living below the poverty line.
- It was reported that the PWE don't adhere to the medication because of lack of food one participant reported to have tried taking the medication on an empty stomach, however that caused them to experience adverse effects such as nausea, headache, dizziness and many more minor illnesses.
- The situation becomes worse when the PWE has comorbid conditions considering that the study revealed that 80% were HIV/AIDS positive

1.5.3 Forgetful

- Some of the PWE reported that their mental ability has declined such that they have brief spells of blockages which cause them to forget taking their medication.
- The findings from the assessment highlighted that the people with epilepsy don't adhere to the medication, don't administer their medication on time and they even overdose the medication due to the decrease in their mental ability.

- lack of treatment supporters and medication reminders such as alarms and pill boxes was also one of the major cause which resulted in them forgetting to not taking their medication,

1.5.4 Drying up of financial sources

- Reference to the findings, a number of people with epilepsy under the Dvokodvweni Inkhundla are not serviced locally.
- Four out of the entire population of study reflected that they are having the medical service at Psychiatric Centre in Manzini. So they sometimes run out of coffers to cater for their travelling costs.

1.5.5 Lack of personal assistance

- The findings revealed that some of the individuals with epilepsy are living in isolation and others have been abandoned by their children and that has contributed greatly to those individuals' poor adherence.

1.6 The rate of discrimination and stigma associated with PWE

- It was observed from the assessment findings that people with epilepsy were being discriminated at schools, communities, workplace and also in the families where they live
- Results from the assessment further indicated discrimination of PWE in the work place this was justifiable by one PWE who indicated he was not employed due to the level of stigma and discrimination he experienced in this previous employent
- The study revealed that there are a number PWE who are not diagnosed due to the stigma associated with epilepsy which is a cause for many being concealed from the public eye as they are labelled as a curse or a bad omen to families.
- The results highlighted that PWE reported a high prevalence of stigma and discrimination and labelled the major cause of epilepsy as demon possess
- Most PWE reported to have self-inflicted -stigma.

1.7 Knowledge gap

- Results from assessment revealed that PWE, families, and rural health motivators have misconceptions on epilepsy management and lack knowledge and skills on taking care of the individuals with epilepsy.
- It was found that most of the families have their own beliefs and perceptions on the ways to control seizures.
- According to the assessment, it was found that unhealthy, harmful and dangerous remedies are being used by family members of the individuals with epilepsy to control the seizures.
- A family reported that they use a shoe to control the seizures, whereby they hit the individual with the shoe on the nose, as they believe that such practice helps to control the seizures once they occur. Others reported they control the seizure with the use of water, whereby they shower the individual with water during the seizure.

1.8 Scarcity of Community services

- The results indicated Scarcity of community service for PWE, there were no services provided by the community and umphakatsi which are specially dedicated for people with epilepsy and other related disabilities.
- The assessment also revealed that the Bagcugcuteli are not educated on Epilepsy, thus PWE face social exclusion. The situation becomes worse when the epilepsy has graduated to a physical and /or mental disability

1.9 Dependence

- With reference to the assessment, it was noted that most of the people with epilepsy are leaning on another for survival.
- The findings also gave light that most of the people that dominate the epilepsy population are from poverty stricken backgrounds thus are highly dependent on their family members. This paints a gloomy picture since most PWE in the

community are from poor families, much against the backdrop that Dvokodvweni Inkhundla where the study was conducted

- The results highlighted that most PWE were the dependant population mainly young children and older generation (60 years and above)

1.10 Disabilities

- The findings from the interviews showed that a number of people with epilepsy under Dvokodvweni Inkhundla have a number of disabilities. Some of them were born with these disabilities, and for others it caught up with them at a later stage of life.
- The findings revealed that the major disabilities are of the likes of mental disability which come with distorted thoughts, dysfunctional perceptions and beliefs.
- The findings also gave light to other forms of disabilities that were reflected by the study population, mainly physical disability which comes as a result of seizures; where they fall either on fire, on objects or hit hard against the ground.

1.11 Hygiene

- The findings ascertained that, most of the people with epilepsy have poor hygiene
- The study assessed cleanliness of the PWE; the clothing they wear, if their bodies were washed, and if their hair was combed, With these 17 PWE, their present ability proved to be opposite to what could be expected of a patient as 14 out of the 17 PWE who were part of the assessment had poor hygiene
- The scarcity of water is one reason for the major cause of poor hygiene , as some households shared their water with animals in the earth dams and sometimes the storm water was used for domestic usage.

2 Introduction

2.1 Overview of EEO Dvokodvweni assessment

This report is produced by the Eswatini Epilepsy Organization (EEO) as results of a study on the epilepsy situation in the sampled area of Dvokodvweni Inkhundla (one of the 59 Constituencies) and it highlights the available evidence on the burden of epilepsy in the country. It represents a collaborative effort between the Eswatini Epilepsy organization (EEO) and Dvokodvweni Inkhundla to help guide policy makers and a range of stakeholders to take actionable steps towards prioritizing epilepsy in the national health agenda. The situational analysis of the sampled area gives a picture of the epilepsy situation in the various communities of Eswatini.

This study was conducted as part of EEO’s Epilepsy Siyancoba Project whose overarching goal is to establish and strengthen efficiencies in epilepsy programming, management and treatment. The study therefore is meant to provide evidence on the actual situation on livelihoods of persons with epilepsy in order to inform and support equitabilities and efficiencies in epilepsy programming, management and treatment in the country. By default the project mirrors the country’s public health response against the required global and regional standards to make epilepsy a health priority in Africa and globally. The report therefore is an important milestone in re-emerging and translating the

WHA 68.20 (2015) Resolution into action as it will provides guidance to government, policy makers and stakeholders as they seek to reduce the disease burden as part of the universal health coverage, coupled with the newly endorsed WHA 73.10 (2020).

Epilepsy is not often recognized as a global public health priority, this is despite the high global prevalence and burden of disease for people with epilepsy and their families, the economic impact, the associated stigma and social exclusion. This report will also try to achieve, the united nations The Sustainable Development Goals (SDGs) goal number 3 (Good Health and Wellbeing for all) while also seeking to achieve global economic, social and environmental sustainable development, which cannot be achieved without investment in physical and mental health for all people, including those with epilepsy.

The report will also respond to the call by the 73rd WHA (November 2020) directive to the WHO Director General to; in consultation with member states, develop an Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders whose aim is to ensure a comprehensive, coordinated response across multiple sectors. Following the WHA 2020 Resolution, the International Bureau for Epilepsy (IBE) Africa region initiated a project to spearhead strategies for Making Epilepsy a Health Priority in Africa (MEHPRI), from which this project was born.

The findings of this report are an evident call for accelerated action to make epilepsy a public health priority in Eswatini especially as it shows the vulnerabilities of PWE and how they struggle with social and economic challenges, and how so many of them have comorbid diseases especially HIV and AIDS.

2.2 Assessment objectives

These report provides an up-to date review that will inform actions to improve the lives of those with epilepsy nationally, it will also outline key information about epilepsy, ranging from its epidemiology and burden, perceptions, knowledge gaps, reasons for poor adherence, and the current state of research available to help the local communities and country at large as we embark on efforts to improve epilepsy care and outcome in the kingdom.

The target audience of this report is broad: They include policy makers, public health experts, specialists and non-specialist health care providers, PWE, primary care givers, communities and civil society organizations.

2.2.1 Primary objectives:

1. To conduct an assessment on the extent of epilepsy in the constituency.
2. To ascertain how the community under the Dvokodvweni Inkhundla perceive and relate to Persons with Epilepsy.
3. To highlight statistics of PWE and other neurological disorders/ comorbidities
4. To assess the social setting of PWE, mainly how they interact within their everyday living experiences, including their social environment in the likes of school, family, community and health facilities.

2.2.2 Secondary Objectives:

1. To explore the causes of epilepsy.
2. To investigate time when PWE are more prone to seizure.
3. To explore means done by PWE and family members to control seizures during occurrence
4. To assess reasons for poor adherence.
5. To examine chronic diseases prevalent amongst PWE
6. To explore the rate of discrimination and stigma associated with PWE
7. To measure the rate of stress related disorders prevalent amongst PWE
8. To assess the knowledge gap of PWE
9. To measure the rate of Disability Induced Epilepsy
10. To investigate the community services available for PWE
11. To explore the rate of social exclusion faced by PWE
12. To explore PWE hygiene
13. To explore the family setup mainly the financial status, income generating activities and opinion expression

3 Purpose of the assessment

The purpose of the assessment was to gather and analyze data on the burden of epilepsy in order to inform epilepsy plans and programs, as well as foster public health policy reconsiderations. The findings from this assessment will set a viable stage to raise epilepsy into a new plane of acceptability in the public domain as per EEO awareness and advocacy goals enshrined in the organization's extended strategic plan of 2013 – 2018 extended to 2023. Advocacy and awareness planning will benefit from this study as it will help guide relevant and tailor made information to the public and to relevant stakeholders such as legislatures, policy makers and other CSOs.

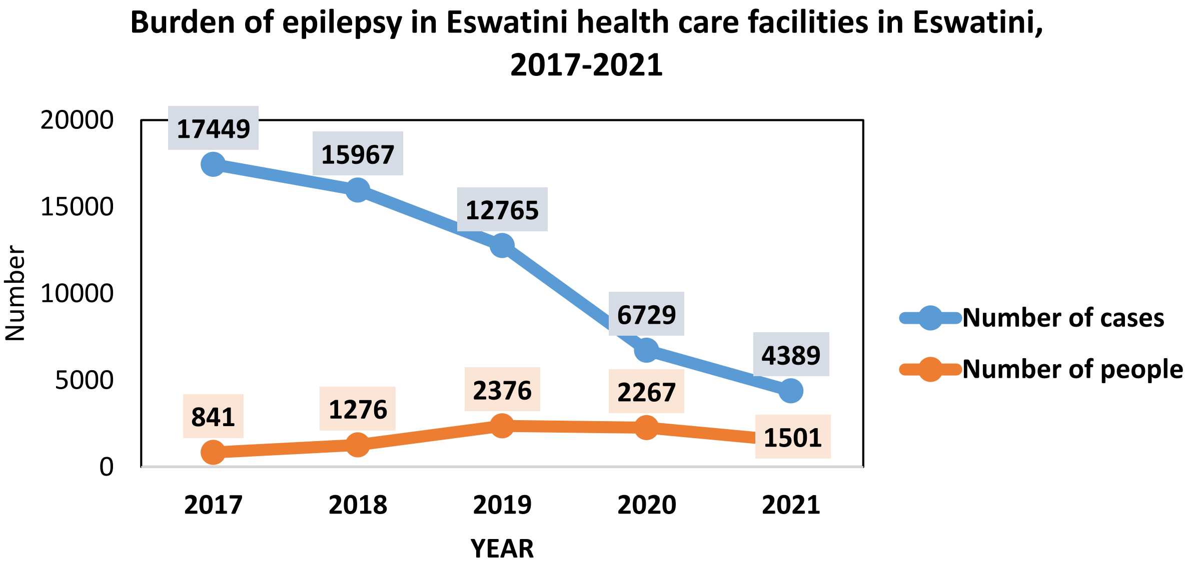
4 Significance of the Assessment

To initiate an assessment of the extent or the magnitude of epilepsy in the constituency, and learn how other people within the area perceive and relate to someone with the condition as means to provide effective, timely and responsive diagnosis, treatment and care while also strengthening the public health approach to epilepsy as means to raise policy prioritization and strengthen governance.

5 Burden of Epilepsy in Eswatini

Statistics from the Health Management Information System show that the number of reported epilepsy cases has declined annually over the past 5 years from 17449 in 2017 to 4389 in 2021. Contribution factors may vary but a notable one is the changes in the health information systems from paper based to electronic which may not necessarily mean that the number of people affected by the condition have declined as well. The number of people reported from the electronic system (CMIS) as shown in the figure below quantifies the individual persons who accessed epilepsy services in 2017-2021. This patient level data better informs on the burden of the disease in the population. The data shows that the number of people seen in health facilities was the highest in 2019 with 2376 and lowest in 2017 with 841 people reported.

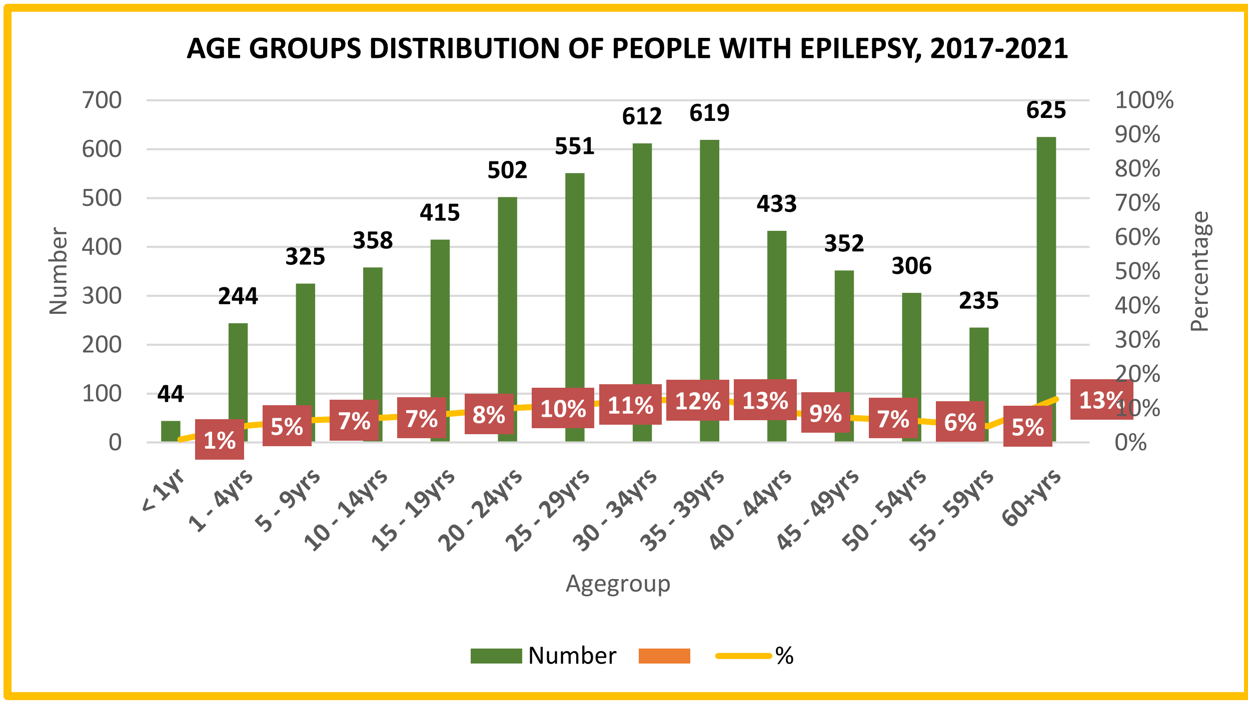
5.1 Burden of epilepsy in health care facilities in Eswatini, 2017-2021



Source: *Ministry of Health (HMIS web portal and CMIS)*

The figure below shows the distribution of people with epilepsy by age group. From the patient level data collected by the electronic system from 2017 to 2021, it shows that the condition increases with increasing age up to age 39 and starts declining from age 40 to 59 years. The 60 years and older are affected the most as they have the highest number of people with the condition with 625 people. With the start of the epilepsy Siyancoba project , the predicted rate of PWE is hoped to increase , Thus the organization has to work tirelessly and seek partnerships that will help make epilepsy a health priority in the country

5.2 Figure 2: Distribution of people with epilepsy seen in health facilities by age group, 2017-2021



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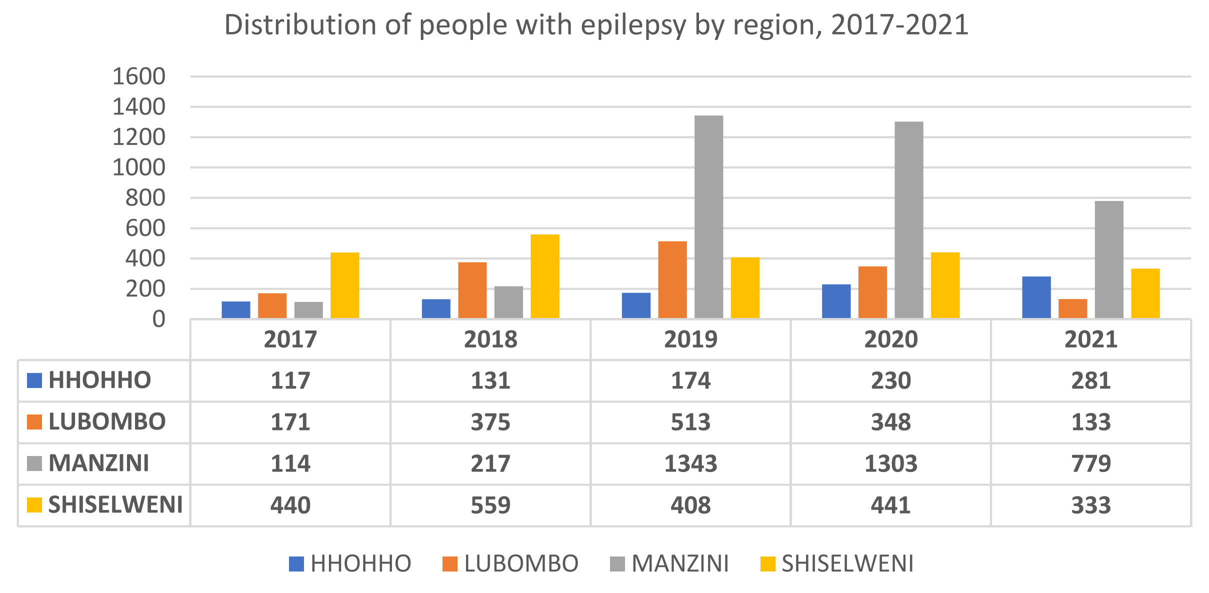
Source: CMIS 2021

Disaggregating by region, the data shows that more epilepsy were reported in Manzini in all the years compared to the other regions ranging from 8810 in 2017 to 2137 in 2021. The lowest number of cases has been reported in the Shiselweni region with numbers ranging from 1681 in 2017 to 435 in 2021. In all the regions the trend has been declining.

5.3 Figure 3: Age group distribution of people with epilepsy seen in health facilities by region, 2017-2021



	2017	2018	2019	2020	2021
🟦 **HHOHHO**	**117**	**131**	**174**	**230**	**281**
🟧 **LUBOMBO**	**171**	**375**	**513**	**348**	**133**
⬜ **MANZINI**	**114**	**217**	**1343**	**1303**	**779**
🟨 **SHISELWENI**	**440**	**559**	**408**	**441**	**333**

. Source: HMIS web portal, 2021

The distribution by sex of epilepsy shows that 54% of males are affected compared to 46% of females

5.4 Figure 4 distribution of people with epilepsy by sex 2017-2021

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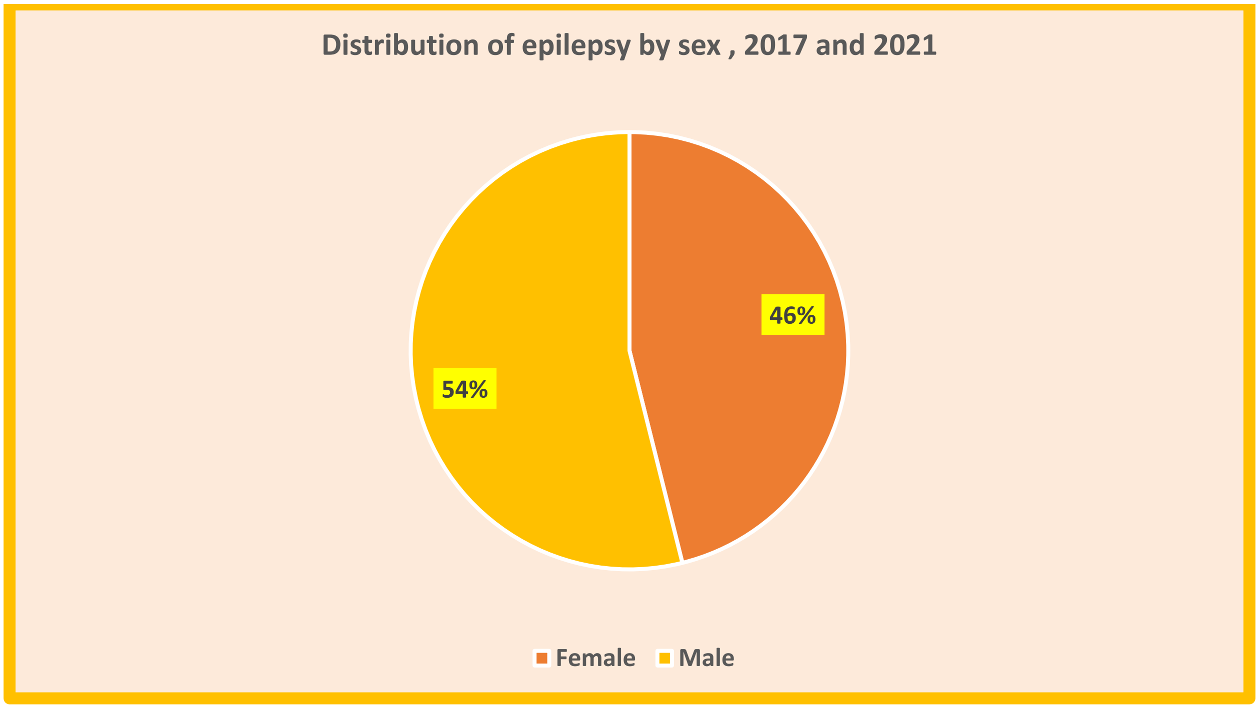
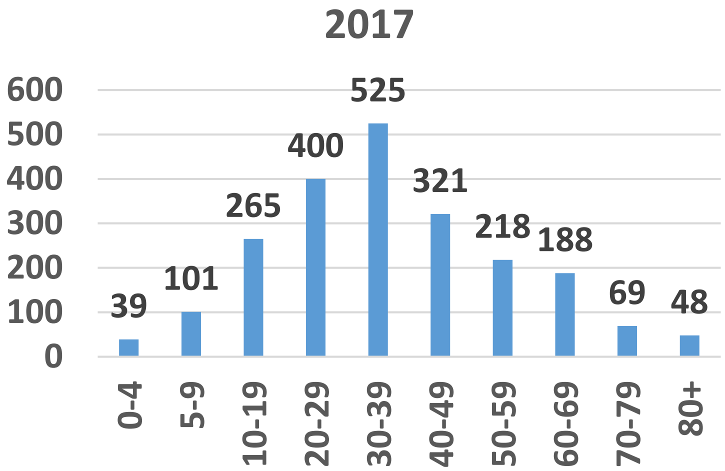


Source: HMIS web portal and CMIS 2021

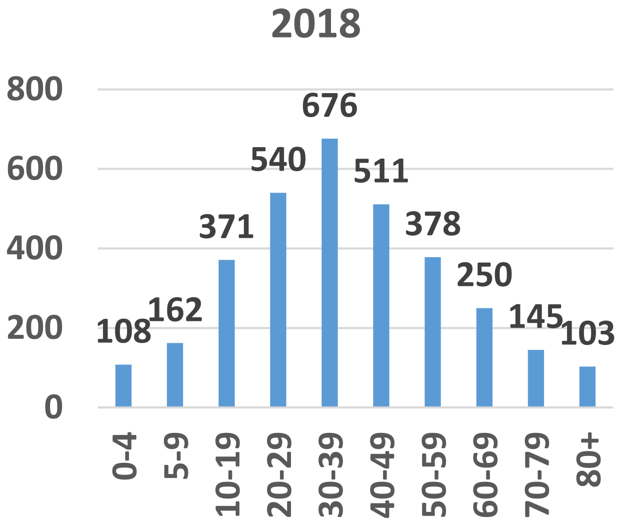
The graphic presentation highlight that persons between the age ranges of 30-39 reported high cases of epilepsy, when compared to other age groups and also gave light that they were still less young people and older people coming forward to seek health assistance on epilepsy management

5.5 Figure 5 epilepsy cases disaggregated by age for year 2017



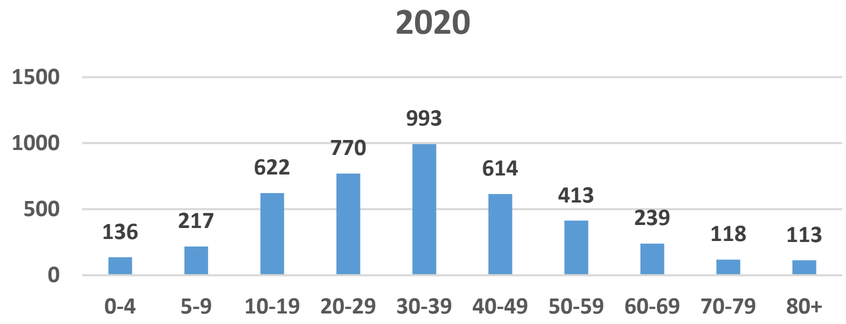
Source: EDCU

5.6 Figure 6 Epilepsy cases disaggregated by age for year 2018



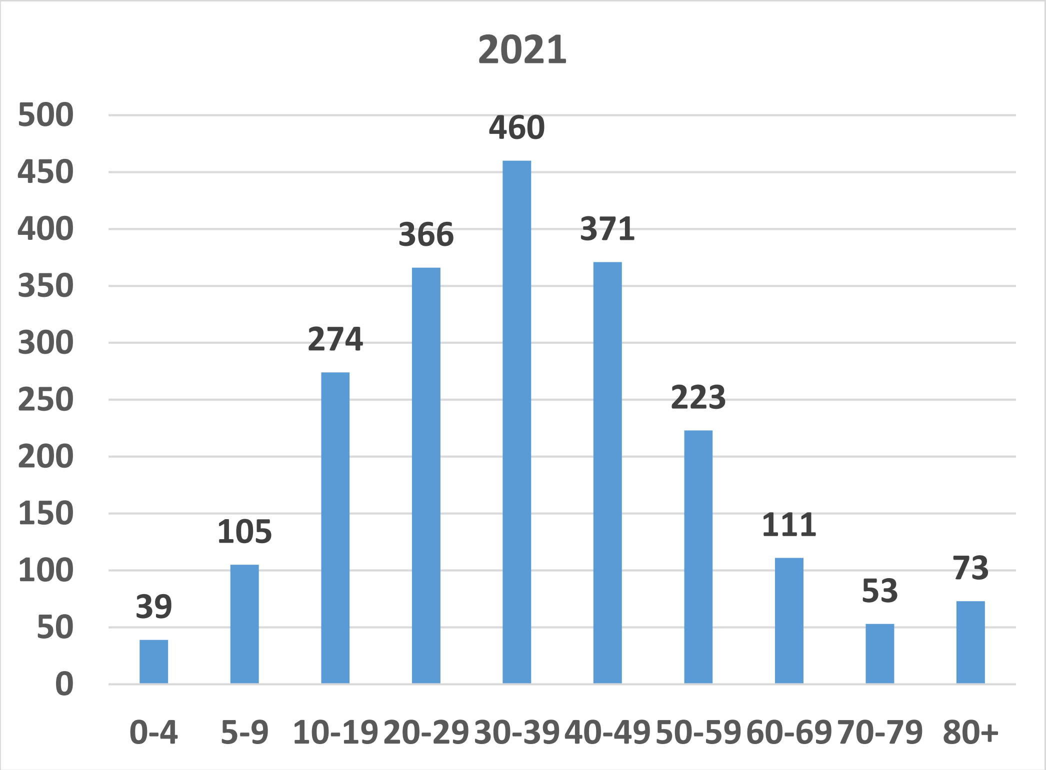
Source :EDCU

5.7 Figure 7: Epilepsy cases disaggregated by age for year 2017



Source: EDCU

5.8 Figure 8 Epilepsy cases disaggregated by Age for the year 2021



Source: EDCU

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6 Common comorbidities with epilepsy

6.1 Introduction

Roughly 50% of adults with active epilepsy have one or more coexisting physical, chronic and psychiatric conditions, these comorbidities are associated with poor health outcomes, such as increased health care needs, decreased quality of life, poor response of treatment and higher mortality, epilepsy is comorbid with several NCDs including psychiatric, Human Immunodeficiency Virus (HIV) and Tuberculosis (TB), which increase burden of the disease.

6.2 Psychiatric comorbidities

6.3 Global

The most common psychiatric comorbidities are depression (23.1%) and anxiety (20.2%), which are more common than the 4.4% and 3.6% of mental health conditions in the general population. They have a reported prevalence of 29–40%, which is 7–10 times higher than that of mental health conditions in the general population. Alcohol consumption (8.7%), drug use (7.8%), and interact psychosis (5.2%) are less common mental comorbidities in epilepsy than in the overall population internationally. The estimated suicide rate for people with epilepsy is between 5.3% and 14.3%.

6.4 Eswatini

Need records from National psychiatric referral center in the case of Eswatini

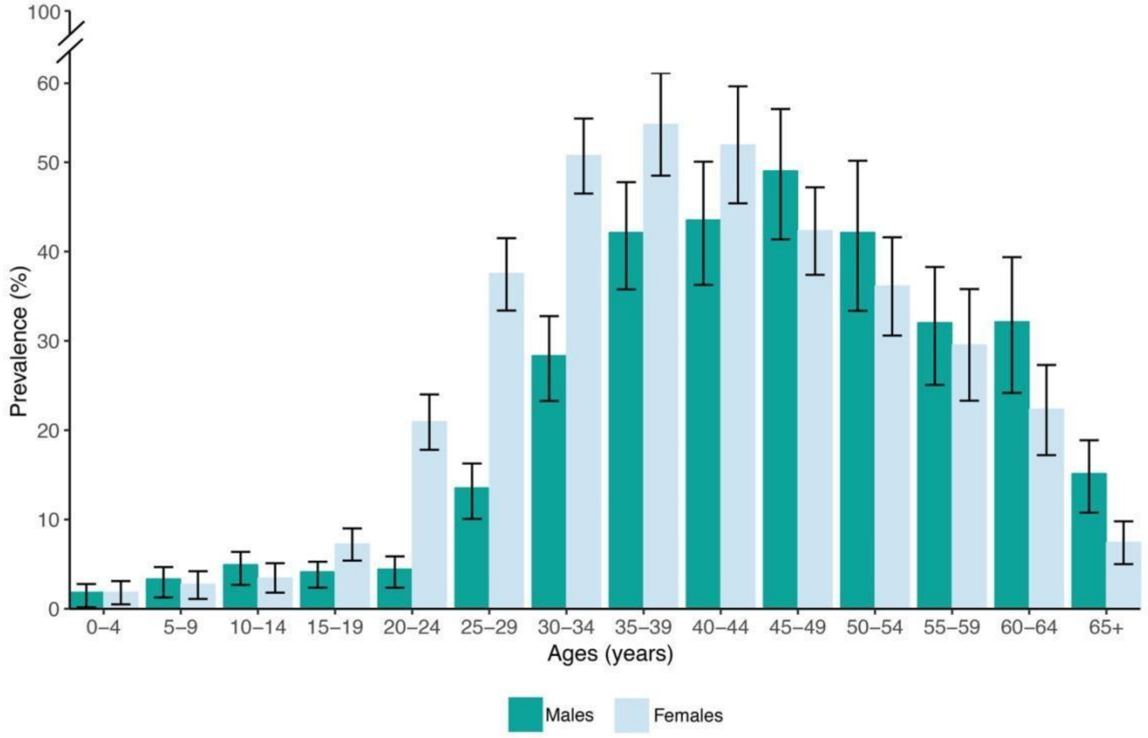
No literature available on databases

6.5 HIV

6.6 Background

As a result of the severity of the HIV and TB epidemics, Eswatinis average life expectancy drastically decreased from 60 years in 1991 to just 46 years in 2005 (UNDP 2017). Life expectancy increased significantly to 57.7 years in 2018, almost regaining its pre-1991 level as a result of the nation's aggressive response to HIV, which included providing life-saving ART. About 20% of children between the ages of 0 and 17 are orphaned, reflecting the lingering effects of the epidemic's high mortality in the past. The Swaziland HIV Incidence Measurement Survey (SHIMS 2) in 2016-17 estimated HIV prevalence among adults aged 15 and older was 27%, the highest of any nation. The highest HIV prevalence of any country was estimated to be 27% in individuals aged 15 and older by the Swaziland HIV Incidence Measurement Survey (SHIMS 2) in 2016–17. The findings demonstrated that women are disproportionately affected by HIV, and that up to age 45, their rates of infection are higher than those of men. Females aged 15 to 24 had an HIV prevalence of 13.9%, while males in the same age range had a prevalence of 4.1%. Among those aged 25 years and older, HIV prevalence was 41.2% among females and 29.9% among males. The most recent national-level statistics and projections for the HIV epidemic in Eswatini show a growing youth and young adult population, and an epidemic that heavily affects younger women compared to their male peers. Additional statistics show a disproportionate burden of TB cases among PLHIV (66% of all confirmed cases).

6.7 Figure 4.1HIV prevalence by age and sex, SHIMS2 2016-2017



HIV prevalence among adults aged 15-24 years was 9.1% and was over three times as prevalent in females (13.9%) than in males (4.1%). Over one in three (36.3%) adults aged 25 years and older was living with HIV. HIV prevalence among adults aged 25 years and older was 41.2% in females and 29.9% in males

Among adults, HIV prevalence peaked at 49.1% in those aged 35-39 years. HIV prevalence was highest in females aged 35-39 years (54.2%) and in males aged 45-49 years (48.8%). In fact, more than half of females aged 30-34 years (50.7%), 35-39 years (54.2%), and 40-44 years (51.9%) were living with HIV. HIV prevalence, when estimated across five-year age groups from ages 20-39 years, was significantly higher in females than in males (ages 20-24 years: 20.9% vs 4.2%; ages 25-29 years: 37.5% vs 13.3%; ages 30-34 years: 50.7% vs 28.1%; ages 35-39 years: 54.2% vs 41.9%;

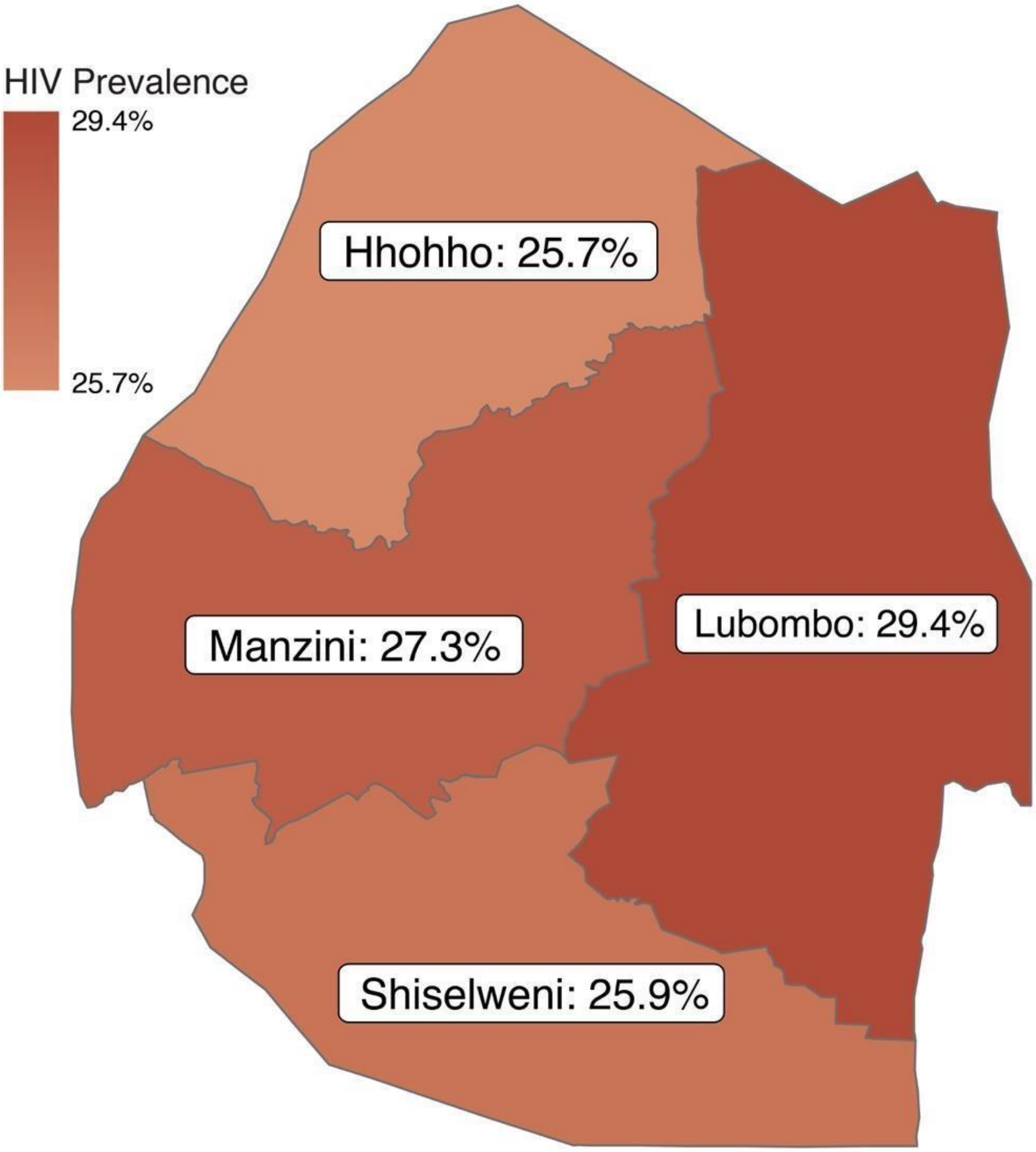
A tenth (10.9%) of adults aged 65 years and older were living with HIV. HIV prevalence was double the percentage in males (14.9%) than in females (7.4%) in this age bracket.

It is important to note that the above prevalence rate (based on the Swaziland HIV Incidence Measurement Survey 2, 2016-2017) masks the reality of HIV infection among men. While fewer men are HIV positive as compared to women in all +15-year age categories (e.g., Three times more women are PLHIV than men in the 15–24-year age category), HIV deaths are not so different between men and women (119 AIDS-related deaths among men compared with 178 deaths among women), which indicates the higher mortality among male PLHIV. This means that HIV treatment is not reaching the men as effectively as women.

6.8 Adult HIV Prevalence by Region

In Eswatini, HIV prevalence among adults did not vary significantly across regions. HIV prevalence was
25.7% in Hhohho, 25.9% in Shiselweni, 27.3% in Manzini, and 29.4% in Lubombo (Figures 6.5.A and 6.5.B).

6.9 Figure 5.1HIV prevalence (map) among adults aged 15 years and older, by region



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6.10HIV incidence amongst PWE

The high rate of HIV infections is one of the main reasons the Eswatini Epilepsy Organization is looking for ways to help combat this high rate of HIV in the constituency since 3.9% of the 29.4% rate of PLWHIV is occupied by PWE, thus the organizations is working tirelessly to develop strategies that will be put in place in various communities to help reduce the rate of HIV infections amongst persons with epilepsy and other neurological disabilities

Need Data from HMIS Systems and SHIMS

Need graphic presentation

6.11Tuberculosis

TB Case Detection and Treatment among PLHIV Eswatini experienced a continuous decline in TB case notifications from 11,057 in 2010 to 2,900 in 2019. This is largely due to enhanced TB/HIV collaborative activities and the roll out of more sensitive Gene pert platform promoting early TB case detection. ART expansion and HIV prevention programs contributed to reduction of the burden of HIV among TB patients from 82% in 2010 to 65% in 2019 according to Eswatini annual program reports. In 2020, WHO estimated the Eswatini TB treatment coverage to be at 69%, showing a drop from 80% reported in 2019, signaling missed opportunities for case detection and treatment. The Eswatini TB drug resistance survey (2018) showed that 58% of rifampicin resistant TB cases are missed by the Gene pert platform due to prevalent Ile491Phe mutation. The Ministry of Health with support from the Germany Ministry of Health is currently working on establishing TB genomic sequencing to identify the Ile491Phe mutation and PEPFAR will collaborate to ensure the success of this initiative.

6.12TB incidence amongst PWE

Need records from National TB UNIT and NCD HMIS data

Literature not available on all public sites

6.13 Other medical comorbidities

Migraine occurs in approximately 19% of people with epilepsy, intellectual disability is relatively common in people with epilepsy with an overall prevalence of around 26%, furthermore due to significance of birth injuries as a cause of childhood epilepsy, as high as 70% of children have comorbidity. comorbidities in children with epilepsy can be categorized as neurological/cognitive including intellectual disability, language impairment category fluency and response to commands of increasing length and complexity especially in those with an earlier age onset, the occurrence of speech disorders may be high as 27.5% in children with epilepsy migraines and sleep problems, psychological/behavioral the most common behavioral disorder include Autism spectrum disorder (ASD) and have increased prevalence of seizures which is estimated to be 20-25% of the whole spectrum , attention deficit hyperactivity disorder prevalence is estimated to be between 12% and 39% and physical comorbid children with epilepsy may experience physical comer conditions resulting from the condition or adverse effects of treatment some anti-seizure related medicine include disturbance of hormonal balance , may potential have a long term impact on physical health and quality of life of children with epilepsy

6.14 Eswatini

Need records, data from NCD research office

Literature not available on databases

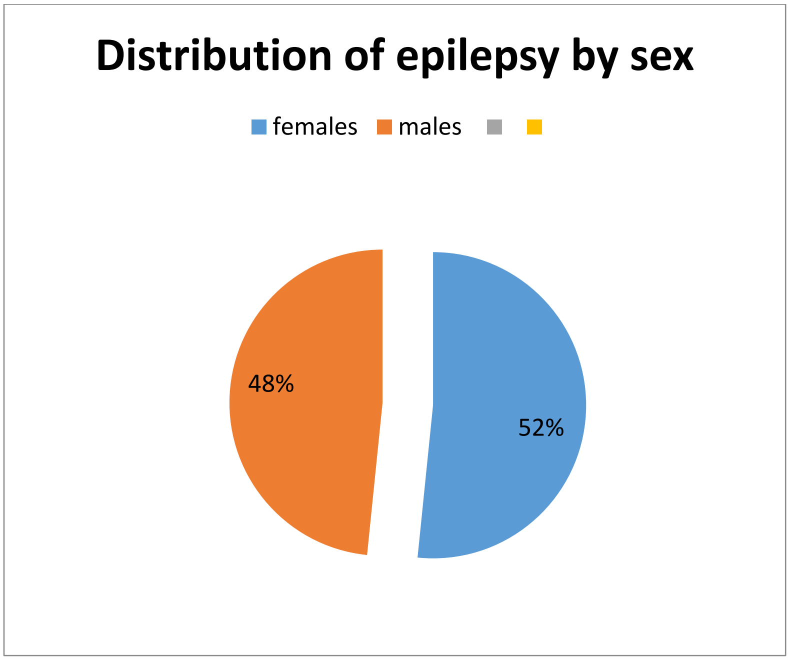
6.15 Burden of epilepsy in Dvokodvweni

Lubombo is a primarily rural region; with a lower population density, higher levels of poverty and food insecurity, a high burden of OVC, female-headed households, reduced access to services and transportation. As a reflection of need, it should be noted that only 52% of the population in this region has access to safe water, compared to the urban regions that have closer to 80%. This level of poverty impacts people's ability to seek health services at facilities and thus there is a greater reliance on mobile services and community engagement and outreach.

Data of the number of PWE was gathered from Mpaka clinic and was presented in a form of graphs from the data it was clearly highlighted that they were more women than men who came to seek assistance in health care facilities pertain epilepsy and it also highlighted on the alarming rise in number of HIV cases mainly in women and young PWE.

6.16 Epilepsy cases in Dvokodvweni Disaggregated by sex

6.17 Figure 1.5 graphic presentation in Dvokodvweni Disaggregated by sex



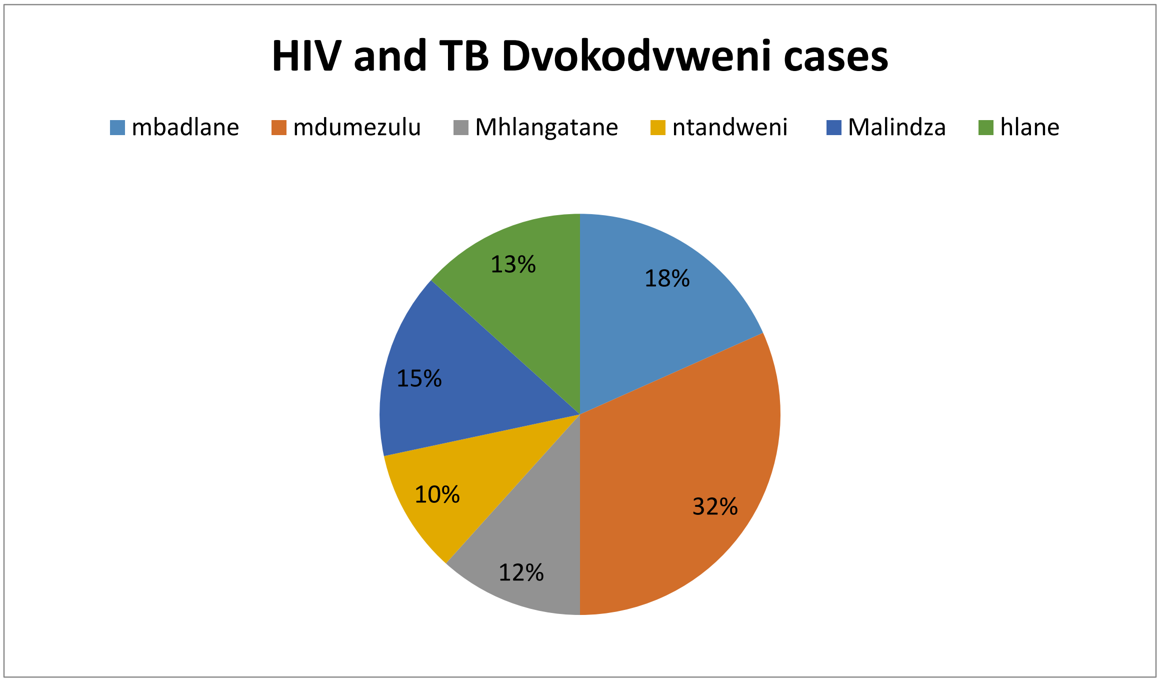
Source: Mpaka clinic records

From the presentation we see that they are more women who came to seek assistance in health facilities the data collected highlighted that majority of women were HIV positive and had other comorbidities such as tuberculosis and mental health disorders, from the data collected it gave a clear indication that the most vulnerable population which is women is heavily affected by stigmas and sexual assaults which have resulted in this high prevalence cases of HIV positive women with epilepsy.

6.18TB and epilepsy statistics in Dvokodvweni

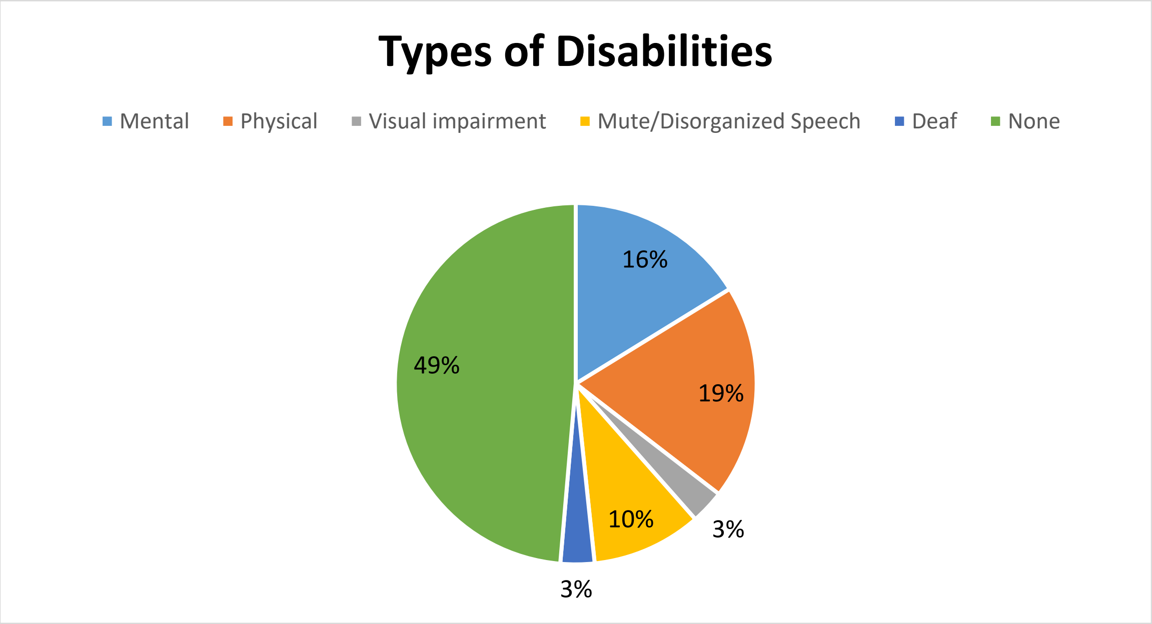
The data collected from Mpaka clinic on Epilepsy highlighted that 70% of the young children and women who were diagnosed with HIV suffered from TB , this rise was caused by late diagnoses, poor ART treatment adherences, low immune systems which resulted in the PWE to be more prone to opportunistic infections, due to lack of food and financial restrain challenge that was highlighted during the assessment, this high poverty rates prevented them getting a balanced diet that their body needs to help fight against opportunistic infections , the results also highlighted that even when the PWE were diagnosed with the TB they still had difficulties when it came to treatment adherence which in some cases resulted in high cases of MDR TB , Thus further resulting in high mortality rate cases recorded due to TB treatment failure and HIV.

6.19Figure 7.1 statistics of HIV and TB co-infection in Dvokodvweni



Source: Mpaka clinic records

6.20Figure 7.1TYPES OF DISABILITIES AND THEIR PROPORTIONS



Source; Mpaka Clinic

Very little proportion of the people with epilepsy are deaf and mute and that also calls for the need for social workers who are trained for sign language in order to actively intervene in the lives of the people with epilepsy. The rural health motivators also need to be educated and be skilled with sign language in order to be able to actively and effectively work with all the people in the communities. It is of paramount importance that rural health motivators be equipped with flexible communication skills. They should know both verbal and nonverbal communication to effectively communicate with diverse population

7 ASSESSMENT DESIGN METHODOLOGY

This section outlines the techniques used in gathering, analyzing, interpreting, and presenting the data that led to the study's final conclusions. It consists of the assessment design methodology which guides the assessment process, population, sample size, data tool, method of data collection and ethical considerations.

7.1 The information sources of this report include:

- People with Epilepsy and other neurological disabilities
- Reports from large groups of experts mainly, health practitioners, rural health motivators.
- observation, conducted by the organization which addressed a broad range of information such as plans and programs for epilepsy, health and social response to epilepsy, access to anti-seizure medication, epilepsy research, epilepsy partnership and collaborations
- Input from an advisory committee across all stages of the report development

7.2 Project setting

This project was conducted at the Dvokodvweni Inkhundla situated in the Lubombo Region of Eswatini. Its population as of the 2007 census was 28,252; the assessment was done successfully in all the 6 chiefdoms under the Dvokodvweni Inkhundla mainly: Hlane, Mbadlane, Malindza, Ntandweni, Mdumezulu and Mhlangatane. One reason which has made this constituency to be the center of attention was because it falls within the bracket of areas with highest numbers of PWE in the Kingdom of Eswatini and the extremely high temperatures of the area which fuels the existence of the condition made the Dvokodvweni Inkhundla an immaculate pilot constituency of the Epilepsy Siyanqoba project.

7.3 Population

The population comprising the Dvokodvweni Inkhundla, all the 6 chiefdoms: Mbadlane, Mdumezulu, Hlane, Malindza, Ntandweni and Mhlangatane formed part of the assessment.

7.4 Project instrument

Sensible to the objectives of this assessment , which was to measure the extent of epilepsy in the constituency , the organization used structured interviews which was developed from a structured assessment tool for data collection, The reason for employing a structured interview was because it made it easier to assist in getting accurate data from respondents in the case of sensitive questions and they are easy to replicate as a fixed set of closed questions are used ,which are easy to qualify.

The project also employed structured overt (PWE are aware they were being observed) observation as a data collection method to assess the social setting of PWED, it involved watching, listening, reading, touching and recording the behavior and characteristic of the social setting of PWE

7.5 Sampling design

7.6 Overview

The project employed a purposive typical sampling as it required researchers to have prior knowledge about the purpose of the study so they can properly choose eligible participants for the assessment, as it looked to investigate a trend and compare it to what is considered typical or average for members of the population. The sample frame was the Dvokodvweni Inkhundla, the participants were sampled from a population of 28,252 which is the whole population of the Dvokodvweni constituency as per the 2017 census, the sample for the assessment consisted of 3 different groups which included the senior nurse at Mpaka Clinic, adults (15 years and older) and children (10-and younger) with epilepsy and other disabilities.

The project interviewed 31 PWE and 1 senior nurse. The first stage comprised of engaging the council of Dvokodvweni as well as 6 councilors who are representatives of the chiefdoms, during the second stage, a sample of households was purposively selected within each of the six chiefdoms, where the average number of PWE selected was 5 individuals per chiefdom totaling up to 31 PWE being sampled (figure 1.1Dvokodvweni constituency database)

7.7 Selection criteria

7.7.1 Inclusion criteria

The selection of individuals for the assessment involved the following steps:

1. Compiling a list of all PWE in the Dvokodvweni Inkhundla from the Mpaka clinic database.
2. Identifying PWE who were eligible for the assessment.
3. Selecting individuals who meet the age and constituency requirements of the assessment.

7.7.2 Exclusion criteria

1. PWE who did not reside within the Dvokodvweni constituency
2. PWE that have comorbidities that could bias the results of the study, or increase their risk of adverse events
3.

7.8 Training of Field Staff

1. Their roles as field staff
2. The contents of the data collection assessment tool and data collection methods to be employed
3. Scientific objectives of the assessment
4. Survey design and methods
5. Completion of assessments forms
6. Staff responsibilities
7. Informed consent procedures, including PWE protection of privacy, and confidentiality.

8. How to handle and store data
9. Protocol deviations, adverse events, and reporting of events

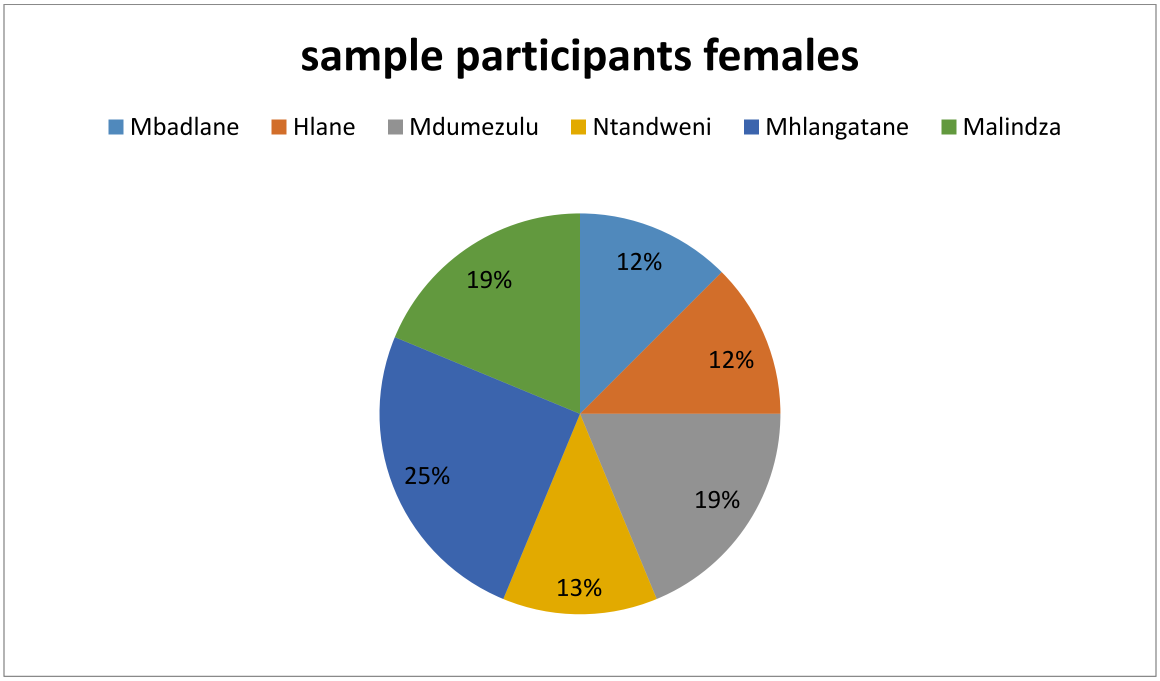
7.9 Community Sensitization and Mobilization

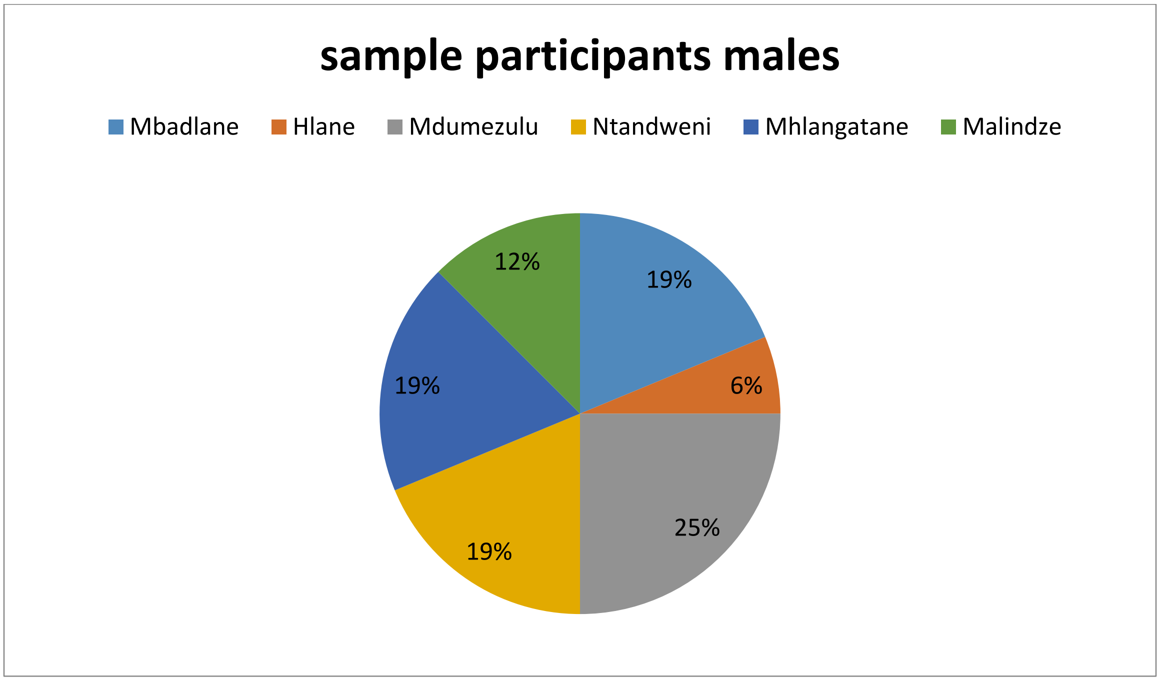
Community mobilization was conducted prior to data collection to maximize community support and participation in the assessment in the Dvokodvweni Inkhundla ,The mobilization began before fieldwork commenced with a high-level national launch meeting that engaged key gatekeepers in the communities mainly the council of Dvokodvweni Inkhundla which comprised of the Member of Parliament (Mr. Mduduzi Magagula), the Indvuna (Mr. Vincent Dlamini) who was chairing the discussions, as well as the six councilors who are representatives of the chiefdoms under Dvokodvweni Inkhundla. The mobilization teams consulted community leaders, held community sensitization meetings; disseminated informational materials to request for a “green light” to initiate an assessment on the extent or the magnitude of epilepsy in the constituency, and learn how other people within the area perceive and relate to someone with the condition.

7.10Table 1.1 Distribution of sample participants

Distribution of Sample participants from the 6 chiefdoms, EEO Dvokodvweni Assessment						
Dvokodvweni constituency						
Chiefdoms	Female	Males	Age range			
1. Mbadlane	2	3	15-45			
2. Hlane	2	1	13-55			
3. Mdumezulu	3	4	15-65			
4. Ntandweni	2	3	19-75			

5. Mhlangatane	4	2	20-45			
6. Malindza	3	2	15-55			
7. Sub Total	16	15				
8. Total	31					





7.11 Eligibility Criteria, ethical considerations, and Consent Procedures

All participants for this assessment, had to exercise their right to autonomy through Informed Consent and assent, for those participants who were below 18, illiterate and with disabilities, their parents and guardians assented for them. All participants had to sign a consent form to show that they were willing to participate in the assessment. This indicated that the participants gave their approval to be a part of the assessment, the researchers made it a point to also ask for consent throughout the interview process, and participants were also given a right to stop without giving a reason why they were stopping during the interview.

The written consent forms were provided in English, illiterate participants or participants with disability ,involved the use of an impartial witness, chosen by the potential participant, who also signed the assent form on their behalf, if no witness could be identified, the potential participant was deemed ineligible to take part in the assessment.

7.12 Measures to ensure trustworthiness for data

In data collection, issues of trustworthiness were given top importance to ensure the adherence to issues of trustworthiness, so that the result of the assessment were trustworthy and were able to be added to a body of literature on epilepsy.

Every step in this empirical assessment was covered in detail, from data collection through outcomes reporting. Every element of the analysis process, including the preparation, organization, and reporting of results, was scrutinized for trustworthiness. Steps were followed to provide a clear indication of the assessment overall credibility. Trustworthiness was addressed in the following: Transferability, Conformability, credibility, dependability and authenticity.

7.12.1 Credibility

The first criterion referring to the confidence in the truth, value of the data and its interpretation, the researcher ensured credibility in this research by continuously reading the assessment guidelines throughout the interview.

7.12.2 Dependability

Dependability is a measure of how well a research instrument produces consistent outcomes or data after multiple trials. If another researcher can do the same assessment under the same topic and use the same population, conclusions drawn can be the same when compared to this assessment. The researcher ensured dependability by keeping the results from this study in the organization's website so that anybody can access it.

7.12.3 Confirmability

Conformability refers to the criterion of neutrality according to which the bias of the researcher should be avoided with regard to the procedures and findings it relates to the degree to which a researcher’s own bias or prejudices may impact on the findings of the study. To enhance conformability, the researchers declared personal biases and prejudices at the beginning of the study to the PWE and nurse so to prevent biases

7.12.4 Transferability

Transferability replaces the notion of external validity, and is close to the idea of theory-based generalizability for the qualitative sourced data transferability measures is imperative and should be ensured. Qualitative data collection involves very small samples or single case studies and it is the role of the researcher to help the reader transfer the specific knowledge gained from the research findings of one study to other settings. The qualitative data of this assessment was collected using face to face interviews, which had 31 participants. For the enhancement of transferability purposive sampling was used in the selection of the PWE.

7.12.5 Authenticity

It involves accurately and fairly documenting and reporting the experiences of the participants, the assessment accomplished authenticity by means of not under reporting on the data gathered from the participants on how they felt about the extent of epilepsy in the constituency and perceptions

7.13 Pre - Testing the Interviews instrument

Before the actual collection of data, the researchers conducted a pre - test of the interview assessment from two participants as it is an important stage for the successful deployment of the large-scale data collection. It was paramount that the instruments were pre – tested before the real data collection process. The researchers conducted a pre - test for the interview instrument with PWE who were not part of the study as much as they were from the same region, the Lubombo region, so that the pilot group shared the same geographical area with those participants who took part in the main study. A pre- testing was conducted to establish errors in the interview schedule and to promote accuracy and establish ambiguous questions. Also of paramount importance to be considered in pre-testing of interviews is the understanding of the questions, if pilot participants interpret the questions being asked from them correctly and accurately on what is really being asked. The researchers made sure they took into consideration their interpretation of the asked questions and came up with straight questions before the real data collection process.

7.14Assessment Implementation

7.14.1Data collection procedure

A national core leadership group led by EEO Acting Director Mr Abraham Dambuza Ntshalintshali, including Social workers, Rural health motivators, Community Health Nurses were selected to provide a high oversight for the assessment, Fieldwork commenced on 27 July 2021 where a Technical Working Group (TWG) was formed to guide the process of planning and implementing of this assessment and to provide technical input as needed. The TWG includes representatives from: Ministry of Health - Non Communicable Diseases, Social Welfare Department, Civil Society Organizations, Police Service Department and Persons Living With Epilepsy (PLWE).

The researchers first engaged with rural health motivators who acted as geographical campuses, face-to-face interviews were performed with the participants, the researchers first introduced themselves to the participant during the interview process. They offered a justification for the assessment to the participants, Consent was then asked to start the interview and responses were written on the interviews assessment tools, the interviews lasted approximately 20 minutes. The medium of communication during the interviews were in English and SiSwati ,as the interviews were in progress the researchers made notes in the assessment forms and recorded all the answers. To enhance understanding of the whole process as it was of fundamental importance during the analysis of the data that the researchers capture all what the interviewees had to say.

The interview schedule which was the assessment tool for data collection, refer to Appendix. The interview was administered to participants aged 15 years and older. The young adolescent interview was administered to participants aged 10-and under

Appendix Participants of any age who reported to have comorbidities were provided with referrals to social and public health services. The interview schedule which was the assessment tool for data collection was administered in the two languages most commonly used in Eswatini. the interview schedule was reviewed and tested thoroughly for acceptability, feasibility, before the real interviews were undertaken this was meant to check if the schedule was well designed and not ambiguous and testing what it was supposed to test

7.15 Response rates

Family, community and school assessment response rate was calculated using the number of complete and incomplete assessment instruments while Individual interview response rates were calculated as the number of individuals who were interviewed divided by the number of individuals eligible to participate in the assessment.

8 Data analysis and presentation

Preparing and organizing data for thematic analysis is one of the phases in qualitative analysis. In practice, this usually entails consolidating all audio or video recorded interview data in one location, as well as translating observational notes to an electronic format. This phase was important for organizing the collected data during interviews; data was then separated into meaningful units for later compilation

Section three presented the design and methodology of this assessment; this chapter presents the findings, presentation, analysis and interpretation of the data. The data was analyzed and discussed using the quantitative data; the data was analyzed guided by the following objectives of this project:

1. To conduct an assessment on the extent of epilepsy in the constituency.
2. To ascertain how the community under the Dvokodvweni Inkhundla perceive and relate to Persons with Epilepsy.
3. To highlight statistics of PWE and other neurological disorders
4. To assess the social setting of PWE, how they interact within their everyday living experiences, including social environment in the likes of school, family community and health facilities
5. To assess reasons for poor adherence
6. To measure reasons for forgetfulness
7. To investigate financial sources
8. To explore availability of personal assistance for PWE
9. To explore the rate of discrimination and stigma associated with PWE
10. To measure the knowledge gap of PWE
11. To investigate the Availability of community services for PWE
12. To measure knowledge gap
13. To measure the level of dependency for PWE
14. To assess disabilities related to epilepsy
15. To explore PWE level of hygiene

The data presented would be from the first objective data and will follow a synchronized approach based on the assessment instrument. The data was collected using the qualitative explorative, descriptive design which mainly wanted to assess the extent of epilepsy in the Dvokodvweni constituency. Data will be presented under the following themes which will contain various sub themes using the following objectives from the study:

.

8.1 Table 2.1 themes and subthemes of findings

Themes	Sub – themes
1.The extent of epilepsy in the constituency	Statics of PWE in constituency
2.Poverty and unemployment	
3.Perception on relation to epilepsy	Witchcraft Head Trauma Ancestral Calling Unknown Causes Severe headaches
4.Social setting of PWE	The school environment The family environment Health The community
5.Forgetfulness 6.Financial sources 7.Personal assistance	
8.Reasons for poor adherence	Scarcity of Medication Lack of food

	Forgetfulness Drying up of financial sources Lack of personal perspectives
9.Rate of stigma and discrimination 10.Knowledge gap 11.Availability of community services 12.Dependency 13.Disabilities 14.Hygiene	

9 Results and Discussion

9.1 Introduction

This section will mainly explore the key finding from the data that was collected from the assessment. The data will be presented and discussed based on the assessments objectives that underpinned the assessment which the main rationale was to find out the extent of epilepsy in the Dvokodvweni constituency and highlight on the statistics of PWE and other neurological conditions available in the constituency.

9.2 Key findings

9.3 The extent of epilepsy in the constituency

It was accentuated from the results that Epilepsy comes third among non-communicable diseases recorded in the Dvokodvweni Inkhundla, Also the magnitude or rough estimate of the population being treated for epilepsy was found to be +/- 60% in the constituency. This was supported by the data that was collected from the Mpaka Clinic, (Appendix)

The results highlighted that PWE reported a high prevalence of stigma and discrimination and labelled the major cause of epilepsy as demon possess, some clients were said to have self-inflicted stigma, Observations from the assessment also highlighted that they only receive partial psychotherapy in local clinics.

9.4 Statistics of PWE and other neurological disorder

Results from the Data of the number of PWE was gathered from Mpaka clinic highlighted that they were more women (59%) than men (49%) who came to seek assistance in health care facilities pertain epilepsy, the data also highlighted the alarming rise In number of HIV cases mainly In women and young PWE mainly 80% of women with epilepsy have been diagnosed with HIV. The findings also postulated that Very little proportion of the people with epilepsy are deaf and mute, while a majority presented with physical disabilities which were caused by the condition.

9.5 PERCEPTION ON THE RELATION TO PWE

The study revealed that people of Dvokodvweni Inkhundla hold diverse perceptions and views about what they believe could be the cause of epilepsy. This impacts the interventions and measures they initiate in means to control the situation.

9.6 Witchcraft

One family highlighted that the epilepsy on their family member came as a result of witchcraft practice which the PWE was subjected to at a tender age, since the person started portraying signs and symptoms of epilepsy as early as three years of age but the pity is that she never had any medical attention which is in relation to epilepsy. The patient uses traditional interventions since the family believes the cause is traditional and for that reason the person should be given a traditional remedy. Traditional problems require traditional solutions that what the proponents of this view postulate. This was attested by one participant who stated that 1 out of the 8 children who were sampled, used traditional medicine to curb the condition

9.7 Head Trauma

Another perception that was prevalent from the assessment was that of head trauma where by the PWE stated that they were assaulted and suffered head injuries which they believed marked the onset of epilepsy in their lives because it was after that experience that they started having seizure eruptions. Commonly, this cause was dominant with the older people (mostly male) and 4 out of the 15 males that were subjects of the study brought forth that they experienced the head injury while they were under the bracket of the working class which according to them later caused epilepsy.

9.8 Ancestral Calling

One person when asked what he thought could be the cause of epilepsy in his life, he stressed that it was because of an ancestral calling that he had, and the ancestors are punishing him for not answering the call. This is a clear indication that there is still a serious need for awareness in the people of the constituency to change distorted beliefs.

9.9 Unknown Causes

About 45% of the total study sample clearly stated that they were not aware of what could be the cause of the epilepsy that they were diagnosed with. Among these PWE, were the 5 patients who showed signs of mental instability? This proved that epilepsy was just a tip of an iceberg in their dysfunctional well-being; there is a need for engaging other social service likes the therapeutic intervention, and administering of psychiatric medication on top of the anti-epilepsy treatment

9.10Severe headaches

One person stated that epilepsy came as a result of suffering severe headaches for quite an extended period of time.

9.11THE SOCIAL SETTING:

Under this theme, the study wanted to assess how the family environment, school setting and how the community relates to PWE. Below are the findings from the social setting:

9.11.1The social environment in the school

The study has proved that most of the people with epilepsy we engaged with at community level were school drop-outs.

One of the participants indicated that whenever she had a seizure, the other learners would withdraw from her and find herself socially unaccepted by her colleagues in the school. This spiked high levels of depression and anxiety thus negatively impacted her mental health as a result dropping out from school. The findings on the results also revealed that most children with epilepsy are slow learners and those who were bright in their earlier grades gradually lose their academic competency.

Another challenge that was established from the assessment was the issue of lack of first aid equipment and knowledge from teachers and learners on seizure management which then made the school setting inclusive for their learning. For some, the fact that they believed it to be good for nothing and the negative labels and words that learners gave deprived them of the comfort of being in school, and so they decided to drop out.

9.12 Family setting

The study established that a majority of the people with epilepsy at the Dvokodvweni Inkhundla are from families which are living below the poverty line. The breadwinners of the families were not employed, those who indicated that they had some form of employment worked in informal sectors and primary levels of production. Some families indicated that for means of living they were engaged in various self-sustaining income generating projects like; handicrafts and street vending. The study revealed most of the PWE are dependent populations who are chronically ill and children of very tender age. Furthermore, these types of families are fully dependent on social grants to make ends meet.

Among other reasons in accordance with the findings, the population is being stigmatized and discriminated against due to the condition they have. One other reason family members under-estimate the intellectual and cognitive functioning of the PWE is due to the fact that some of these people gradually experience a decline in decision making capability. As a result the PWE are being stripped off their rights to partake in the decision making process, be it at familial level. Thus, the people with epilepsy are perceived by the family and community members as “good for nothing “and this in-turn negatively affect their self-esteem.

9.13 Health facilities

Drawing from the data it was established that most of the women with epilepsy were living with chronic diseases like HIV, TB which subject the PWE to mental health disorders Stress related disorders, depression and anxiety disorders. From the data collected from the senior nurse at Mpaka clinic opined that that they were shortage of anti- epilepsy medication in the healthcare facilities

Furthermore, from the findings, it was highlighted that epilepsy tempers damage the brain. One example, highlighted by a 23-year-old patient, reported that she was never treated for epilepsy, yet she started showing signs of epilepsy at the age of 3 years, due to lack of health care facilities available within their community.

9.14Community

Drawing from the empirical data it was highlighted that neither one of the chiefdom situated under Dvokodvweni Constituency provide services at the community level, specially dedicated to address the needs of the people with epilepsy, with an aim to optimize clients functioning in the society. Furthermore, Available support systems of the likes of umphakatsi and Nearest Care Point (NCPs) provide no social services to people with epilepsy. From the findings it was revealed that the caretakers (Bagcugcuteli) are not capacitated in handling epilepsy cases as they had little to no knowledge on epilepsy first aid guide and management, which resulted in majority of PWE in the constituency being socially shunned by the community they live in

9.15 REASONS FOR POOR ADHERENCE

9.15.1 Scarcity of medication

From the findings it was ascertained the scarcity of medication in the hospitals was one of the major reasons of poor adherence to medication by persons with epilepsy and that has had them resulting in changing medication several times because of its unavailability and scarcity in the hospitals. It was reported that the PWE would be given any anti-epilepsy drug that is available at that particular time; this was caused by the unavailability of epilepsy drugs in the hospital. According to the assessment, it was opined by the senior nurse that if the PWE has been taking an anti-epileptic drug such as tegmental, and the hospital runs out of that drug, the health practitioners at the clinic would supply any anti-epilepsy drug that is available at that particular period of the shortage of the drugs in the hospitals.” Such that a patient who has been taking tegmental is changed to taking pilling due to the shortage” their strength, doses and effectiveness are not the same, such that the tegmental drug is way stronger than the pilling drug, in terms of the effectiveness and the strength, resulting in spike of levels of non-adherence.

9.15.2 Lack of food

According to the assessment done, the people with epilepsy are living below the poverty line. It has been reported that the patients don’t adhere to the medication because of lack of food one participant reported to have tried taking the medication on an empty stomach, however that caused them to experience adverse effects such as nausea, headache, dizziness and many more minor illnesses.

9.15.3 Forgetful

One of the PWE reported that their mental ability has declined such that they have brief spells of blockages which cause them to forget taking their medication. The findings on the assessment highlighted that the people with epilepsy don’t adhere to the medication or don’t administer their medication on time and they even overdose the medication due to the decrease in their mental ability. Furthermore, lack of treatment supporters and medication reminders such as alarms and pill boxes was also one of the major causes which resulted in them forgetting to not taking their medication

9.16 Drying up of financial sources

Reference to the findings, a number of people with epilepsy under the Dvokodvweni Inkhundla are not serviced locally. Four out of the entire population of study reflected that they are having the medical service at Psychiatric Centre in Manzini. This due to referral from the local health facilities that they need an extra service as a result of portraying delusional and hallucination episodes in addition to epilepsy. So they sometimes run out of coffers to cater for their traveling costs. Thus, the clients either decline from treatment or do not comply with the doctor’s orders in taking treatment.

9.17 Lack of personal assistance

The findings revealed that some of the individuals with epilepsy are living in isolation and others have been abandoned by their children and that has contributed greatly to those individuals' poor adherence. One PWE reported that due to the severity of her condition she was ordered to bring company whenever she went to the health care facilities, however she reported that she has had no one to bring with her since her family members verbalized they had enough of them. Due to that reason, the PWE resulted in the termination of their treatment, as the nurses scolded her when they came on their own. Furthermore, the findings revealed most of the PWE have abandoned them and have established their own homesteads.

9.18The rate of discrimination and stigma associated with PWE

It was observed from the assessment findings that people with epilepsy were being discriminated against at schools, communities, workplace and also in the families where they live; this was evidenced by one of the participants who reported that her family members consider her as someone who is insane. This made her to be socially excluded in most of the family discussions and even those that perceive her as a person with epilepsy.

Results from the assessment further indicated discrimination of PWE in the work place this was justifiable by one PWE who indicated he was not employed due to the discrimination thus most of the PWE are reliant on entrepreneurial skill and activities. and piece jobs to make ends meet. Most of these jobs are the manual and low paying jobs which expose them to extremely harsh weather conditions. One PWE echoed that he installs and mends barbed wire fencing for the local community's territorial boundaries as means to generate money which he uses to go for medical services at Manzini Psychiatric Center. He also stated he starts his task as early as 4 am so by the time weather temperature begins to be extreme, the client will call it a day because his seizures among other factors are triggered by high weather conditions.

9.19 Knowledge gap

Results from assessment revealed that the PWE, families and rural health motivators have misconceptions on epilepsy management and lack of knowledge and skills on taking care of the individuals with epilepsy. It was found most of the families have their own beliefs and perceptions on the ways to control seizures. According to the assessment, it was found that unhealthy, harmful and dangerous remedies are being used by family members of the individuals with epilepsy to control the seizures., one family reported that they use a shoe to control the seizures, whereby they hit the individual with the shoe on the nose, as they believe that such practice helps to control the seizures once they occur. Others reported to control seizures with the use of water whereby they shower the individual with water during the seizure.

9.20Scarcity of Community services

The results indicate Scarcity of community service for PWE, there were no services provided by the community and umphakatsi which are especially dedicated for people with epilepsy and other related disabilities. The assessment also revealed that, the Bagcugcuteli are not educated on Epilepsy Social Exclusion as it was reported that not even one of the Bagcugcuteli under Dvokodvweni Inkhundla is a person with epilepsy, thus they are not well represented which makes them to be left out in most of the things that occur in the communities. The results also gave light on the need for capacity building for the rural health motivators on epilepsy management.

9.21Dependence

With reference to the assessment, it was noted that most of the people with epilepsy are leaning on others for survival. Common to a majority of the assessment population, they lean on the aging population for their medical expenses, clothing and food, the Primary caregivers also alluded that they do not have a steady source of income but rely on the elderly grant which comes once in 4 months.

9.22 Disabilities

The findings from the interviews showed that a number of people with epilepsy under Dvokodvweni Inkhundla have a number of disabilities. Some of them were born with these disabilities, and for others it caught up with them at a later stage of life. The findings revealed that the major disabilities are of the likes of mental disability which come with distorted thoughts, dysfunctional perceptions and beliefs. The findings also gave light to other disabilities that were reflected by the study population mainly physical disability which resulted from seizures; whereby PWE fall either on fire, on objects or hit hard against the ground.

9.23 Hygiene

The findings ascertained that, most of the people with epilepsy have poor hygiene; from observations made Thus makes them more prone to opportunistic infections which could worsen the impact of epilepsy. In reference to the study carried out, 17 out of 31 people who comprised the sample were seen to be unhygienic. The study assessed cleanliness of the people; the clothing they wear, if they have their bodies washed, and if their hair is combed. With these 17 clients, their present ability proved to be opposite to what could be expected of a patient

10 Conclusion and Recommendations

10.1 The planned interventions in relation to Epilepsy National Plan of Action conceptual Framework.

10.1.1 Overreaching recommendations based on findings:

The recommendations highlighted below will be based on the key findings that were gathered from the assessment.

10.1.1.1 Awareness and education

1. Education and awareness need to be done in schools, communities and families in order to help to reduce this misconceptions, stigmatization and discrimination regarding people with epilepsy and their families that are widespread in many countries and regions
2. Furthermore, communities also need to be educated about epilepsy to reduce the stigma and discrimination attached to the individual with epilepsy. Education and awareness would help families to accept, love and take good care of their family/relatives with epilepsy following healthy measures that will be taught.
3. Education on contraception Birth control measures/AIDS mainly importance of self-testing, and educate on Pre-Exposure Prophylaxes and Post exposure prophylaxis
4. Educating ,encouraging and empowering the family and treatment supports to help PWE stick to their prescribed regime
5. Encourage PWE to use medication Adherence aids such as electronic reminders (texts and alarms), pillboxes to help remind PWE to take their anti-epilepsy medication
6. Host awareness campaigns in various communities across Eswatini to help raise awareness on epilepsy cause, management and treatment
7. Write and publish weekly articles on the Sunday observers, website and social media pages as means to raise awareness on epilepsy
8. Target media houses about the type of language used when talking about epilepsy

9. Educate traditional and religious healers on epilepsy issues and encourage them to refer clients to clinics
10. Communicate with PWE and provide a collaborative approach in treatment planning so they can easily adhere to it
11. Health care providers should simplify medication taking instructions to be in line with PWE level of educate and literacy levels
12. Educate PWE that if she missed taking her regime at her normal set time, she should take it as soon as she remembers
13. Provide education on the importance hygiene and provide assistive devices
14. Establish an epilepsy volunteer’s programmes in local communities

10.1.1.2 Advocacy

1. Advocate all companies to promote inclusion and diversity by updating their policies and start hiring PWE to be part of their teams.
2. Fixing policies by analysis, reviewing the law, amendment and implementation of laws and policies that support and protect the rights and welfare of the people with epilepsy.
3. Lobby government and other related ministries and stakeholders to stretch their budget and offer more resources to fund projects
4. Write proposals to existing partners and donors and potential donors
5. Host an epilepsy workshop for key policy makers in the country especially parliamentary health government endorses and portfolio committee chairs
6. Advocate that all clinics and hospitals in communities receive brain scanner from the ministry as means to increase diagnoses rate

10.1.1.3 Capacity building

1. Epilepsy volunteers will be trained together with the community workers more about epilepsy so they can then go educate others in different communities, families and at schools about epilepsy
2. The Community should also be trained on epilepsy, across the country
3. School children should also be trained on epilepsy first aid guide
4. Primary caregivers should also be trained management of PWE
5. Train local nurses on neurological knowledge and how to operate brain scan
6. Formation of support groups in all communities Support groups' economically empowerment
7. The community care takers also need to be educated and be skilled with sign language in order to be able to actively and effectively work with all the people in the communities

10.1.1.4 Socio-economic Empowerment

1. Individuals with epilepsy will be empowered and equipped with life skills to be able to be self-independent and not dependent on others. They will learn about different skills including hand-craft gardening

10.1.1.5 Drug shortages

1. To help mitigate drug shortages the organization is working on means to enhance access to seizure medication in the local epilepsy center being built at Sikhuphe to address the issue of limited medication/ shortage.
2. Engage with the director of health services to ensure fair distribution of epilepsy, education in all local clinics
3. The organization will continue to write proposals to donors to provide financial aid to help curb the drug shortage crisis

○

10.1.1.6 Counseling intervention

1. Formulates Individual counseling and group therapy
2. Advocate for local school to raise to the call by the minister of education on inclusive education being made available in all schools in local communities
3. Advocate for Family therapy intervention to help bring family members together, help them communicate and find way to ensure that the elderly with epilepsy is safe and not isolated.
4. Advocate for local clinics to have qualified psychologists

10.1.1.7 Research

1. Plans should be put in place on how the community can be mobilized to ensure that it develops the capacity to support epilepsy issues
2. Advocate for the upgrade of means at which information can be quickly accessed from institutions of the likes of clinics and map out effective ways that can be initiated to ensure efficiency of the medical services given to people with epilepsy and other neurological conditions
3. Conduct a series of surveys across the country to better understand the social, health and economic factors affecting PWE
4. Receive and review data from strategic partners and give feedback
5. Work with consultants to review organizations data

10.2 Appendix A Consent Letter

Dear Participant

You are requested to take part in this assessment. It is important that you should have some general understanding of what the assessment is about. Please take time to read the following message.

The study is about strengthening and establishing efficiency in epilepsy programming management and treatment in the Kingdom of Eswatini. The general outcomes from this assessment will set a viable stage to raise epilepsy into a new plane of acceptability in the public domain, you are assured that all information you provide will be strictly kept confidential, therefore do not say your name, during the interview.

By signing this consent form, I confirm that I have read and understood the information and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without costs. I voluntarily agree to take part in this assessment.

NAME:

……………………………………………………………………………………………

…………………………………

Signature ……………………………………………………………………… Date:
…………………………………………

Thank you for your participation and cooperation in this Assessment.

10.3 Appendix B

Please provide Assent letter

○

10.4Appendix C

GENERAL WAYS OF ASSESSMENT OF INDIVIDUALS, FAMILIES AND COMMUNITIES

THE GUIDELINES FOR ASSESSMENT

DEFINITION

ASSESSMENT CAN BE DEFINED AS A PROCESS OF GATHERING AND ASSESSING MULTIDIMENSIONAL INFORMATION ABOUT CLIENTS SITUATION, USING APPROPRIATE SOCIAL WORK KNOWLEDGE AND THEORY, WITH A FOCUS ON STRENGTHS BASED ASSESSMENT TO DEVELOP A PLAN THAT INVOLVES ALL THE RELEVANT PARTIES AND LEVELS.

THE IMPORTANCE OF ASSESSMENT;

ASSESSMENT IS VITAL AS IT IS USED TO GATHER EVIDENCE TO UNDERSTAND PRESENTING PROBLEM, TO EVALUATE PROGRESS AND OUTCOME AND TO ASSESS THE EFFECTIVENESS OF INTERVENTIONS AND

PROGRAMS. MOREOVER, ASSESSMENT IS A CORE ACTIVITY IN SOCIAL WORK PRACTICE WITH INDIVIDUALS, FAMILIES, GROUPS AND COMMUNITIES.

THERE ARE SEVERAL TOOLS USED IN ASSESSMENT, ONE OF WHICH IS CALLED THE BIOPSYCHOSOCIAL CULTURAL SPIRITUAL TOOL. IN THIS ASSESSMENT TOOL, YOU ASSESS THE BIOLOGICAL ASPECTS OF THE PERSON, THE PSYCHOLOGICAL ASPECTS, THE CULTURE AND THE SPIRITUALITY OF THE PERSON.

ASSESSMENT IN SCHOOL SETTING

- ACADEMIC PERFORMANCE
- PUNCTUALITY
- SOCIAL LIFE
- EATING PATTERNS

ASSESSMENT AT FAMILY LEVEL

- BE OBSERVANT, E.G. SCARS OR BRUISES ON THE CHILD
- ASSESS THE ENVIRONMENT E.G. THE TYPE OF HOUSING IS LIVING IN
- BEHAVIOR, E.G. SHOUTING AT OTHER CHILDREN OR FAMILY MEMBERS
- FAMILY ITSELF, ARE THE PARENTS INTO ALCOHOL OR DRUGS
- SOCIAL SUPPORT, E.G. FAMILY SOURCE OF INCOME,
- THE TYPE OF RELATIONS IN THE FAMILY, E.G. BLENDED FAMILIES, THERE IS LIKELIHOOD OF VULNERABILITY OF A CHILD TO ABUSE.
- ASSES THE LINE OF COMMUNICATION, EG. WHO IS RESPONSIBLE FOR MAKING DECISIONS,?
- WHO PLAYS THE ROLE OF BEING A BREADWINNER?
- SLEEPING PATTERNS

COMMUNITY LEVEL

IN COMMUNITIES, IT IS VITAL TO ASSESS THE CULTURE OF THE PEOPLE TO BE ABLE TO WORK WITH THEM SUCCESSFULLY. FOR EXAMPLE; IN RURAL COMMUNITIES, THEIR MORALS AND VALUES IMPLIES THAT FOR A WOMAN TO BE PRESENTABLE AND RESPECTFUL, SHE HAS TO WEAR A SKIRT NOT TROUSERS.

WHEN ASSESSING A COMMUNITY, YOU CONDUCT INTERVIEWS TO THE COMMUNITY GROUP, THE INTERVIEW CONTAINS QUESTIONS ABOUT THE COMMUNITY NEEDS, STRENGTHS, CHALLENGES, AND ASSERTS. THE ASSETS REFER TO THE SKILLS, THE TALENTS AND ABILITIES OF INDIVIDUALS AS WELL AS THE RESOURCES THAT LOCAL INSTITUTIONS CONTRIBUTE TO THE COMMUNITY

10.5Appendix D

CLIENT’S ASSESSMENT FORM AT FAMILY LEVEL

CLIENT’S NAME:

CONTACT DETAILS:

RESIDENTIAL AREA:

FAMILY SIZE:

ASSESSMENT CRITERIA	**ELEMENTS**		**COMMENT**
PARENTING CAPACITY	BASIC CARE	FOOD	
		HOUSING	
		CLOTHING	
		MEDICATION	
	PARENTING STYLE	MANNER OF OPINIONS EXPRESSION	
		LEVEL OF REASONING & INDEPENDENCE	

		EXPRESSION OF WARMTH & NURTURING	
	FAMILY GUIDANCE	ADHERANCE TO MEDICATION	
		DINNING SUPERVISION	
		CAREER GUIDANCE	
	EMOTIONAL WARMTH	LOVE	
		LEVEL OF ATTACHMENT	
	FAMILY STABILITY	FUNCTIONING	
		CARING	
		SUPPORTIVE	
FAMILY & ENVIRONMENTAL FACTORS	HOUSING CONDITIONS		
	INCOME SOURCE	FAMILY-BASED ENTREPRENEURIAL ACTIVITIES	
		EMPLOYMENT QUALITY (BREADWINNER)	
	FAMILY HISTORY (INHERITED) & FUNCTIONING		

	FAMILY’S SOCIAL INTEGRATION (RELATIONSHIP TYPE MAINTAINED)		
DEVELOPMENT NEEDS	EMOTIONAL & BEHAVIORAL DEVELOPMENT(SELF ESTEEM & HYGIENE)		
	FAMILY & SOCIAL RELATIONSHIPS (BLOOD RELATED/SURROGATE)		
	SOCIAL PRESENTATION	PHYSICAL WELLBEING	
		SELF ESTEEM	
		CLEANLINESS	

10.6Appendix E

MPAKA CLINIC ASSEMENT FORM

INVESTIGATION ON EPLEPSY, NEUROLOGICAL DISABILETIES, AND OTHER DISABILETIES IN GENERAL.

Day…………………….**.**month……………………………..**.**year…………………………….

Time……………………….a.m./ p.m.

Name of Institution/ participant…………………………………………………………….

Name of respondent……………………………………………………………………….

Inkhundla……………………………………. Chiefdom/Sigodzi…………………………….

Region……………………………………………………………………………………….

PART A.

1. According to your assessment or records, to what extent is the epilepsy in this area?

____

____

2. What is the magnitude or rough estimate of the population being treated for epilepsy?

3. Do the people living with epilepsy report of any stigma/ discrimination?

4. Are there any measures taken to reduce the stigma assigned to the people living with epilepsy?

5. What other challenges do these people face?

6. According to your assessment/ in your view, what is the treatment gap?

7. According to your assessment what other challenges do the people living with epilepsy face when coming for treatment or being treated?

8. Apart from the medical intervention given to the people living with epilepsy is there any other support/assistance they receive from the hospital? If, yes what type of support/assistance? E.g. food & nutritional support (food packages), PSS/ psychotherapy

PART B.

1. According to your assessment/ own view, what is the extent and prevalence of the neurological disabilities?

2. What is the magnitude of the people diagnosed with neurological disabilities?

3. What is the magnitude of people living with disabilities in general? (E.g. physical/ mental/..etc.).

4. According to your assessment/ own view, what are the most common forms/types of disabilities that people are living with?

Interviewer: Ncobile Fortunate Simelane

Signature: ………………………………..

Contact details: (+268) 76643822

Supervisor: Mr. Ntshalitshali

10.7Appendix F

Assessing Phase Form

Physical, emotional, and cognitive functioning

Physical

Emotional

Cognitive

Assessment of the home and safety

Availability of community resources

Assessment of health condition

Clients Strengths:

10.8APPENDIX G

SCHOOL SETTING ASSESSMENT FORM

CLIENT’S NAME:

CONTACT DETAILS:

RESIDENTIAL AREA:

ASSESSMENT CRITERIA	**ELEMENTS**	**COMMENT**
ACADEMIC PEFORMANCE	GRADE AGAINST AGE	
	CLASSROOM WORK	
	LEVEL OF PARTICIPATION	
	CONCENTRATION SPAN	
PUNCTUALITY	TIME OF LEAVING	
	TIME OF ENTERING	
SOCIAL LIFE	DEGREE OF SOCIALIZATION	

	FRIENDS	
EATING PATTERNS	LEVEL OF APPETITE	
	QUANTITY OF PORTION TAKEN AGAINST GENDER	
	ANY POCKET MONEY GIVEN TO SUPPLEMENT SCHOOL MEAL?	

10.9 Appendix H

Stratification Phase

1. Presence and the number of physical health condition

2. Medication intake

3. Substance, Alcohol and tobacco use

4. Emotional, Mental and behavioral health

5. Assess availability of psychosocial support (relatives, community support groups)

6. Nutrition and exercise habits

7. Socio-economic financial status

8. Categorizing risk presented

High risk	Medium risk	Low risk

10.10 APPENDIX I

FORM FOR COLECTING PERSONAL DETAILS OF PWE

Client name	Contact details	Date of birth	Age	Gender	Region	Inkhundla	Next of kin	Contact details

10.11 Appendix J

Evaluation Phase

1. Financial status

2. Improvement in quality of life

3. Physical functioning

4. Self-care Management Ability

10.12 APPENDIX K

TEACHING GUIDE

What Are the Causes of Epilepsy?
Epilepsy is a general term for the tendency to have seizures. Epilepsy is usually diagnosed only after a person has had more than one seizure. When identifiable, the causes of epilepsy usually involve some form of injury to the brain. For most people, though, epilepsy's causes aren't known.

What Are Seizures?
A seizure occurs when a burst of electrical impulses in the brain escape their normal limits. They spread to neighboring areas and create an uncontrolled storm of electrical activity. The electrical impulses can be transmitted to the muscles, causing twitches or Convulsions.

Types of Seizures
There are two types of seizures:
Focal seizures. These seizures involve abnormal activity in just one part of your brain. You may lose consciousness, or you may stay alert when you have them.

1. *Without loss of consciousness* . These seizures may just change your emotions, or alter your sense of sight, smell, taste, or sound. You might also jerk an arm or a leg without meaning to, or feel tingling,
dizziness, or see flashing lights.
2. *With loss of consciousness* . During these seizures, you aren't quite aware of your surroundings as usual. You may stare into space, or move repetitively by chewing, rubbing your hands, or walking in circles.

Generalized seizures.
This type of seizure tends to involve all the parts of your brain.
There are six kinds of generalized seizures:
1. *Absence seizures* > happen mostly in children and involve small movements such as lip smacking or eye blinking.
2. *Tonic seizures* > make you stiffen the muscles in your arms, legs, back and sometimes fall down as a result.
3. *Atonic seizures* > take away your muscle control. They're also called drop seizures, because they can make you collapse onto the floor.
4. *Clonic seizures* > often make you repeat jerking movements in your neck, face, and arms.
5. *Myoclonic seizures* > involve short, twitching and jerking motions in your arms and legs.
6. *Tonic-clonic seizures* >, which used to be called grand- mal seizures, can make you lose

consciousness, stiffen your whole body, and shake. You may also bite your tongue or lose control of your bladder.

Causes of Epilepsy

There are around 180,000 new cases of epilepsy each year. About 30% occur in children. Children and elderly adults are the ones most often affected.

There is a clear cause for epilepsy in only a minority of the cases. Typically, the known causes of seizure involve some injury to the brain .

Some of the main causes of epilepsy include:

- Low oxygen during birth
- Head injuries that occur during birth or from accidents during youth or adulthood
- Brain tumors
- Genetic conditions that result in brain injury, such as tuberous sclerosis
- Infections such as meningitis or encephalitis
- Stroke or any other type of damage to the brain
- Abnormal levels of substances such as sodium or blood sugar
- Developmental disorders, such as autism and neurofibromatosis
- Injury before birth, such as brain damage from an infection in the mother, poor nutrition or oxygen deficiencies.
- Shaken Baby Syndrome (SBS) - violently shaking the brain; brain moves back and forth within the skull tearing blood vessels & nerves inside and around the brain causing it to bleed. Brain swells building pressure in the skull, which makes it hard for blood carrying Oxygen and nutrients to reach the brain, further harming it.

NB: In up to 70% of all cases of epilepsy in adults and children, no cause can be discovered.

Causes of Seizures

Although the underlying causes of epilepsy are usually not known, certain factors are known to provoke seizures in people with epilepsy. Avoiding these triggers can help you avoid seizures and live better with epilepsy:

- Missing medication doses
- Heavy alcohol use
- Cocaine, ecstasy, or other illegal drugs
- Lack of sleep
- Other medicines that interfere with seizure medications
- Flashing lights, images, and repetitive patterns may cause seizures in persons with photosensitive seizure disorder.

NB: For about 1 in 2 women with epilepsy, seizures tend to occur more around the time of menstrual periods. Changing or adding certain drugs before menstrual periods can help.

Facts about Epilepsy

- You cant swallow your tongue during a seizure. Its physically impossible.

- You should never force something into the mouth of someone having a seizure. Absolutely not! Forcing something into the mouth is a good way to damage teeth, cut gums or even break someones jaws.
- Don’t restrain someone with having a seizure. Most seizures end in seconds or few minutes and will end on its own
- Seizure is not contagious. You cant catch epilepsy from another person
- In adults over 65 years, Epilepsy can start as a result of health problems like stroke and heart disease.
- People with epilepsy can handle jobs with epilepsy can handle jobs with responsibility and stress
- People with epilepsy are usually not physically limited to what they can do. During and after a seizure, a person may have trouble moving or doing their usual activity. Some may have trouble with physical abilities due to other neurological problems. Aside from these problems, a person who is not having a seizure is usually not limited in what they can do physically.
- A person can die from epilepsy. While death in epilepsy does not happen frequently, epilepsy is a very serious condition and individuals do die from seizures. The most common cause of death is the sudden unexpected death in epilepsy. 1/1000 people die from SUDEP yearly.

NB: 65 Million people globally live with Epilepsy
: 6/10 people with epilepsy cause is unknown

Home Safety Tips for People With Epilepsy

The kinds of seizures you have, where you are when one happens, what you're doing, and who you're with all play into whether or not you'll be hurt. If your epilepsy is well-controlled, an accidental injury may not be a big concern for you. But it's still a possibility and something you should think about. The things most likely to cause trouble at home are heights, water, heat, and electricity. So what can you do to make your little corner of the world a safer haven? Your doctor can refer a visiting nurse or physical therapist to look at your living situation and make specific recommendation for your type of epilepsy and your environment

Bathroom

A lot of hard edges, often in a small space, plus hot water, plus the need for personal privacy make the bathroom a challenging place. The first house rule should be, "Do NOT lock the door." Instead, hang a sign over the doorknob that can be flipped to say "occupied." That way, if you have a seizure while in the bathroom, help can get to you. Hinge the door so it swings outward. It can still be easily opened, even if you fall against it. Showers with a clear-running drain are better than baths, so water doesn't build up and create a chance of drowning . A curtain, instead of a shower door, gives easier access for help to get to you if needed. If you tend to fall during seizures, you may want to sit on a shower chair or the floor and use a hand-held shower nozzle. Keep the water temperature lukewarm to avoid the possibility of burning yourself. Be wary of heated styling tools like flat irons.

Kitchen and Dining

● If you live alone, consider using a food processor rather than a knife to chop ingredients, or buy prepared meals. If you live with others, have someone else nearby while you use knives or the stove.

- Cooking with a microwave greatly lowers your chances of getting burned. An electric stove is better than the open flame of gas. Put food on the back burners, so you're less likely to fall on the hot surface or spill hot food if you go down. Bring plates and dishes to the pots and pans, rather than moving the cookware to the table to serve a meal.
- Wear rubber gloves when cleaning up, or use unbreakable dishes, to help avoid cuts in case you drop a heavy plate or glass.
- A chair with armrests could help prevent falls. Family members and dining companions should know how to do the Heimlich maneuver in case you have a seizure while you're eating and start choking.

Living Room

Have carpeted floor space in case of falls. Wall-to-wall carpet is better than area rugs to prevent tripping and to cushion you if you do. Securely anchor TVs and other heavy items on a table or shelf. Bundle cables and cords, and keep them out of the way. Put corner guards on furniture and padding on hard or sharp edges. Avoid using glass tables. A fireplace on a cold night may be cozy, but it needs a screen in place at all times.

Bedroom

Wall-to-wall carpeting and covered edges on dressers and tables are also a good idea here. Don't put your bed against a wall or near a radiator. If you might fall out, a futon or mattress on a low platform or the floor is a safer bet than a bed you have to climb into. And place cushions or pillows around it. Limit the number of pillows you sleep with. Consider having a monitor in the room if you're alone to alert someone nearby for help.

First Aid for Epilepsy Seizures

There isn't much you can do to stop a seizure once it starts. But you can help protect someone from harm during one. Some seizures are more dangerous than others, but most aren't an emergency. If you want to do something for the person, focus on keeping them safe.

What Seizures Look Like

The type of seizure most people will think of is the generalized tonic-clonic seizure, better known as a grand mal seizure. They're frightening to watch, and someone who has one rarely knows or remembers what's happening.

These seizures follow a pattern:

1. The person seems to "check out." They won't answer if you talk to them. They won't react if you wave a hand in their face or shake them. They may collapse.

2. Their muscles clench and they become as rigid as a board. (This is the tonic phase. It lasts a few seconds.)

3. Next comes a series of jerking movements. (This is the clonic phase. It can last a few seconds or several minutes.)

4. Eventually, the jerking stops and they're alert and can talk again, but they may be dazed or unsteady for a little while.

>***Any generalized seizure***: can be dangerous because the person is unaware of their surroundings and can't protect themselves from harm. The uncontrolled thrashing raises their chances of getting hurt.

>***Focal seizures*** are different. They're less intense and usually last no more than a minute or two. Part of their body, like an arm, might get stiff or go floppy. You may see repeated, rhythmic, or jerking movements in one place or that spread to different body parts. The person could zone out or stare at nothing. They may or may not realize what's happening but can't control it. When it's over, they won't remember a thing.

What You Can Do

For someone having a generalized tonic-clonic seizure:

- Give them room. Keep other people back.
- Clear hard or sharp objects, like glasses and furniture, way.
- Cushion their head.
- Loosen clothing around their neck, if you can safely.
- Don't try to hold them down or stop their movements.
- Don't put anything in their mouth .

NB: Contrary to popular myth, you can't swallow your tongue during a seizure.
But putting something in their mouth could damage their teeth , or they might bite you. If their head isn't moving, turn it to one side.

- Look at your watch at the start of the seizure, so you can time its length. Remember, this probably isn't an emergency, although it may look like one.
- After the jerking stops, gently place them on their side, to help keep their airway clear.

For milder seizures, like a bit of staring or shaking arms or legs;

- guide the person away from hazards, including traffic, stairs, and water.

NB: Don't leave someone who's had a seizure alone. Stay until they're fully aware of where they are and can respond normally when you talk to them. Speak calmly. Reassure them and explain what they missed if they're confused or frightened. Don't give them anything to drink or eat until they've completely recovered.

Get medical help when:

- It's a child's first seizure.
- The seizure lasts longer than 5 minutes.
- Another seizure begins soon after the first.
- The person doesn't "wake up" after the movements have stopped.
- The person was injured during the seizure.
- If you're concerned that something else may be wrong, or the person has another medical condition such as heart disease or diabetes , call a doctor.

Parenting Children Living with Epilepsy

Dealing With Emotions

It's natural for a child with a chronic illness, or who is different from other kids, to feel resentful.

Children with an illness like epilepsy may have emotional problems, like low self-esteem or depression . This can come from within (anger, embarrassment, frustration), or from outside (teasing).

Helping your kid deal with these feelings.

- Make sure your child understands as much about the disease as possible.
- Try to get them to be positive about their disease and focus on things they can do. Having epilepsy may place restrictions on your child. Still, they should be able to take part in most activities. At the same time, make sure to help them learn how they can minimize risk.

Family adjustments:

- Be sure your other children understand their sibling's illness.

If they feel neglected, try to spend more time with them.

- Seek family counseling .

It can help everyone understand how to handle the effects of the illness together.

- Show everyone what to do if your child has a seizure .

That way, they won't be afraid when one comes.

Children and Epilepsy Medicine

If your child is taking drugs for their epilepsy, work with their doctor to make sure they're taking them correctly.

You'll need to:

- Know the schedule for the medications (how many times a day to take them, whether they should take them with food, etc.).
- Learn what to do if your child forgets to take a dose.

Know if any medications require blood tests.

- Be aware of side effects and learn what to do about them.
- Ask the doctor what to do if your child is ill or has a fever (that can bring on seizures).
- Make sure your child's school knows they take medicine for epilepsy.

NB:

Keep an eye on your child near water, whether at home or outside.

At home:

- Make sure the bathroom door opens outward so that you can open it, in case your child falls. Take locks off the bathroom door.
- Check your bathtub drain to make sure it's working properly.
- Keep tub water at low levels.
- Keep water temperature low to prevent scalding.

Away from home:

- Don't let them swim alone.
- If they have a seizure while swimming , get them out of the water as soon as possible.

Does epilepsy change during pregnancy?
All women's bodies react differently to pregnancy. For most pregnant women who have epilepsy, seizures remain the same. For a few, seizures become less frequent. For others, particularly women who are sleep deprived or don't take medication as prescribed, pregnancy increases the number of seizures.

What about medication?
Medication you take during pregnancy can affect your baby. Birth defects — including cleft palate, neural tube defects, skeletal abnormalities, and congenital heart and urinary tract defects — are a few potential side effects associated with anti-seizure medications. The risk seems to increase with higher doses and if you take more than one anti-seizure medication.

If you haven't had a seizure for nine months before you conceive, you're less likely to have a seizure during your pregnancy. If you haven't had a seizure for two to four years, you might be able to taper off medications before you conceive and see if you remain seizure-free. Talk to your health care provider before discontinuing your medications. For most women, however, it's best to continue treatment during pregnancy. To minimize the risks for you and your baby, your doctor will prescribe the safest medication and dosage that's effective for your type of seizures and monitor your blood levels throughout your pregnancy.

What does my epilepsy mean for my baby?
Beyond the effects of medications, babies born to mothers who have epilepsy also have a slightly higher risk of developing seizures as they get older.

How should I prepare for pregnancy?
Before you try to conceive, schedule an appointment with the health care provider who'll be handling your pregnancy. Also meet with other members of your health care team, such as your family doctor or neurologist. They'll evaluate how well you're managing your epilepsy and consider treatment changes you might need to make before pregnancy begins. If you have frequent seizures before you conceive, you might be advised to wait to get pregnant until your epilepsy is better controlled. Take your anti-seizure medication exactly as prescribed. Don't adjust the dose or stop taking the medication on your own. Uncontrolled seizures likely pose a greater risk to your baby than does any medication.

It's also important to make healthy lifestyle choices. For example:

- Eat a healthy diet.
- Take prenatal vitamins.
- Get enough sleep.
- Avoid smoking, alcohol, illegal drugs and caffeine.

Do I need more folic acid than other pregnant women do?
Folic acid helps prevent neural tube defects, serious abnormalities of the brain and spinal cord. Because some seizure drugs affect the way the body uses folic acid, your health care provider will recommend a high-dose folic acid supplement — ideally starting three months before conception.

What can I expect during prenatal visits?

During pregnancy, you'll see your health care provider often. Your weight and blood pressure will be checked at every visit, and you might need frequent blood tests to monitor your medication level. If you're taking anti-seizure medications, your health care provider might recommend oral vitamin K supplements during the last month of pregnancy to help prevent bleeding problems in the baby after birth.

What if I have a seizure when I'm pregnant?

Seizures can be dangerous, but many mothers who have seizures during pregnancy deliver healthy babies. Report the seizure promptly to your health care provider. He or she might adjust your medication. If you have a seizure in the last few months of your pregnancy, your health care provider will monitor your baby at the hospital or clinic.

How can I make sure my baby is OK?

Your health care provider will monitor your baby's health throughout the pregnancy. You might have frequent ultrasounds to track your baby's development. Your health care provider might recommend other prenatal tests, as well.

What about labor and delivery?

Most pregnant women who have epilepsy deliver their babies without complications. Women who have epilepsy might be able to use the same methods of pain relief during labor and delivery as other pregnant women. Seizures don't commonly occur during labor. If you have a seizure during labor, it might be stopped with intravenous medication. If the seizure is prolonged, your health care provider might deliver the baby by C-section. If you have frequent seizures during your third trimester, you're more likely to have a seizure during delivery. Your health care provider will review the best delivery method with you to avoid increased risk of seizures during your delivery. If your anti-seizure medication dose is altered for pregnancy, talk to your health care provider about returning to your pre-pregnancy levels shortly after delivery to continue keeping your seizures under control and your medication at safe levels.

Will I be able to breast-feed my baby?

Breast-feeding is encouraged for most women who have epilepsy, even those who take anti-seizure medication. Discuss adjustments you'll need to make with your health care provider ahead of time. He or she might recommend taking your medication after a feeding. Sometimes a change in medication is recommended. Epilepsy during pregnancy raises special concerns. While most women who have epilepsy deliver healthy babies, you might need special care during your pregnancy. Here's what you need to know.

Does epilepsy make it more difficult to conceive?

Some drugs used to treat seizures might contribute to infertility. However, certain anti-seizure medications can also reduce the effectiveness of hormonal birth control methods.

How does epilepsy affect pregnancy?

Seizures during pregnancy can cause:

- Slowing of the fetal heart rate

- Decreased oxygen to the fetus
- Fetal injury, premature separation of the placenta from the uterus (placental abruption) or miscarriage due to trauma, such as a fall, during a seizure.

10.13 APPENDIX P

Designing an Action Plan for displaced people

Individual Examination of the displaced (Place of origin)

Name:

Date of birth:

Contact details:

Marital status:

Assessment criteria	Elements		Comments
Personal Details	Region (Residential Area)		
	Occupation		
	Duration of residence		
	Sentimental Attachment	Number of relatives burried in that place (Ancestral site)	

Environmental Assessment	Geographic location	
	Climatic conditions	
	Land size previously owned	
Healthy Examination	vision	
	Auditory	
	Physical	
	Mental/psychological	

	Source of income	
	Effects of COVID19 (Redundancy/Retrenchment)	
	Effects of political unrest (Redundancy/Retrenchment)	
	Social Grants	

10.14 APPENDIX

CURRENT PLACE OF RESIDENCE

NAME:

DATE OF BIRTH:

CONTACT DETAILS:

MARITAL STATUS:

Assessment criteria	Elements		Comments
Personal Details	Region (Residential Area)		
	Occupation		
	Duration of residence		
	Sentimental Attachment	Number of relatives burried in that place (Ancestral site)	
Environmental Examination	Geographic location		
	Climatic conditions		
	Land size previously owned		

Healthy status	vision	
	Auditory	
	Physical	
	Mental/psychological	
Financial examination	Source of income	
	Effects of COVID19 (Redundancy/Retrenchment)	

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Gathering information

Who: Bagcugcuteli

Why: They are the one working hand in hand with the community members and they have vast knowledge about each one of them

They are at the forefront in community level to provide first aid to the people who are victims of the brutal killing and injuries which have been brought by the recent political unrest

How: Engaging with them

Number of people death, number of people injuries, degree of their injury, How they relate to their families, Types of families they death or injured are from, Number of people who were dependent on the victim, Job losses-Effect of the retrenchment on family provision.

10.15 APPENDIX

Family Examination of the displaced

Who: Family members

Assessment Criteria	Elements	Comments
Family Composure	Types of family	
	Number of Family Members	
	Type of family relationship	
Resources Available	Land size	

	Quantity of Agricultural		
Loss	Number of lives lost during the struggle		
	Number of retrenchment within the family		
	Agricultural products	Crops (commercial gardening)	
		Livestock	