

Epilepsy associated stigma in Zambia

Tina Chisenga

Zambia

50th International Course in Health Development

September 16, 2013 to September 5, 2014.

KIT (ROYAL TROPICAL INSTITUTE)

Development Policy & Practice/

Vrije Universiteit Amsterdam

Epilepsy associated stigma in Zambia

A thesis submitted in partial fulfilment of the requirement for the degree of
Master of Public Health

By

Tina Chisenga

Zambia

Declaration:

Where other people's work has been used (either from a printed source,
internet or any other source) this has been carefully acknowledged and
referenced in accordance with departmental requirements.

The thesis **Epilepsy associated stigma in Zambia** is my own work.

Signature:.....

50th International Course in Health Development (ICHHD)

September 16, 2013 to September 5, 2014.

KIT (Royal Tropical Institute)/Vrije Universiteit Amsterdam

Amsterdam, The Netherlands

September, 2014

Organised by:

KIT (Royal Tropical Institute), Development Policy & Practice

In co-operation with:

Vrije Universiteit Amsterdam/ Free University of Amsterdam (VU)

Amsterdam, The Netherlands

Table of Contents

Table of Contents	i
Table of Figures.....	iii
Acknowledgements	iv
Abstract	v
List of Abbreviations	vi
Glossary of Terms.....	vii
INTRODUCTION.....	viii
CHAPTER 1: BACKGROUND INFORMATION ON ZAMBIA	1
1.1. General Background	1
1.2. Health profile	1
CHAPTER 2: PROBLEM STATEMENT, OBJECTIVES AND METHODOLOGY	3
2.1. Problem Statement.....	3
2.2. Justification	3
2.3. General Objective	4
2.4. Specific Objectives.....	4
2.5. Methodology	4
CHAPTER 3: EPILEPSY AND ITS ASSOCIATED STIGMA	8
3.1. Epilepsy	8
3.2. Stigma	9
3.3. Epilepsy associated stigma	10
3.4. Manifestations of epilepsy associated stigma.....	11
3.5. Intersecting stigmas	13
CHAPTER 4: THE STIGMATIZATION PROCESS, OUTCOMES AND IMPACTS OF EPILEPSY ASSOCIATED STIGMA	15
4.1. The agents of stigmatization process	15
4.2. Drivers and facilitators of epilepsy associated stigma	18
4.3. Stigma outcomes	21
4.4. Impacts of epilepsy associated stigma.....	22
CHAPTER 5: INTERVENTIONS FOR THE REDUCTION OF EPILEPSY ASSOCIATED STIGMA	24

5.1. Interventions related to reduction of epilepsy associated stigma in Zambia	24
5.2. Interventions related to reduction of epilepsy associated stigma in other countries	25
CHAPTER SIX: DISCUSSION	28
6.1. The individual, family and peers, the general public, structures and institutions	28
6.2. Actionable drivers and facilitators	28
6.3. Marking or Labelling, Epilepsy associated stigma and intersecting stigmas	29
6.4. Stigma Manifestations	30
6.5. Stigma Outcomes	30
6.6. Stigma Impacts.....	31
6.7. Good practices or interventions to reduce epilepsy associated stigma	31
6.8. Reflections on the conceptual framework.....	32
6.9. Study limitations	32
CHAPTER SEVEN: CONCLUSION AND RECOMMENDATIONS.....	33
7.1. Conclusion	33
7.2. Recommendations	33
REFERENCES	35
ANNEXES	42
Annex 1: Screening Process	42
Annex 2: Other Conceptual Frameworks considered	43
Annex 3: Table 1. Health system and mental health expenditure	44

Table of Figures

Figure 1: Modified Conceptual Framework.....	7
Figure 2: The multiple interacting factors that contribute to the totality of epilepsy for an individual patient.....	9

Acknowledgements

I would like to firstly thank God the Almighty, because it is because of Him that I am here today and that I had the strength to get through this Masters' degree program.

Secondly my family for always being there for me and giving me the support that I needed throughout the year. My dearest friends Nachilima and Monica, for making it easy for me to be away from home.

I would also like to thank my thesis supervisor and back-stopper for all their efforts and wise advice throughout the thesis process, as well as all the Royal Tropical Institute staff for all their help and support. May God continue to bless you in your future endeavours.

To my course mates, you have all been so wonderful and thank you for the rich cultural blend.

Lastly I would like to thank all the people with epilepsy who participated in the studies included in this thesis, and also the researchers whose work I have used. I am very grateful to you for making it possible for me to do this thesis.

Abstract

Background: Zambia is a country in Southern Africa and has an epilepsy prevalence of 12.5/ 1000 people in the rural areas and affects the day to day life of those with the condition (Birbeck & Kalichi 2004).

Stigma has been recognised as one of the factors that has an impact on the lives of those with epilepsy and consequently on the large treatment gap. Therefore, in order to reduce this treatment gap, the mechanisms of stigma have to be understood and addressed and this is the aim of this thesis.

Methodology: To achieve the objectives of the study, a literature review on available information was conducted. Sixty-three articles were included and presented using a modified version of the adapted global framework for HIV stigma which was used in India by ICRW and STRIVE in 2013.

Findings: The analysis revealed that felt stigma, enacted stigma and courtesy stigma are highly present in relation to epilepsy in Zambia. Lack of knowledge, beliefs and practices, and, lack of commitment by policy makers are likely drivers of epilepsy associated stigma.

Conclusion: While the study revealed that epilepsy stigma is present in the Zambian society and that it has effects on diagnosis and treatment, more still needs to be done to reduce these effects. As we work on improving knowledge about epilepsy, evidence based interventions need to be contextualized and could help reduce the level of stigma, and, possibly improve diagnosis and treatment, invariably reducing the treatment gap.

Key Words: Zambia, Epilepsy, Stigma, Diagnosis, Treatment

Word Count: 12, 311

List of Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
BC	Before Christ
CSO	Central Statistics Office
CT	Computed Tomography
EEG	Electroencephalogram
HIV	Human Immunodeficiency Virus
ICRW	International Centre for Research for Women
ILAE	International League Against Epilepsy
Km ²	Kilometres squared
MCDMCH	Ministry of Community Development, Mother and Child health
MOH	Ministry of Health
MRI	Magnetic Resonance Imaging
PWE	People or Person(s) with epilepsy
SSA	Sub – Saharan Africa
WHO	World Health Organisation
ZANIS	Zambia National Information Service

Glossary of Terms

Healthcare workers: refers to “all people engaged in actions whose primary purpose is to enhance health,” (WHO 2006). But in this study, this is only limited to those found in a recognised health facility.

Traditional Medicines: the sum of total knowledge, skills and practices based on the theories, beliefs and experiences indigenous in different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness (WHO 2000).

Traditional Healers: those that practice traditional medicine (WHO 2000).

Disability-adjusted life years: the sum of years of potential life lost due to premature mortality and the years of productive life lost due to disability (WHO 2014).

Care-seeking behaviour: any action undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding appropriate remedy (Olenja 2003).

INTRODUCTION

"Epilepsy is a chronic disorder of the brain that affects people in every country of the world," (WHO 2012). It is the third most frequent consultation to neurologists usually in the rural areas (WHO 2004). A survey in rural Zambia, estimated that 12.5/ 1000 people have epilepsy of which the highest were between the ages of 5-15 years at 26.2/ 1000 population and more predominant in males at ages below 45 (Birbeck & Kalichi 2004).

Epilepsy is sometimes perceived as an African ailment brought about by supernatural beliefs in ancestral curses or evil spirits (WHO 2004). Epilepsy has an impact on the economy due to the healthcare needs of those with epilepsy, premature deaths and loss of productivity at work (WHO 2012).

In my work as a medical doctor in Zambia, people would come to me privately to ask for anti-epileptic medications because they did not want to be seen in the epilepsy clinic. After asking why they feared to be seen in the clinic many revealed that they would be excluded from community events, ridiculed or banished, if it were known they were epileptic. It is difficult to describe the English word "Stigma" in Zambian languages but for discrimination, the commonly used term is "akapatulula" which means "isolating of a person who is not wanted" (Bond et al, 2003).

I therefore concluded that this was some form of stigma according to the definition of stigma by Hatzenbuehler et al which says, "The co-occurrence of labeling, stereotyping, separation, status loss, and discrimination in a context in which power is exercised"(Hatzenbuehler et al, 2013).

This thesis therefore seeks to describe epilepsy associated stigma in Zambia by exploring the scope of stigma of epilepsy in Zambia, describing the factors that influence epilepsy associated stigma, examining the impact of epilepsy associated stigma on the diagnosis and treatment of epilepsy and identifying good practices or interventions that can be practiced in Zambia.

The study is divided in seven chapters, beginning with a background about Zambia. The second chapter presents the problem statement, objectives and methodology of the study, while the third chapter describes epilepsy and its associated stigma, including outcomes. The fourth chapter describes the stigmatization process and impacts of epilepsy associated stigma. The fifth chapter reviews interventions for stigma reduction, while the sixth chapter discusses findings and the last chapter draws on the conclusion of the study and highlights recommendations for good practices or interventions for Zambia.

CHAPTER 1: BACKGROUND INFORMATION ON ZAMBIA

1.1. General Background

1.1.1. Geography

Zambia is one of the countries in Southern Africa with a land surface of approximately 752,612 kilometre-squared (km²) and has eight neighbouring countries (CSO 2011). These are, in the north, Tanzania and the Democratic Republic of Congo, east, Malawi and Mozambique, south, Zimbabwe, Botswana and Namibia while in the west there is Angola. Zambia has ten provinces.

1.1.2. Demographic and socio-economic profile

The census of 2010 estimated the population at 13 million with an average annual growth rate of 2.8% and a population density of 17.3 persons per km² (CSO 2011). Copper is the main export commodity in Zambia but because of its unstable prices, poverty levels are high with about 64% living below the poverty line (WHO 2009).

1.2. Health profile

1.2.1. Health sector management and coordination

Health services in Zambia are mainly provided by the public sector although both private for profit and non-profit providers are also available. The Ministry of Health (MOH) has the responsibility of all health policy, secondary and tertiary health care. The Ministry of Community Development Mother and Child Health (MCDMCH), is in charge of primary care health services. The country has 1489 public health facilities, 271 private health facilities and 122 mission health facilities (MOH 2011).

Government funds most of the health services in Zambia in collaboration with co-operating partners although patients have to pay user fees in order to access health at secondary and tertiary level (MOH 2011).

1.2.2. Health Workforce

There is a negative impact on health service delivery because of human resource for health in Zambia is grossly low across all professions (WHO 2010). There are 0.7 physicians per 10,000 population in Zambia 12 non-physicians per 10,000 population which is less than half of the WHO recommended health workforce (WHO 2010). So most of the primary care level facilities are manned by non-physician healthcare workers (MOH 2011).

1.2.3. Accessibility of health services

Most Zambians have difficulties in accessing health services with approximately 46% of those in the rural areas having to travel beyond 5km to access health services (MOH 2011). Those that are able to access services,

which are usually in inappropriate infrastructures, encounter long waiting time before being attended (MOH 2011).

1.3. National Policy on Mental Health in Zambia

The Mental health policy is still in draft form but according to a review done by World Health Organisation (WHO), the language in Zambia's policy reflects commitment to change although the content is too general avoiding real commitment. The policy was also deemed as over ambitious with many objectives but no clear indication of how they would be achieved. The Zambian policy also does not actively promote integration of mental health services into general health nor a community based approach. It did include promotion of human rights of those with mental disability (WHO 2008).

All efforts to obtain a copy of the draft policy deemed futile and therefore the study relies on reviews done by others.

CHAPTER 2: PROBLEM STATEMENT, OBJECTIVES AND METHODOLOGY

2.1. Problem Statement

Majority of people with epilepsy (PWE), approximately 80%, live in developing countries with a proportion of about 6 to 10 people per 1000 population (WHO 2012). The main symptoms of epilepsy are unpredictable seizures and their frequency may vary from one person to another with some having one every hour or one in 1-2 years (WHO 2003). However, regardless of the frequency, the day-to-day life of those with this disorder is affected (WHO 2003). One in every 10 people will have an epileptic seizure worldwide at least once and approximately 50million people will have recurrent seizures (WHO 2004).

Epilepsy can be treated and controlled with anti-epileptic drugs (AEDs) and currently, a lot of knowledge and information is available on the condition (WHO 2003). The treatment of epilepsy is generally affordable costing USD 6 per year per patient (Lugthart 2011). But, one of the reasons that living conditions for those with epilepsy are worse than is expected in most parts of the world is that, it is associated with misconceptions, myths and traditional beliefs from as far back as 4000BC (WHO 2003).

Epilepsy associated stigma is experienced in both the developed and the developing world (Atadzhanov et al, 2011). Factors associated with stigma are multifaceted with some being culturally dependent and others universal but are more disabling in Sub-Saharan Africa (SSA) (Atadzhanov et al, 2011). The lives of people with epilepsy in Zambia are limited because of issues such as being poor, the expectations of the community in terms of social roles and beliefs in traditional values (Baskind & Birbeck 2005).

The epilepsy treatment gap in Zambia which is the difference between those who require treatment and those who actually receive the treatment is >80% (Atadzhanov et al. 2011). Some of the reasons why there is a huge treatment gap include access to quality healthcare services including AEDs, poverty and cultural beliefs (WHO 2004).Therefore this treatment gap causes many PWE to have uncontrollable seizures which may result in burns, fractures and possibly, drowning (Baskind & Birbeck 2005).

2.2. Justification

Approximately 10% of mental disorders in the world are caused by epilepsy and account for a significant amount of disability-adjusted life years, not including the social exclusion due to stigma (WHO 2003). This is due to physical disability such as severe burns or fractures as well as psychological manifestations due to the seizures (Baskind & Birbeck 2005).

A study done in Zambia showed that most PWE, especially women, live with a sense of abandonment and lack of care and support due to epilepsy (Birbeck et al. 2009). In addition, PWE have less education opportunities especially in poor families but also due to embarrassment from having seizures in public settings. With the limited education, the chances of getting gainful employment reduces and thus, further reduces their quality of life (Baskind & Birbeck 2005). And stigma does not only affect the individual but extends to family and associates including health workers providing services (Baskind & Birbeck 2005).

The MOH of Zambia, through the efforts of WHO Global Campaign against Epilepsy, have committed to working on the epilepsy associated stigma (MOH 2011). Although information exists about epilepsy associated stigma through a number of studies conducted in Zambia, and a mental health policy was drafted in 2005 which is currently under review, stigma is still experienced by PWE in Zambia. It is certainly essential to explore why there is still stigma of people with epilepsy in Zambia and whether this has an impact on the high treatment gap.

This thesis will therefore try to answer this question by exploring factors influencing, and impacts of stigma on epilepsy in Zambia, reviewing the current interventions locally and internationally to make recommendations for good practices.

2.3. General Objective

To explore the factors influencing epilepsy associated stigma in Zambia and to identify good practices or interventions locally and internationally, in order to make recommendations to policy makers.

2.4. Specific Objectives

1. To explore the scope of stigma of epilepsy in Zambia
2. To describe the factors influencing epilepsy associated stigma
3. To examine the impact of epilepsy associated stigma on diagnosis and treatment of epilepsy
4. To identify good practices/ interventions to reduce stigma of epilepsy
5. To make recommendations on how these interventions can be practiced in Zambia

2.5. Methodology

2.5.1. Study design

This thesis is a descriptive study of information that is currently available.

2.5.2. Study Method

A literature review was conducted on available information on epilepsy associated stigma specifically in Zambia. The study uses information collected in studies done by WHO, studies in Africa, Sub-Saharan Africa, and African countries with similar health indicators and conditions to Zambia, in order to try and give a comparative analysis onto which conclusions can be based and added on to the findings on the Zambian scenario.

2.5.2.1. Search strategy: Published studies as well as grey literature were identified by using different key word combination strategies from databases such as Pubmed, Google, Google scholar, Vrije University e-library, Medline, Cochrane Library and, WHO, and Zambian government websites. At times, truncation symbols were used for combination of key words

2.5.2.2. Search words used: Epilepsy, stigma, diagnosis, treatment, interventions, seizures, attitudes, knowledge, beliefs, culture, discrimination, perceived, enacted, courtesy, laws, policies, religion, traditional, healers, health, workers, socio-economic, poverty, labelling, gender, Zambia, Sub-Saharan, Africa.

2.5.2.3. Inclusion criteria: Any articles in English addressing epilepsy associated stigma and Zambia implicitly or explicitly from the year 2000-2014 in order to have a focussed search process with relatively recent to very recent data.

2.5.2.4. Screening process: The search strategy identified 156 articles. A total of 63 full text papers were obtained and met the inclusion criteria and are in this study review. For illustration on screening process refer to annex 1.

2.5.3. Conceptual framework

The conceptual framework to be used in this thesis was initially adapted from the global framework for Human Immunodeficiency Virus (HIV) stigma and used in India. I further modified it to be used for epilepsy. Therefore where it had 'people living with HIV' it was changed to 'people with epilepsy'.

The framework looks at stigma as occurring as a process, not just to an individual but also the family and peers and general population within certain institutions and structures (ICRW AND STRIVE 2013).

It also incorporates factors that influence stigma termed 'actionable' because if an intervention is made, they may change positively.

The 'drivers' as is used in the framework are: Lack of knowledge and awareness; Social judgement (blame and shame); Fear of contagion through contact and added to the framework is, Beliefs and practices because these are the determining factors through which stigma breeds in society.

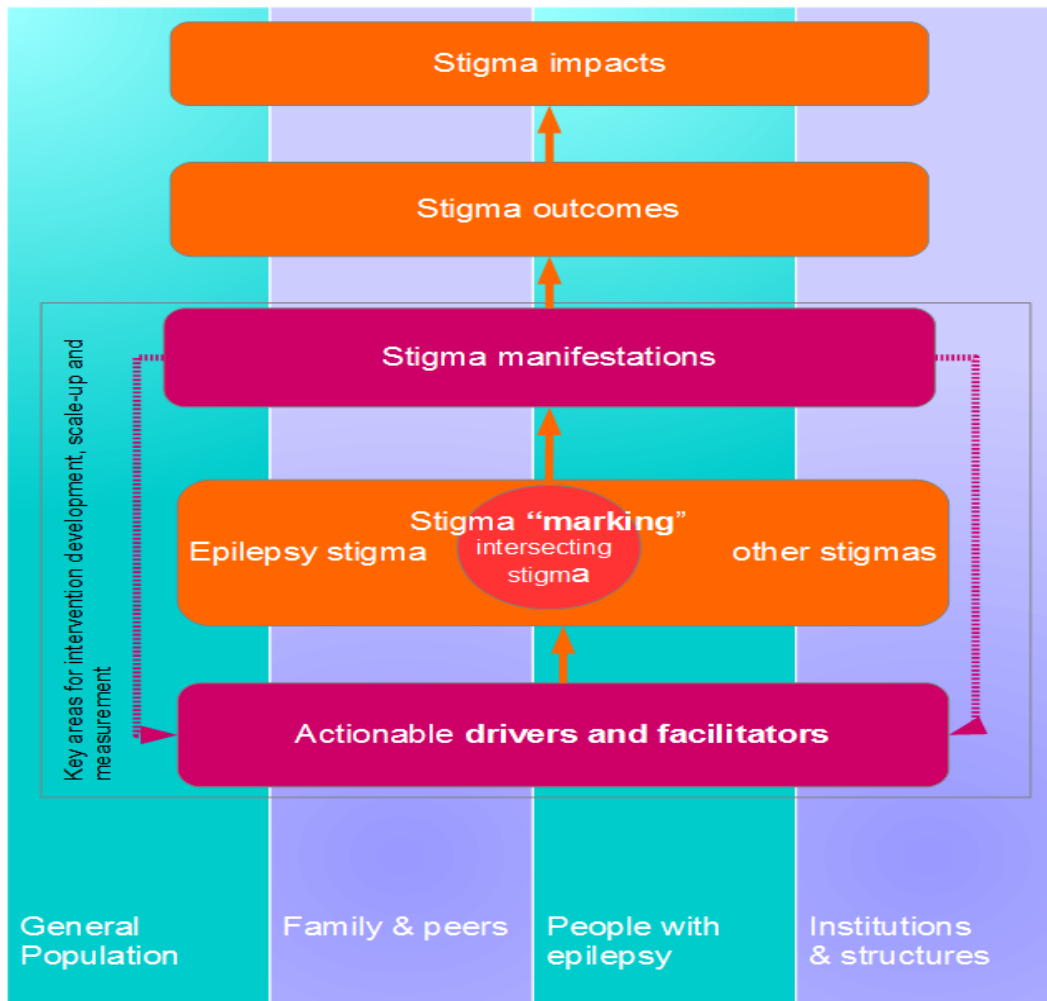
Although the drivers may be negative, the 'facilitators' might have an influence on stigma both in a positive and negative way. In this study, the facilitators are laws and policies.

This framework looks at how an individual can both be stigmatized and be the stigmatizer and can be in an already stigmatized situation such as gender stigma and poverty stigma which may intersect (ICRW AND STRIVE 2013). Manifestations in this framework refer to felt stigma and enacted stigma. Whereas outcomes refer to care seeking behaviour of people with epilepsy including adherence to AEDs. The stigma impacts refers to diagnosis capabilities and treatment uptake, and impact of epilepsy associated stigma on quality of life (ICRW AND STRIVE 2013).

The framework incorporates clear areas to which interventions can be applied.

Below is a figure of the framework and refer to annex 2 for description of other frameworks that were considered for this study but not used.

Figure 1: Modified Conceptual Framework



(Source: ICRW & STRIVE, 2013)

The next three chapters are going to describe the findings from the literature review by the use of the conceptual framework. In each section of the framework, attempts were made to find information on all the four agents of stigma described, but, in most cases this was not done due to insufficient information found. The findings have been split according to the factors influencing epilepsy associated stigma, stigmatization process and the interventions to reduce epilepsy associated stigma.

CHAPTER 3: EPILEPSY AND ITS ASSOCIATED STIGMA

This Chapter describes epilepsy, stigma and thereafter, epilepsy associated stigma in the Zambian context.

3.1. Epilepsy

Epilepsy refers to a condition in which someone has had more than one unprovoked recurrent seizures due to abnormal cell activity in the brain (Gault 2008). Some conditions such as brain tumours, brain infections, strokes and alcohol or drug withdrawal cause recurrent seizures and are considered risk factors (Parmet 2011). A seizure in epilepsy occurs when the brain cells (neurons) electrical signals have a sudden change in the way they communicate, therefore, sending abnormal signals which stops other cells from working properly (Engel & Pedley 2008). It affects people of all ages but especially the very young and the very old (Gault 2008).

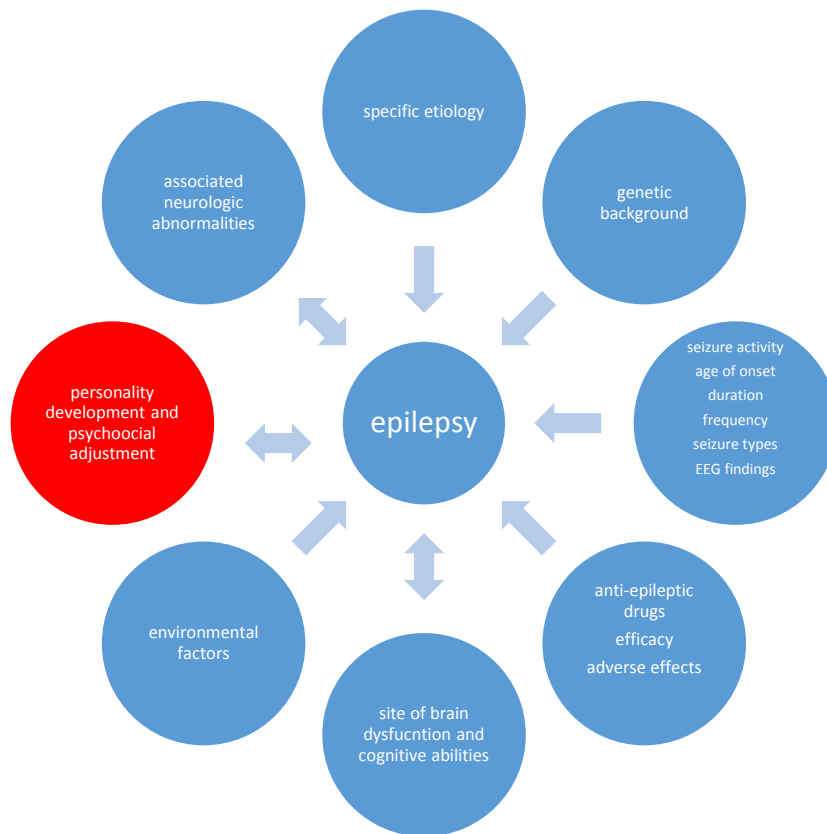
Although many types of seizures exist, depending on where the abnormal activity begins, they are classified into two main categories partial and general seizures (Gault 2008; Parmet 2011; Engel & Pedley 2008). According to Gault, seizures have no harmful effect and are not contagious.

To diagnose epilepsy, proper description of the nature of seizures and timing needs to be made, assessment of brain activity using electroencephalogram (EEG) or computed tomography (CT) scans and, Magnetic Resonance Imaging (MRI) (Parmet 2011).

Epilepsy is treatable with AEDs such as carbamazepine and phenobarbital which are readily available in Zambia. It can also be treated by Vagus nerve (large nerve in the neck) electric stimulation and sometimes brain surgery (Parmet 2011).

However, the International League Against Epilepsy (ILAE), has expanded the definition and describe epilepsy as a "Chronic condition of the brain characterized by an enduring propensity to generate epileptic seizures, and by neurobiological, cognitive, psychological and social consequences of this condition." This means that the ILAE's definition acknowledges the aspect of the psychological and social consequences of epilepsy and that epilepsy is more than just the seizure, it is multifaceted, as illustrated in the figure below (Engel & Pedley 2008):

Figure 2. The multiple interacting factors that contribute to the totality of epilepsy for an individual patient (Engel and Pedley, 2008)



Therefore epilepsy is considered a public health issue because it is multifaceted in nature (WHO 2004). The many aspects detailed in the illustration above contribute to the individual with epilepsy's quality of life as evidenced by people who have undergone surgery and have become seizure free but still experience social isolation (Engel & Pedley 2008). Meaning that therapeutic interventions are only optimal if these other factors are addressed as well.

3.2. Stigma

One of the aspects that affect an individual with epilepsy as highlighted in the illustration is the psychological and social consequences of epilepsy. This study focuses on Stigma which is one of these consequences under psychological and social aspect. The word 'Stigma' comes from the ancient Greeks which was a label or mark for those who were to be avoided because of their immorality (WHO 2005). Goffman in his classical study looked at stigma as a social construction of identity in which the 'normal' reduce the social status of the person with a condition (Cited by Kleinman & Hall-Clifford 2014). The groups become more dominant and create inequalities therefore limiting those

that are stigmatized and eventually they start accepting their status as made by society(Nyblade et al. 2003).

The sociology field incorporates stigma into the social processes that occur within an individual due to their socio-cultural environment (Kleinman & Hall-Clifford 2014). This therefore allows chance to see how power affects stigma in the social realms. Usually the stigmatized are not able to meet social obligations and norms such as wealth, relationships and life chances (Kleinman & Hall-Clifford 2014).

Stigma can manifest in three main forms, felt stigma (also known as perceived or self-stigma which can be internalised by the person), enacted stigma and courtesy stigma. Felt stigma is the feeling of fear by the individual with the condition of being stigmatized (Baskind & Birbeck 2005).

Enacted Stigma is the act of discrimination against the person with a disease or condition and courtesy stigma is stigma experienced by close family and friends due to being associated with a person with a stigmatizing condition (Baskind & Birbeck 2005). Courtesy stigma may include both felt and enacted stigma.

Stigma in a medical condition is usually unwarranted and may have effects that negatively affect public health policy as well as the health status of the individual with the medical condition (Weiss et al. 2006). It is important not to forget that those being stigmatized and the stigmatizer are interdependent through their social networks (Kleinman & Hall-Clifford 2014). Thus, there is a need to understand the socio-cultural processes that enable stigma in these social networks and this will help focus on how to combat it.

The next section will elaborate on how and why epilepsy becomes a stigmatising condition in society.

3.3. Epilepsy associated stigma

Epilepsy as stated earlier has some social effects which may vary from country to country. The stigma surrounding epilepsy is quite often more harmful to the person with epilepsy than the seizures themselves due to the effects it may have on them seeking treatment if they are identified with the disorder (WHO 2012) and it is difficult to conceal epilepsy especially in those with generalized seizures.

According to the dimensions of stigma mentioned by Jones and colleagues, all apply to epilepsy, but disruptiveness is the most crucial, which in the case of epilepsy would be the seizures which cause social interaction disruption and may also not be pleasant aesthetically (WHO 2004). Social exclusion of people with epilepsy may be significant for example if they are abandoned during a seizure episode, they may end up with injuries that may become visible and further their social exclusion (WHO 2004).

Scambler's "hidden distress" model shows that after diagnosis an adult with epilepsy goes through felt stigma even before their condition is exposed in order to have enacted stigma. They will therefore try to conceal their condition and in the end cause more harm to themselves. And this is all dependent on cultural and clinical aspects of a community (cited by WHO 2004).

The degree of stigmatization in epilepsy is dependent on the clinical course of the disease, whether the individual has side-effects and even socio-economic determinants such as education and employment (Baskind & Birbeck 2005). It has been also shown that stigma in epilepsy is more pronounced than in other stigmatizing conditions such as other mental illnesses or HIV/AIDS infections (WHO 2004).

3.3.1. Marking or labelling of Epilepsy

Marking or labelling in a Stigmatizing condition causes social deviance or exclusion. Once one is labelled (for instance as having epilepsy), it affects the social interaction that the marked individual has with the rest of the social group and forces them to act in a way that is acceptable to their new social role (Degirmenci et al. 2013). Being labelled means one is left to society's cultural 'prescriptions' of how to be treated.

The label of being PWE in Zambia changes the experiences of those with the condition in society before their condition was known to others and after (Birbeck et al. 2009). In a study done in amongst women with epilepsy in Zambia, it was revealed that before it was known to the public that they were epileptic, the women functioned normally in society but after it was known, they did not get visitors coming to their homes anymore. And when they walk in the streets, they get taunted by children being called all sorts of humiliating names because they are epileptic (Birbeck et al. 2009). The societies in Zambia are that of close communities and open housing especially in the rural areas, therefore, it is often difficult for the PWE to conceal their condition especially if they have generalized recurrent seizures (Baskind & Birbeck 2005).

Also, the most feared mark or labelling by those with epilepsy in Zambia is burns which is a consequence of having a seizure near an open fire used for cooking (Baskind & Birbeck 2005). Having burn scars is associated with being epileptic and implies a sealed fate meaning the disease is incurable.

3.4. Manifestations of epilepsy associated stigma

As was stated earlier, stigma manifests in three main forms namely felt stigma, enacted stigma and courtesy stigma. Described below are the three manifestations for epilepsy associated stigma in Zambia.

3.4.1. Felt stigma

Felt stigma results in a person with a stigmatizing condition or disease perceiving they have been stigmatized or will be stigmatized even when the act of stigmatizing has not occurred (Atadzhanov et al. 2011). The result of felt stigma is that the individual who feels stigmatized may lose out on life's opportunities for fear of being stigmatized (Baskind & Birbeck 2005).

According to a study done in Zambia, it revealed that women were worried about seizures in terms of taboo breaking (when they have seizures, they may not be well covered showing their under garments, as well as urinating and defecating in public) (Birbeck et al. 2009). For instance in the Tonga people of southern province of Zambia, a married woman's underwear is only purchased for her by her husband. So the state of the underwear reflects the regard in which the husband holds the wife. In most women with epilepsy, they are usually abandoned meaning they might not have underwear or might have worn-out underwear. So if they have a seizure in public, this might not only reveal that she has epilepsy but also that she is abandoned by her husband (Birbeck et al. 2009).

Those with felt stigma try to conceal their condition as much as possible because they fear that if they disclose, they would face discrimination. It does not allow them to actually see if what they believe is actually true (Jacoby 2002).

It was shown in a study done by Barker and colleagues that those people who felt stigmatized experienced more health problems such as injuries, side effects of AEDs, and less seizure control than those who did not feel stigmatized (cited by WHO 2003).

3.4.2. Enacted stigma

Enacted stigma is the act of discrimination and according to Baskind and colleague, people with epilepsy in Zambia still experience a substantial amount of enacted stigma (Baskind & Birbeck 2005).

Because of the treatment gap in Zambia, many people with epilepsy end up having frequent seizures which consequently may lead to burns (the most feared mark or labeling), drowning and fractures and thus making their condition known to the public making them prone to acts of discrimination (Baskind & Birbeck 2005).

According to Baskind and colleague, PWE are subjected to social exclusion either voluntarily or involuntary and may not even be allowed to use communal utensils or sleeping quarters or are hidden away when visitors come to visit (Baskind & Birbeck 2005).

Some women with epilepsy in Zambia mentioned a lot of physical abuse in their homes including banishment (Birbeck et al. 2009). A study revealed that there were higher rates of physical abuse in PWE at 37% compared to 5% in the control group with other chronic medical conditions and in the women with epilepsy, 20% reported being raped compared to 3% in the control group (Birbeck et al. 2007).

Birbeck and colleagues argue that women in Zambia with epilepsy who have the condition before they get married find it hard to find partners because men are usually discouraged from marrying them and those that are married continually have fear of being abandoned and losing their children. Some may not be abandoned or divorced but do not get any physical contact from their husbands (Birbeck et al. 2009).

Some traditional healers in Zambia actually enable enacted stigma and courtesy stigma because they associate epilepsy to a curse on the whole family unit (Baskind & Birbeck 2005). Birbeck and colleagues say that some families of those with someone with epilepsy fear that whatever "curse" was put on the PWE might spread to everyone in the household and hence they are kicked out of the house (Birbeck et al. 2009).

3.4.3. Courtesy Stigma

Goffmann's study on stigma suggested that courtesy stigma was stigma in people who do not have the stigmatizing condition but are associated with someone who does and may themselves experience discrimination and social rejection (Cited by Parfene et al. 2009). Therefore the negative characteristics associated with the person with the stigmatizing condition may be transferred to those with whom they have been associated.

In a study done to determine the psychiatric morbidity and stigma among mothers of children with epilepsy in Zambia, it showed that 39% perceived their child to be stigmatized and 20% felt that they themselves were stigmatized because of their child's condition (Elafros et al. 2013). Some parents actually encourage their children to conceal their condition because of fear of them themselves being stigmatized. Whereas some parents actually have levels of shame and self-blame because their child has epilepsy and this in the end affects the entire families' chances or opportunities and quality of life (Jacoby 2002). This can be attributed to why some families actually abandon their children or banish them from their homes.

3.5. Intersecting stigmas

Epilepsy associated stigma needs to be seen in a wider context in which other things are occurring at the same time. As such, other stigmas occur to those with epilepsy because as much as they belong to a social group of people with

epilepsy, they also belong to other social groups such as social economic status and gender.

Some of the other stigmas that also occur in Zambia are poverty stigma (affecting those from lower social economic status) and gender stigma (affecting women who are perceived to be at a lower social status) (Bond et al. 2003) and both of these can occur in someone with epilepsy therefore intersecting the stigmas.

According to Ssebunnya and colleagues a relationship exists seen between stigma of mental illness and poverty which is in a vicious cycle, (Ssebunnya et al. 2009). Majority of the people in Zambia are poor with 64% living below the poverty line (CSO 2011). So most people are not willing to look after someone who will not contribute to the household wealth having negative attitudes towards those that are sick especially if it is chronic (Bond et al. 2003). In Zambia, a study showed that during famine, PWE were excluded from food rations and they lost a lot of weight (Lugthart 2011). Atadzhanov also argues that the wealthier people probably have larger homes and spend less time outside which makes it possible to conceal their condition (Atadzhanov et al. 2011).

Discrimination is not only in homes but also at health facilities where those with money get preferential treatment (Nyblade et al. 2003).

Bond and colleagues continue to say that women in Zambia suffer more stigma than men because they are more dependent on their husbands or relatives. If they end up sick, they are chased from home or sent back to their parents (Bond et al. 2003). Some are subjected to sexual abuse because they have been abandoned by their families and husbands.

Birbeck argues that gender roles are jeopardized as an effect of epilepsy. In her study, women in Zambia showed concern for accidental injuries because they cannot carry out their daily duties such as cooking on a fire, drawing water even walking or bathing on their own (Birbeck et al. 2009). There was also fear of intentional injuries if they had a seizure in public unaccompanied, such as being abducted, robbed or even murdered.

This chapter has given an overview of epilepsy, stigma and epilepsy associated stigma in Zambia including manifestations of epilepsy associated stigma. The next chapter will go into more detail of the stigmatization process of epilepsy as it occurs in Zambia in order to give further understanding into what has been described in this chapter.

CHAPTER 4: THE STIGMATIZATION PROCESS, OUTCOMES AND IMPACTS OF EPILEPSY ASSOCIATED STIGMA

This chapter focuses on the stigmatization process of epilepsy associated stigma, and then ends with description of the outcomes of stigma and the impacts of stigma on diagnosis and treatment of epilepsy and quality of life of those with epilepsy.

4.1. The agents of stigmatization process

The main agents of stigma are the individual with epilepsy, the family and peers, the general public or community and the institutions and structures.

4.1.1. The individual- people with epilepsy

It is said that the stigmatization process starts with a person being labelled as having epilepsy or being epileptic. This can be at the moment that they have their first seizure or at diagnosis (Stajić & Bosnjak 2002).

The individual with epilepsy experiences both felt stigma and enacted stigma as was depicted in the earlier chapter. Therefore voluntary disclosure of being epileptic is not common in Zambia for those with epilepsy because of fear of being stigmatized and those that have disclosed have higher felt stigma including those who believed that their disease was contagious (Atadzhanov et al. 2011).

4.1.2. Family and peers

The immediate people who the individual with epilepsy encounters in society is their family and peers. It is important to understand the wellbeing of the caregivers and family of those people with a stigmatizing condition such as epilepsy because they may suffer from courtesy stigma and sometimes they may be the ones doing the stigmatizing.

The way the family and peers respond to PWE has a big impact on the self-perceptions of those with the condition (Birbeck et al. 2009). And according to Thomas and Nair, family is also important in determining how stigmatized the person with epilepsy feels because the perceptions and attitudes of the family will determine the quality of life of the PWE (Thomas & Nair 2011). In a study done by Chomba and colleagues, children with epilepsy in Zambia obtained less education than their non-epileptic sex-matched siblings leading to them having less job opportunities and being subjected to casual work (Chomba et al. 2009).

4.1.3. General population – the community

The community in which a person lives plays a big part in determining whether a condition is stigmatizing or not because it is at this stage that the “tainted” become different from the “usual” and the level that people distinguish

between the “us” and “them” (Nyblade et al. 2003). This therefore determines whether the person with epilepsy experiences felt stigma or enacted stigma because of the cultural norms and beliefs related to the disease.

A study in Zambia noted that PWE were more subjected to stigmatizing conditions in the rural areas than in urban areas and this was attributed to lack of knowledge about the disease and a culture embedded in traditional beliefs (Pupillo et al. 2014). Because of close communities and open housing in the rural areas, it is often difficult for the PWE to conceal their condition (Baskind & Birbeck 2005).

The status of someone within the community is very important in Zambia, especially in the rural areas where people rely on each other for daily chores, the social worth of a person is dependent on whether they are able to carry out their allocated chores diligently. Therefore those PWE with uncontrollable seizures are put in a precarious position. If they are not able to carry-out their duties it reduces their social standing and therefore increases stigma (Baskind & Birbeck 2005). This also affects their socio-economic opportunities and quality of life.

4.1.4. Institutions and structures

Institutions and structures refers to policies and actions in both private and governmental institutions that may intentionally infringe upon the opportunities of someone with epilepsy. They may also include actions or policies that are not meant to harm or discriminate the person with epilepsy but nevertheless hinder their options and opportunities (Corrigan et al. 2004). This next section is going to look at four areas which were found to be influential in the lives of those with epilepsy during the literature search namely; the school (majority of those with epilepsy in Zambia are of school going age between, 5-15 years old), the work place, religious institutions, and health facilities. No information was found on actual policies about mental health or epilepsy in these areas in Zambia but the attitudes of those who would be the ones implementing these policies might give an insight into how these institutions and structures might influence epilepsy associated stigma. The more general laws and policies will discussed later in the chapter.

4.1.4.1. Schools –Teachers’ attitudes

Research has shown that children with epilepsy have difficulties in school and it is important to know at what proportion this is due to the illness itself, the AEDs and the social interaction (Prpic 2003). At the school the child acquires knowledge and skills including social skills.

Because of high demand for education in Zambia as compared to supply, teachers may send unwanted pupils away from the classrooms or may apply pressure to the parents to have their children removed from the school

(Birbeck et al. 2006). Therefore, the teacher's attitude towards a child with epilepsy at school can tremendously affect the future prospects of that child.

A study done to ascertain the attitudes of Zambian teachers towards epilepsy, consisting of 171 participants from both rural and urban schools, revealed that although most of the teachers had heard about epilepsy, and majority had witnessed a seizure, some still associated it to evil spirits and demon possession and about 40% of them said that if a child had a seizure in school, they would not allow that child to remain a pupil in their class (Birbeck et al. 2006). And about half of them said they would recommend treatment via a church healing session. This therefore limits the chances of child with epilepsy getting appropriate treatment, as well as life opportunities if they are sent away from school.

4.1.4.2. Religious leaders' Attitudes

Zambia is a Christian nation with only 2% of the population being non-Christian (Atadzhanov et al. 2006). Cultural norms as well as religious beliefs can either increase or decrease epilepsy associated stigma. According to Atadzhanov and colleagues, religious leaders in Zambia are held at high status with a high influence on the community. In a setting where epilepsy is viewed as a possession by evil spirits it may lead people with epilepsy seeking help from religious leaders instead of going to a health facility, therefore, these religious leaders may play a role in determining at what level epilepsy is a stigmatizing condition in society (Atadzhanov et al. 2006).

In a study done in the rural region of Zambia and as well as in the capital city, it revealed that most religious leaders in the study were familiar with epilepsy and out of the 225 respondents, 61.6% related epilepsy to brain injury, whilst 25% related it to supernatural causes with majority recommending prayer as a healing treatment for epilepsy therefore reducing chances of those with epilepsy utilizing health facilities to get appropriate care. Tolerance towards epilepsy was from those religious leaders who would recommend a doctor than those who would recommend a healing prayer session (Atadzhanov et al. 2006).

4.1.4.3. Work place

In order to have a good quality of life, it is important for one to be employed and have an income (Smeets et al. 2007). It is also a way in which one integrates into society and has self-worth with an identity. Evidence has shown that issues to do with employment of PWE is not only limited to severity of seizures but also internal and external social factors (Smeets et al. 2007). Bandstra and colleagues say that PWE were sometimes characterized as mentally retarded, violent or hostile and physically unappealing which caused people not to want to work alongside them (Bandstra et al. 2008).

Stigma at the workplace is also attributable to the social acceptance at the workplace of PWE. This affects the ability of those with PWE to disclose their status to their employers (Smeets et al. 2007).

Employment both in the formal and informal sector is difficult for PWE in Zambia. Those who go into selling of products faced problems as soon as the general public knew they had epilepsy, business would go down. Those in the formal sector experienced termination of employment as soon as they had a seizure at the workplace (Birbeck et al. 2009).

4.1.4.4. Healthcare workers' attitudes

The first contact any person with an illness will have with a health facility is a healthcare worker and they are one of the key elements in a patients' perception of quality of care. Therefore for someone with epilepsy in a stigmatizing community, the attitude and knowledge of the healthcare worker on epilepsy is of utmost importance because they are the ones that provide information about epilepsy and essentially determine how epilepsy is viewed in the societies in which they work (Chomba et al. 2007).

It was reported that 95% of health workers in a study done in Zambia would allow their child to play with someone who had epilepsy and 25% would not allow their child to marry someone with epilepsy (Chomba et al. 2007). Baskind and Birbeck argue that sometimes health care workers may be uncomfortable in diagnosing and treating seizures or epilepsy even though this is what they are supposed to do. Some physicians in Zambia also attribute seizures to supernatural causes which may be a result of limited neurological education (Baskind & Birbeck 2005). It was also noted that those healthcare workers who had a family member with epilepsy were less tolerant to people with epilepsy than those who did not. They also indicated that people with epilepsy were feared in their communities or rejected (Chomba et al. 2007).

4.2. Drivers and facilitators of epilepsy associated stigma

The drivers and facilitators refers to issues or factors stemming from the social realm that may have an influence on the stigmatization process either negatively or positively. These have been described in more detail below beginning with lack of knowledge, which leads to certain beliefs and practices (including fear of contagion), which results in social judgement. The general laws and policies are also described to give an insight on how they can facilitate epilepsy associated stigma.

4.2.1. Lack of knowledge and awareness

Knowledge on any subject improves our understanding of the given subject and therefore affects how we respond. It has been shown in the earlier sections of this chapter that a lack of knowledge about epilepsy exists in

Zambia. For example according to Chung et al, due to the lack of knowledge about epilepsy at the workplace, discrimination towards people with epilepsy was noted especially if seizures occurred at work (Chung et al. 2012). This may make it difficult for PWE to sustain employment.

In a study done to determine the distribution of knowledge about epilepsy in Zambia, it showed that there was no significant difference in knowledge between the urban and rural groups (Pupillo et al. 2014). However, in a study done about knowledge of epilepsy in Zambian teachers, less than 40% characterized it as a brain disorder although 90% recognized it as a chronic condition (Birbeck et al. 2006), revealing that although knowledge about epilepsy as a disease exists, the intricate details about its causes and treatments may be deficient.

4.2.2. Beliefs and practices

Beliefs and practices stem from the cultural norms and values. This combined with a lack of knowledge and awareness leads to people relying on beliefs that are passed on from those most influential in their lives such as people in the community, family including elders, religious leaders and sometimes teachers as was mentioned earlier.

Gureje and Colleague noted that attitudes towards mental health, especially in Africa are influenced by traditional beliefs such as supernatural causes and traditional methods of treatment (Gureje & Alem 2000). According to Jacoby, those with epilepsy are viewed as people who are violent or mad or with a contagious disease that was afflicted on them due to a curse (Jacoby 2002). Such negative beliefs further propagate stigma in epilepsy and invariably affect those with the condition

In the study done in Zambia, it was noted that traditional healers attributed seizures or epilepsy to witchcraft. This was also noted in nurses and physicians that were interviewed, although some traditional healers mentioned that when they were unable to cure the seizures, they would refer the patient to other traditional healers or even to a health facility (Baskind & Birbeck 2005).

4.2.2.1. Fear of contagion

One of the important aspects that results from beliefs and practices is fear of contagion. It makes the difference between someone with epilepsy being helped or not. According to Baskind and Birbeck, traditional healers in Zambia identified bodily fluids emitted during a seizure like urine, saliva and faeces as contagious and that epilepsy or seizures could be transmitted to family members or bystanders through these substances (Baskind & Birbeck 2005). Engel and colleague suggest that the belief of contagion through epileptics' saliva comes from it being associated with rabies which can have similar manifestations as epilepsy and is indeed infectious (Engel & Pedley 2008).

Birbeck adds on to say that most PWE in Zambia are not helped by the family when they are burning or having a seizure due to fear of contagion (Birbeck 2012). Such beliefs and fears become dangerous to the livelihood of people with epilepsy.

4.2.3. Social judgement (blame and shame)

Social judgement comes about before the actual act of discrimination as a result of intersection between lack of knowledge and a persons' beliefs and practices. This can consequently lead to the person doing the stigmatizing having feelings of blame towards the person with the condition and the stigmatized having feelings of shame. This was noted in a study done amongst women in Zambia with epilepsy in which feelings of shame and rejection were mentioned especially when they were asked to leave the urban area by their families and sent to live in the villages due to their condition (Birbeck et al. 2009).

According to Jacoby, having epilepsy is seen as a "weight" people have to carry and can be more terrifying than having seizures (Jacoby 2002). In a study done amongst PWE in Zambia it was noted that they would present to the hospital with seizure complications such as burns or fractures after a seizure, but would not mention the seizure episode to the clinician because of shame (Birbeck 2012).

4.2.4. Laws and Policies

Laws and policies have three areas in which they can affect the operation of stigma in society. They can be used as a way to prevent or rectify stigma, as a way in which stigma is enacted or disputed, or, a way in which an individual can be resistant towards stigma (Link & Phelan 2006).

Chung et al argue that there is discrimination in terms of restriction to driving for PWE which causes them to be more dependent on family members and friends (Chung et al. 2012). Because of this PWE have to find work close to their homes or those accessible by public transportation (Chung et al. 2012). Even in developed countries PWE are subjected to legal discrimination in their search for employment and getting a driver's license even though they are protected by the law (WHO 2004).

In Zambia, it is prohibited to urinate or defecate in public by law and it is also a social taboo. And as mentioned earlier, during a seizure one may lose sphincter control functions. In Zambia, the police are usually called first when an epileptic person has seizures in public (Mbewe et al. 2007). According to a study done by Mbewe et al, it was found that all police officers who participated in the study said they would 'quarantine' the person with epilepsy and some said they would have them arrested (Mbewe et al. 2007).

In terms of health policies, Zambia like other countries in Sub-Saharan Africa, does not prioritize mental health because of competing needs such as communicable diseases and malnutrition and only allocates 0.34% of its total health expenditure towards mental health (Gureje & Alem 2000; Mwape et al. 2011). Refer to annex 3 for a comparative table with other African countries of money spent on mental health.

In addition, the mental health policy is still under review. This in itself is a form of structural stigma as those with epilepsy may not get the comprehensive care they may require and consequently affect their options and opportunities.

4.3. Stigma outcomes

The stigmatization process ends with stigma outcomes which have a profound effect on the health and quality of life of people with epilepsy. This study focuses on the stigma outcome of care-seeking behaviour.

4.3.1. Care-seeking behaviour of people with epilepsy

It has been elaborated in the previous chapter and in this chapter how epilepsy associated stigma affects and leads to certain behaviour of people with epilepsy not seeking medical care after having a seizure because of fear of being isolated. Because of myths and beliefs in traditional causes of epilepsy Chin argues that PWE may therefore seek help from traditional healers (Chin 2012).

A study done in Zambia confirmed Chin's argument and gave evidence that 61% of the people with epilepsy in the study had first used traditional medicines and only 31% had ever been treated with appropriate AEDs (Birbeck 2000). Mbuba and Newton added that some symptoms of epilepsy such as hallucinations may not be seen as such and may be tied to traditional beliefs, thus, the person with epilepsy may not be taken to the health facility (Mbuba & Newton 2009). Another study done in Zambia, showed that less than 4% of PWE sought treatment at a medical facility while all had been to a traditional healer (Baskind & Birbeck 2005).

Because of the social stigma associated with epilepsy in Zambia, PWE are even at a worse social and economic disadvantage (Baskind & Birbeck 2005). They may not have the money to enable them to get to the health care facilities which may be at far away distances and may also not have the social networks to help mobilize transportation to health facilities (Baskind & Birbeck 2005).

According to Engel and Pedley, usually families and patients with epilepsy do not shun biomedical treatment but complain that they do not get an explanation about the condition or diagnosis in contrast to the traditional healers who give "believable" and "better" explanations about the disease (Engel & Pedley 2008). Thus they may end up seeking care from traditional

healers who may be more accessible and have cultural and conceptual familiarity (Baskind & Birbeck 2005). For instance in Chikankata area of Zambia serving 55,000 people, has only 4 physicians compared to 18 traditional healers (Baskind & Birbeck 2005). This makes the traditional healers more accessible and according to Engel and colleague, beliefs embedded in witch-craft flourish more in places without medical care (Engel & Pedley 2008).

The care-seeking behaviour of PWE will determine the adherence to anti-epileptic drugs. Because adherence is dependent on accessibility to medication and acceptability of the medications (Dillip et al. 2012).

4.4. Impacts of epilepsy associated stigma

Epilepsy associated stigma definitely has an impact on epilepsy in its entirety. Therefore the next sections are going to look at how epilepsy associated stigma has an impact on the diagnosis of epilepsy, its treatment, and the quality of life of people with epilepsy.

4.4.1. Impact of stigma on diagnosis of epilepsy

According to Mbuba and colleague, epilepsy associated stigma has an impact on diagnosis of epilepsy evidenced by the large numbers of those who go undiagnosed in Lower and Middle Income Countries (Mbuba & Newton 2009). No evidence was found on an actual study for Zambia to confirm this argument but it was described earlier that in a study with healthcare workers in Zambia many mentioned their lack of knowledge about epilepsy which would obviously affect their capability of diagnosing it accurately. This is also combined with the beliefs and practices and the care-seeking behaviour that have an influence on whether a person with epilepsy actually goes to a health facility for them to be diagnosed elaborated in earlier sub-chapters.

4.4.2. Impact of stigma on treatment

The treatment gap in Zambia is over 80% and this could be attributed to stigma associated with epilepsy due to the beliefs and practices embedded in tradition.

This is evidenced by a study done which showed that women with epilepsy in Zambia are prone to physical abuse, rape and even robbery because of their condition, and are unable to travel alone and therefore it may be difficult to find a companion in order for them to attend epilepsy clinics regularly (Birbeck et al. 2009). This therefore can cause issues with adherence to anti-epileptic medications.

Epilepsy associated stigma is also distributed according to socio-economic status in Zambia, with the poor and marginalized being more stigmatized than the rich (Atadzhanov et al. 2011). This leads the poor more to concealing their

condition and has an impact on whether they seek treatment or not (Atadzhanov et al. 2011).

4.4.3. Impacts of stigma on quality of life of those with epilepsy

Stigma is a factor in determining life chances such as well-being and socio-economic status (Atadzhanov et al. 2011). In a study done in Zambia amongst those with epilepsy and a control group with chronic medical problems such as asthma, diabetes mellitus, hypertension and rheumatic heart disease, it showed that people with epilepsy were less likely to get married, had fewer children that were alive and received fewer years of formal education than those in the control group (Birbeck et al. 2007).

It also showed that they were likely to be unemployed compared to those in the control group and the type of housing was a lower quality with less access to water and improved sanitation. In the control group, about 50% had electricity in their homes whereas those with epilepsy, only 20% had electricity. They also had poorer food security as compared to the control group with household wealth being at US\$232 versus US\$517 for the controls (Birbeck et al. 2007).

In another a study done, it revealed that children with epilepsy were less likely to go to school as compared to those with other chronic conditions of the same age and same sex (Chomba et al. 2009). This was due to worry from parents that the child might get a seizure whilst in school. It was also noted that the mothers of those with epilepsy were more likely to stay home and unemployed making the mean wealth in the homes of those with epilepsy less than those with children with other chronic conditions. The children with epilepsy also received fewer protein meals than those with other chronic conditions with less than three meals a day (Chomba et al. 2009).

The next chapter will therefore look at interventions to reduce epilepsy associated stigma.

CHAPTER 5: INTERVENTIONS FOR THE REDUCTION OF EPILEPSY ASSOCIATED STIGMA

In this Chapter, the interventions currently in place to reduce epilepsy associated stigma will be described. These will be separated according to those in Zambia and those internationally categorized as individual or public interventions.

5.1. Interventions related to reduction of epilepsy associated stigma in Zambia

5.1.1. Interventions targeted towards the individual with epilepsy

Peer support groups are used in Zambia, because it is believed that if information or counselling comes from someone who has been through a similar situation, it will be better accepted and believed (Elafros et al. 2013). They have been conducted in three sites in Zambia, two in Lusaka and one in Chikankata area of Southern province through the Chikankata Epilepsy Care Team (Birbeck 2012). The care team has been successful in Chikankata to point where the burn unit was closed in 2005 because majority of patients who were being admitted for burns had epilepsy and the burns were caused by seizures due to cooking on fire wood (Birbeck 2012).

A study by Elfaros et al done to assess the effectiveness of peer support groups in Zambia showed that there was no significant difference in felt stigma between those who attended the group for more than six weeks and those who attended the group for less than six weeks amongst the adult participants. But among the youth attending the peer support group felt stigma reduced significantly (Elafros et al. 2013). Considering the most affected age group of PWE is 5-15years, this can continue to be a way to reduce felt stigma in this age group.

5.1.2. Interventions targeted towards specific groups in the public

The care team in Chikankata is also involved in community education in order to improve awareness about epilepsy and thereby reducing stigma. Even research findings are usually interpreted and disseminated back to the community (Birbeck 2012). And Epilepsy Association of Zambia has been conducting sensitization campaigns against epilepsy associated stigma along the line of rail but it is poorly funded affecting its ability to carry out their work (ZANIS 2010).

The traditional healers in Zambia focus on social and psychological context of the disease rather than the disease based care which is given at the hospitals (Baskind & Birbeck 2005) and this was cited as one of the reasons people

prefer traditional healers than health facilities. There is an informal agreement in Chikankata district of Zambia in which the healthcare workers can visit those with epilepsy diagnosed by the traditional healers in the villages and the traditional healers are welcome on the wards in the hospital (Engel & Pedley 2008). In countries where involvement of traditional healers has been tried, very little success was achieved because the policies failed to articulate and specify what the traditional healers or the clergy could do (Gureje & Alem 2000).

5.2. Interventions related to reduction of epilepsy associated stigma in other countries

5.2.1. Interventions targeted towards the individual with epilepsy

WHO is working to reduce the treatment gap which invariably will have an impact on the quality of life of PWE and with improved seizure control, reduced stigma in epilepsy (Fernandes et al. 2011).

The global campaign against epilepsy together with WHO, works to help reduce epilepsy associated stigma. And in many countries many support groups have been registered in order to reduce epilepsy associated stigma (Fernandes et al. 2011).

Although it was noted in a six week psycho-educational program by Snead and colleagues to decrease the emotional impact of epilepsy, no significant impact was seen on their quality of life (Birbeck 2006). But according to Mbuba and colleague, a significant improvement in knowledge and the coping of living with epilepsy was noted in a study to assess effectiveness of psych -education interventions (Mbuba & Newton 2009).

In some lower and middle income countries such psycho-education interventions have been done but the long term effect may be difficult to identify requiring long follow-ups and good data collection (Mbuba & Newton 2009). This was evidenced in a study done in Tanzania, in areas that had organized epilepsy care as well as public education compared to those that did not have such programs. A positive impact was noted especially when the care was maintained over a long period of time (Birbeck 2006).

5.2.2. Interventions targeted towards specific groups in the public

Many interventions to address epilepsy associated stigma are aimed at the stigmatizer and emphasis is put on education and social marketing which is through different ways such as demonstrating against inaccurate displays of PWE in the media, educating the social groups as well as PWE and increasing publics' interaction with PWE (Birbeck 2006). Anti-stigma campaigns have

been recommended by WHO in its guidelines to reduce mental health treatment gaps (Dua et al. 2011).

Some educational interventions targeted towards health care workers to improve their knowledge and diagnosis has shown some improvement in epilepsy associated stigma in countries like Zimbabwe and Ethiopia (Mbuba & Newton 2009). And in Brazil, a study among participants that included students from both private and public schools showed that as much as education is a good intervention, it is important to have positively framed education programs in order to have an impact on epilepsy associated stigma (Fernandes et al. 2011).

The center for disease control, together with the epilepsy foundation in America, has focused on educating those who are the first respondents, police, nurses in the schools and including parents of children with epilepsy. The evaluation of these programs showed an improved knowledge and reduced misconceptions about epilepsy (England et al. 2014).

A retrospective study done in Canada showed the positive effects of media on reducing stigma especially in those children who had seen a health promotion announcement about stigma (Lugthart 2011). Most people in the general public rely on news and media for health information.

In a Chinese project, which is the most successful project of the WHO global campaign against epilepsy started with a media based awareness program that emphasized that epilepsy is treatable (Mbuba & Newton 2009). It also involved lectures and group discussion with PWE, their families, community leaders and teachers. And the treatment gap reduced from 63% to 50% (Mbuba & Newton 2009).

And an intervention that seems to be a good approach is one documented by Baschal et al that includes PWE in the forming of an agenda for awareness campaigns targeted to the public, including choice of the target audience and the content (Fernandes et al. 2011).

5.2.3. Structural Interventions

Epilepsy has been recognized as a disability and the people with epilepsy are now more protected by the law in most developed countries although discrimination still exists in some areas such as driving and employment (Fernandes et al. 2011).

Legislative efforts have been noted in countries like the United Kingdom, America and Australia through disability acts that have helped with the challenges of stigma in epilepsy although it has been said that such laws just push discrimination underground (Fernandes et al. 2011).

According to Taylor et al, the traditional healers in Kenya provided causes of epilepsy that were consistent with patients' perceptions about the disease. And in terms of payment, the traditional healers have flexible methods of payment (Kendall-Taylor et al. 2008). This is one of the reasons South Africa registered about 20,000 of its traditional healers, incorporating them in its medical system and having room for dialogue (Baskind & Birbeck 2005).

It has also been noted by WHO that it is best to incorporate epilepsy services into primary health services and this has proved effective in both Ethiopia and India where it was incorporated in the existing health care infrastructure and wider programs respectively (Mbuba & Newton 2009). Other countries like Malawi and Uganda have involved the community in providing care as well as having nurse led epilepsy clinics in the communities which have shown success in reducing stigma and the treatment gap (Lugthart 2011).

CHAPTER SIX: DISCUSSION

This Chapter discusses the findings of the study. The conceptual framework helped to systematically organize the thoughts from the findings.

6.1. The individual, family and peers, the general public, structures and institutions

Epilepsy associated stigma in Zambia transcends over all aspects of society, ranging from the immediate family to the schools and the churches. This means that for those with epilepsy, may encounter stigma in every aspect of their lives, be it, at home or at school or at work.

Epilepsy associated stigma affects the psychological well-being and quality of life of people with epilepsy although advancements have been made in the treatment of epilepsy and the interventions for its stigma (Jacoby 2002).

We have seen that powers in a social realm will determine the level of stigma. The people with high status and evidently power such as religious leaders, traditional healers and even teachers have little knowledge about the causes of epilepsy and how it should be treated. Meaning that their practices and beliefs would determine how society views epilepsy. Therefore incorporating them in any key interventions is not only cardinal but essential. This has been tried in Chikankata where they have incorporated traditional healers and reductions have been noted in the treatment gap.

There is a clear lack of access of health services which leads most to access traditional healers or faith based healers. There is a need to move these services closer to the people as possible. In Malawi, an increase in patients being reviewed at a mission hospital was noted by merely having an action committee that included 100 village representatives in the campaign against epilepsy. This invariably helped reduce stigma and consequently the treatment gap (Lugthart 2011). Therefore interventions for epilepsy associated stigma need to be targeted in such a way that all agents of stigma are addressed.

6.2. Actionable drivers and facilitators

Strategies and interventions need to address drivers and facilitators of stigma in order to reduce epilepsy associated stigma.

Lack of knowledge increases traditional beliefs and myths in society about epilepsy because if people do not know the real causes of epilepsy, what is passed onto them through their elders and community leaders, will continue to prevail. These beliefs are not only in local communities but also in the professional communities such as teachers, police, religious leaders and healthcare workers especially in the rural areas because it is here that more levels of stigma are encountered. So focus on dispelling such beliefs should not only be towards those that are not educated, but to the society as a whole

bearing in mind that even the educated and the professionals have similar beliefs. These beliefs also have an influence on the promptness in seeking appropriate care for those with epilepsy (Gureje & Alem 2000).

Because the majority of people with epilepsy in Zambia are between the ages of 5-15years, there is need for emphasis to be placed on improving knowledge of teachers and students in the schools about epilepsy if stigma is to be reduced. This can be done by having it as a part of the curriculum in science as was done in Brazil which showed improved outcomes (Fernandes et al. 2011).

Because of lack of commitment from the government and policy makers, mental health including epilepsy, continue to be neglected as is noted by the number of health workers in mental health and the lack of implementation of the mental health policy. Due to this lack of accessibility PWE including their care-givers, prefer to seek help from the more accessible traditional healers who offer 'better' and more 'believable' causes of the disease because they focus on the psycho-social aspect of the disease rather than the biomedical aspect. It is therefore important to try and integrate traditional healers in the healthcare system and find ways to assess the efficacy of their treatments by working with them hand-in-hand.

According to Chin, it is necessary to increase patient knowledge by having community based programs which educate on epilepsy and eventually can help reduce stigma as well as improve medication adherence and seizure control (Chin 2012). In addition, it is important to partner with traditional healers, religious groups and community leaders to disseminate correct information about the causes of epilepsy and consequently reduce stigma (Chin 2012).

As much as the mental health policy has not been enacted, according to the review done by WHO, it clearly needs to be modified and there is need for it to be more specific with clear implementation strategies and ways these can be achieved (WHO 2008).

6.3. Marking or Labelling, Epilepsy associated stigma and intersecting stigmas

Because of lack of conceal ability in epilepsy either via burns or seizures, it is necessary that those with epilepsy as well as their families are educated about epilepsy. The peer support groups done in Zambia showed reduced felt or self-stigma in adolescents which means that by use of those who have undergone a similar situation, better improvements in reducing stigma would be achieved. Emphasis should be placed on dispelling myths about contagion so that the livelihood of those with epilepsy are not jeopardized and they can be helped during a seizure.

Because women suffer more stigma than men, the interventions need to put this into context. Women with epilepsy need to be targeted and empowered, and campaigns need to be sensitive to this aspect.

Mbuba and Newton emphasise on educating PWE and caregivers about epilepsy to help reduce complications of seizures like burns and fractures and also dispel any community beliefs about epilepsy and thus reduce both felt and enacted stigma (Mbuba & Newton 2009).

6.4. Stigma Manifestations

Felt stigma has been shown as an even bigger problem than actual stigma, as it may cause an increase in seizures and even depression causing a vicious cycle in which those with epilepsy have even higher levels of felt stigma.

Many PWE in Zambia experience felt stigma as some times the stigma may not be enacted. This is attributed to the belief in society of what and how people will treat them or act towards them once it is known that they are epileptic. This further reduces possibility of disclosure and further affects care-seeking behaviour and has impacts on adherence to treatment.

It has been shown that families also experience felt stigma and has consequences on how they treat the PWE in their families. We therefore need to have interventions and strategies that will not neglect this important aspect and families will be incorporated. This can be by including them in education activities that enhance knowledge about the disease and also in psycho-education. This will help in reducing acts of discrimination towards PWE with improved treatment outcomes if there is family support and consequently empowerment because education will be encouraged.

Community based interventions to improve awareness have been advocated as the best way in which to reduce stigma but the causes of stigma has to be addressed first (Mbuba & Newton 2009). This will then be the basis of information or education to try and increase compassion and reduce self-blame. Such community based intervention was conducted in Uganda which involved community assistants during mobile epilepsy clinics who were able to address the local beliefs and hence bring more people to the clinic (Lugthart 2011).

6.5. Stigma Outcomes

Enacted stigma affects many aspects of the life of a PWE because it not only affects the care-seeking behaviour but has socio-economic impacts and life opportunities of the PWE. In Zambia, PWE are not only physically abused and women sexually abused, but sometimes they are banished from home or even denied food. This definitely has an impact on their well-being and may affect their self-confidence as well as their progress at school, at work and in society. It worsens their status in society and are treated like "second

class” citizens below being “human” whose rights are violated. And by having such manifestations, the epilepsy stigma has certain outcomes that have an influence on the care- seeking behaviour of people with epilepsy as mentioned earlier.

Majority of Zambians are poor and if they end up having epilepsy they are likely to suffer intersecting stigma which would hinder them from accessing healthcare. Measures have to be put to ensure equal access to healthcare and no discrimination at the health facilities. Government and policy makers should look at ways to address this issue, for instance a national health insurance can be implemented which may improve access to healthcare and consequently improve the quality of lives of those with epilepsy with better seizure control.

6.6. Stigma Impacts

Epilepsy associated stigma outcome of poor care-seeking behaviour will have impacts on diagnosis and treatment of epilepsy and impact on the socio-economic status of the people with epilepsy, which is one of the determinants of health. Because some health care workers do not know the causes of epilepsy or have their own personal traditional beliefs about epilepsy, this may have an impact on diagnosis (Mbuba & Newton 2009). Due to the missed opportunities because of the high stigmatization, those with epilepsy end up living in poor quality housing, being poor with reduced food security and the women especially, are vulnerable being subjected to physical and sexual abuse.

Birbeck argues that, knowledge of epilepsy improves attitudes towards PWE but additional efforts are necessary if it is to be sustained over time (Birbeck 2006). Focused programs can be useful in combating stigma especially if they are aimed at key social groups that have an important role in stigma such as traditional healers, community leaders, teachers and religious leaders (Birbeck 2006). And social marketing has to strike a balance between showing PWE are no different from any other person and at the same time that they need special treatment for their condition.

6.7. Good practices or interventions to reduce epilepsy associated stigma

When we look at interventions to address epilepsy associated stigma, we need to remember that epilepsy is multifaceted and that other aspects that may contribute to its incidence and treatment gap also need to be addressed. In order to implement most of these interventions, there has to be a proper working relationship between MOH and MCDMCH which would prove problematic because most of the interventions are community based and this falls under MCDMCH. Whereas all policy is the responsibility of MOH. A well-

established strategy needs to be in place in order for coordination between the policy makers (MOH) and the implementers (MCDMCH).

Currently, some interventions are in place to try and reduce epilepsy associated stigma with evidence only found in Chikankata district. These interventions seem to be working well and it can be taken as an example through which the MOH and MCDMCH can work towards scaling up to the rest of the country. They can also incorporate education and social marketing which have seemed to work in other countries and would not be so difficult for Zambia to implement. Aspects of which were mentioned earlier like incorporating the community leaders, healthcare workers, traditional healers, religious leaders and even the community as a whole.

With the help of cooperating partners, media campaigns can also play a vital role in combating epilepsy associated stigma and as was seen in the Chinese project, this can slowly reduce the treatment gap tremendously. But of course media campaigns have to be contextualised to the Zambian scenario and translated in common local languages in order to reach all the masses. This is an important fact if the campaign is to be successful as well as the depiction of PWE in a positive manner.

6.8. Reflections on the conceptual framework

The conceptual framework used in the study was useful in understanding the concepts involved in stigma and has helped in putting together the findings presented in the study. However it seemed like some of the areas were repetitions, for instance when discussing epilepsy associated stigma and the stigma manifestations, it is difficult to separate the two. As well as discussing the individual, family, community and institutions and structures, one cannot help but discuss the manifestations again. The other area that seemed to overlap was the institutions and structures and the laws and policies which are also found under actionable drivers and facilitators. I would therefore suggest for other studies to use a framework that avoids these repetitions and presents findings systematically although stigma has been noted through this study to be a complex subject that has a lot of intertwined concepts.

6.9. Study limitations

Because the study methodology is based on a literature review as mentioned earlier, the limitations of the study therefore is that although some information exist on the stigma of epilepsy in Zambia, very little information is available on current interventions in place and the evaluation of those interventions. But an attempt to address this limitation was done by looking at various information available on the subject both regionally and worldwide in order to get a better understanding of variations and if the findings could be related to the Zambian context.

CHAPTER SEVEN: CONCLUSION AND RECOMMENDATIONS

This chapter makes a conclusion of the findings according to the objectives that were stipulated and details recommendations for good practices or interventions to reduce epilepsy associated stigma.

7.1. Conclusion

The study has clearly shown that epilepsy associated stigma exists in Zambia at levels ranging from the immediate family, the community and also structures and institutions including the professional sector. The review of the stigmatization process shows a complex situation in which epilepsy associated stigma is deep in the society, with varying manifestations. This is due to lack of knowledge about epilepsy and a society embedded in myths and beliefs about the disease with little prioritization in terms of policies on mental health.

It has been noted that in order to reduce stigma, a holistic or multi-layered approach needs to be used because stigma impacts negatively on the diagnosis and treatment of epilepsy and therefore increasing the treatment gap. This implies that there are a great number of people who are not aware that they actually have epilepsy and that it is treatable. Clear interventions to help reduce epilepsy associated stigma have been identified but these have to be adapted to the Zambian context.

7.2. Recommendations

For policy

- The mental health policy should be finalized and clear objectives outlined as well as implementation strategies and improved funding towards mental health.
- The social aspects of those with epilepsy needs to be addressed in addition to the medical aspect. This involves, reducing unemployment and homelessness in such groups therefore improving the social well-being.

For interventions

- Key groups needed to be targeted such as healthcare workers who should be trained on epilepsy at the primary level of care especially in the rural areas and, traditional healers as well as religious leaders in order to dispel myths about contagion and supernatural possession and can be trained to provide basic epilepsy care with referral to the primary care facilities.
- Stigma and misconceptions about epilepsy can be addressed by use of Social marketing through educational programs including those on media about epilepsy and its stigma. Although the Media should be educated about epilepsy so that it is portrayed accurately without negative perceptions.

- Local celebrities can be used as spokespersons in order to reduce stigma as well as having an epilepsy week nationwide as is done for child health week. But the campaigns have to be culturally sensitive so that the local community will understand.

For future research

- A countrywide survey needs to be done to ascertain a clear prevalence and incidence of those with epilepsy and consequently getting a clear estimation of how many people would be affected by stigma.
- To determine the reason attributable to the main preventable causes of epilepsy in order for preventive measures or interventions be introduced by the Ministry of health. If there are less cases of epilepsy, fewer people would be subjected to its stigma.
- A participatory and projective research can be done by incorporating the epilepsy association of Zambia, PWE and the community to find ways in which to improve healthcare access and treatment as well as reduce stigma of those with epilepsy

REFERENCES

- Atadzhanov, M. et al., 2011. Epilepsy-Associated Stigma in Zambia: What factors predict greater felt stigma in a highly stigmatized population? *Epilepsy Behav*, 19(3), pp.414–418.
- Atadzhanov, M. et al., 2006. Knowledge, attitudes, behaviors, and practices regarding epilepsy among Zambian clerics. *Epilepsy & Behavior: E&B*, 9(1), pp.83–8. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/16713361> [Accessed July 16, 2014].
- Bandstra, N.F., Camfield, C.S. & Camfield, P.R., 2008. Stigma of epilepsy. *The Canadian journal of neurological sciences. Le journal canadien des sciences neurologiques*, 35(4), pp.436–40. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/18973059> [Accessed July 16, 2014].
- Baskind, R. & Birbeck, G.L., 2005. Epilepsy-associated stigma in sub-Saharan Africa: the social landscape of a disease. *Epilepsy & Behavior: E&B*, 7(1), pp.68–73. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/15978874> [Accessed February 22, 2014].
- Birbeck, G., 2006. Interventions to reduce epilepsy-associated stigma. *Psychology, health & medicine*, 11(3), pp.364–6. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/17130072> [Accessed July 16, 2014].
- Birbeck, G. et al., 2007. The social and economic impact of epilepsy in Zambia: a cross-sectional study. *Lancet Neurology*, 6(1), pp.39–44. Available at: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2938018&tool=pmcentrez&rendertype=abstract> [Accessed July 16, 2014].
- Birbeck, G.L., 2000. Seizures in rural Zambia. *Epilepsia*, 41(3), pp.277–81. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/10714398> [Accessed July 10, 2014].
- Birbeck, G.L. et al., 2009. Women ' s Experiences Living with Epilepsy in Zambia. *Am J Trop Med Hyg*, 79(1813), pp.168–172.

- Birbeck, G.L., 2012. Working Together to Improve the Lives of People Affected by Epilepsy in Zambia. *Journal of Higher Education Outreach and Engagement*, 16(3), pp.175–184.
- Birbeck, G.L. et al., 2006. Zambian teachers: what do they know about epilepsy and how can we work with them to decrease stigma? *Epilepsy & behavior : E&B*, 9(2), pp.275–80. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/16877045> [Accessed July 16, 2014].
- Birbeck, G.L. & Kalichi, E.M.N., 2004. Epilepsy prevalence in rural Zambia: a door-to-door survey. *Tropical medicine & international health : TM & IH*, 9(1), pp.92–5. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/14728612>[Accessed July 12, 2014] .
- Bond, V. et al., 2003. Kanayaka “The light is on”:Understanding HIV and AIDSrelated stigma in urban and rural Zambia, Lusaka, Zambia.
- Central Statistics Office, 2011. Quaterly Employmen & Earnings Inquiry Report 2010/2011, Lusaka, Zambia.
- Chin, J.H., 2012. Epilepsy treatment in sub-Saharan Africa: closing the gap. *African health sciences*, 12(2), pp.186–92. Available at: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3462534&to=ol=pmcentrez&rendertype=abstract> [Accessed July 16, 2014]
- Chomba, E. et al., 2009. The socioeconomic status of children with epilepsy in Zambia: implications for long-term health and well being. *Epilepsy & behavior : E&B*, 13(4), pp.620–623.
- Chomba, E.N. et al., 2007. Zambian health care workers’ knowledge, attitudes, beliefs, and practices regarding epilepsy. *Epilepsy & behavior : E&B*, 10(1), pp.111–119.
- Chung, K. et al., 2012. Quality of life in epilepsy (QOLIE): insights about epilepsy and support groups from people with epilepsy (San Francisco Bay Area, USA). *Epilepsy & behavior : E&B*, 24(2), pp.256–63. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/22521676> [Accessed July 16, 2014].
- Corrigan, P.W., Markowitz, F.E. & Watson, A.C., 2004. Structural levels of mental illness stigma and discrimination. *Schizophrenia bulletin*, 30(3), pp.481–91. Available at:

<http://www.ncbi.nlm.nih.gov/pubmed/15631241>[Accessed July 10, 2014].

Degirmenci, Y. et al., 2013. Perception of epilepsy in Turkey in the light of two different cities. *Acta clinica Croatica*, 52(1), pp.59–67. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/23837274> [Accessed July 10, 2014].

Dillip, A. et al., 2012. Acceptability--a neglected dimension of access to health care: findings from a study on childhood convulsions in rural Tanzania. *BMC health services research*, 12, p.113. Available at: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3405484&tool=pmcentrez&rendertype=abstract> [Accessed July 16, 2014].

Dua, T. et al., 2011. Evidence-based guidelines for mental, neurological, and substance use disorders in low- and middle-income countries: summary of WHO recommendations. *PLoS medicine*, 8(11), p.e1001122. Available at: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3217030&tool=pmcentrez&rendertype=abstract> [Accessed July 10, 2014].

Elafros, M. a et al., 2013. Peer support groups as an intervention to decrease epilepsy-associated stigma. *Epilepsy & behavior : E&B*, 27(1), pp.188–92. Available at: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3602129&tool=pmcentrez&rendertype=abstract> [Accessed July 16, 2014].

Engel, J. & Pedley, T., 2008. *Epilepsy: A Comprehensive Text book Second*. J. Engel & T. Pedley, eds., Philadelphia: Lippincotts,Williams & Wilkins.

England, M.J. et al., 2014. Erasing epilepsy stigma: eight key messages. *Health promotion practice*, 15(3), pp.313–8. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/24662897> [Accessed July 16, 2014].

Fernandes, P.T. et al., 2011. Epilepsy stigma: what do we know and where next? *Epilepsy & behavior : E&B*, 22(1), pp.55–62. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/21458385> [Accessed July 16, 2014].

Gault, L., 2008. Epilepsy: Resources on the internet. *Epilepsy, Journal of consumer health on the internet*, 8:1(July 2014), pp.37–41.

- Gureje, O. & Alem, a, 2000. Mental health policy development in Africa. Bulletin of the World Health Organization, 78(4), pp.475–82. Available at:
<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2560723&tool=pmcentrez&rendertype=abstract> [Accessed July 14, 2014]
- Hatzenbuehler, M, Phelan, J, Link, B., 2013. Stigma as a Fundamental Cause of Population Health Inequalities. Am J Public Health, 103(5), pp.813–821.
- ICRW AND STRIVE, 2013. A global HIV stigma reduction framework adapted and implemented in five settings in India, Washington, DC.
- Jacoby, A., 2002. Behavior Stigma , epilepsy , and quality of life. Epilepsy & behavior : E&B, 3, pp.10–20.
- Kendall-Taylor, N. et al., 2008. Traditional healers and epilepsy treatment on the Kenyan coast. Epilepsia, 49(9), pp.1638–9. Available at:
<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3672948&tool=pmcentrez&rendertype=abstract> [Accessed July 14, 2014]
- Kleinman, A. & Hall-Clifford, R., 2014. Stigma : A Social , Cultural , and Moral Process. Journal of Epidemiology and Community Health, 63(6), pp.3–8. Available at: <http://nrs.harvard.edu/urn-3:HUL.InstRepos:2757548> [Accessed July 16, 2014]
- Link, B.G. & Phelan, J.C., 2006. Stigma and its public health implications. Lancet, 367(9509), pp.528–9. Available at:
<http://www.ncbi.nlm.nih.gov/pubmed/16473129>[Accessed July 16, 2014]
- Lugthart, L., 2011. Epilepsy management in Africa : major obstacles and solutions. Africa Health, (March), pp.17–20.
- Mbewe, E. et al., 2007. Epilepsy-related knowledge, attitudes, and practices among Zambian police officers. Epilepsy & behavior : E&B, 10(3), pp.456–62. Available at:
<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2749646&tool=pmcentrez&rendertype=abstract> [Accessed July 16, 2014].
- Mbuba, C.K. & Newton, C.R., 2009. Packages of care for epilepsy in low- and middle-income countries. PLoS medicine, 6(10), p.e1000162. Available at:

<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2752812&to=ol=pmcentrez&rendertype=abstract> [Accessed July 16, 2014].

MOH, 2011. National Health Strategic Plan 2011-2015, Lusaka, Zambia.

Mwape, L., Mweemba, P. & Kasonde, J., 2011. Strengthening the health system for mental health in Zambia, Lusaka, Zambia.

Nyblade, L. et al., 2003. Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia, Washington, DC.

Olenja, J., 2003. Health seeking behaviour in context. *East African Medical Journal*, (February), pp.61–62. Available at: <http://www.ajol.info/index.php/eamj/article/viewFile/8689/1927> [Accessed July 16, 2014]

Parfene, C., Stewart, T.L. & King, T.Z., 2009. Epilepsy stigma and stigma by association in the workplace. *Epilepsy & behavior: E&B*, 15(4), pp.461–6. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/19570726> [Accessed July 16, 2014].

Parmet, S., 2011. Epilepsy. *The Journal of the American Medical Association*, 305(16), p.1722. Available at: <http://jama.jamanetwork.com/> [Accessed July 14, 2014].

Prpic, I., 2003. Teachers' opinions about capabilities and behavior of children with epilepsy. *Epilepsy & Behavior*, 4(2), pp.142–145. Available at: <http://linkinghub.elsevier.com/retrieve/pii/S1525505003000258> [Accessed July 16, 2014].

Pupillo, E. et al., 2014. Knowledge and attitudes towards epilepsy in Zambia: a questionnaire survey. *Epilepsy & behavior: E&B*, 34, pp.42–6. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/24681384> [Accessed July 15, 2014].

Smeets, V.M.J. et al., 2007. Epilepsy and employment: literature review. *Epilepsy & behavior: E&B*, 10(3), pp.354–62. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/17369102> [Accessed July 16, 2014].

Ssebunnya, J. et al., 2009. Stakeholder perceptions of mental health stigma and poverty in Uganda. *BMC international health and human rights*, 9, p.5. Available at:

<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2670268&tool=pmcentrez&rendertype=abstract> [Accessed July 16, 2014].

Stajić, B.S. & Bosnjak, M.C., 2002. Stigma in psychiatry. *Medicinski pregled*, 66(9-10), pp.357–9. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/24938185>[Accessed July 10, 2014].

Thomas, S. & Nair, A., 2011. Confronting the stigma of epilepsy. *Annals of Indian Academy of Neurology*, 14(3), pp.158–163. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3200035/?report=reader> [Accessed July 16, 2014].

Weiss, M.G., Ramakrishna, J. & Somma, D., 2006. Health-related stigma: rethinking concepts and interventions. *Psychology, health & medicine*, 11(3), pp.277–87. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/17130065> [Accessed July 10, 2014].

WHO, 2005. Atlas: Epilepsy care in the World- 2005, Geneva, Switzerland.

WHO, 2008. Developing Effective Mental Health Policies and Plans in Africa 7 key lessons, Geneva, Switzerland.

WHO, 2012. Epilepsy Fact Sheet. Media Centre World Health Organization, 999(October). Available at: <http://www.who.int/mediacentre/factsheets/fs999/en/> [Accessed July 10, 2014].

WHO, 2004. EPILEPSY IN THE WHO AFRICAN REGION : Bridging the Gap The Global Campaign Against Epilepsy “ Out of the Shadows ,” Geneva, Switzerland.

WHO, 2000. General Guidelines for Methodologies on Research and Evaluation of Traditional Medicine, Geneva, Switzerland.

WHO, 2003. Global campaign against epilepsy. , 66(5), pp.733–733.

WHO, 2010. Human Resources for Health Country Profile, Geneva, Switzerland. Available at: http://www.hrh-observatory.afro.who.int/images/Document_Centre/zambia_hrh_country_profile.pdf . [Accessed July 10, 2014]

WHO, 2014. Programmes: Health statistics and information systems. Available at:
http://www.who.int/healthinfo/global_burden_disease/metrics_daly/en/
[Accessed July 23, 2014].

WHO, 2009. Who country cooperation strategy 2008-2013, Geneva, Switzerland. Available at:
http://www.who.int/countryfocus/cooperation_strategy/ccs_zmb_en.pdf.
[Accessed July 10, 2014]

WHO, 2006. Working together for health: The World Health Report 2006, Geneva, Switzerland. Available at:
http://whqlibdoc.who.int/publications/2006/9241563176_eng.pdf
[Accessed July 15, 2014].

ZANIS, 2010. Government urged to avail epileptic drugs. Lusaka Times, p.1. Available at: <http://www.lusakatimes.com/2010/07/27/government-urged-avail-epileptic-drugs/>[Accessed July 10, 2014].

ANNEXES

Annex 1: Screening Process

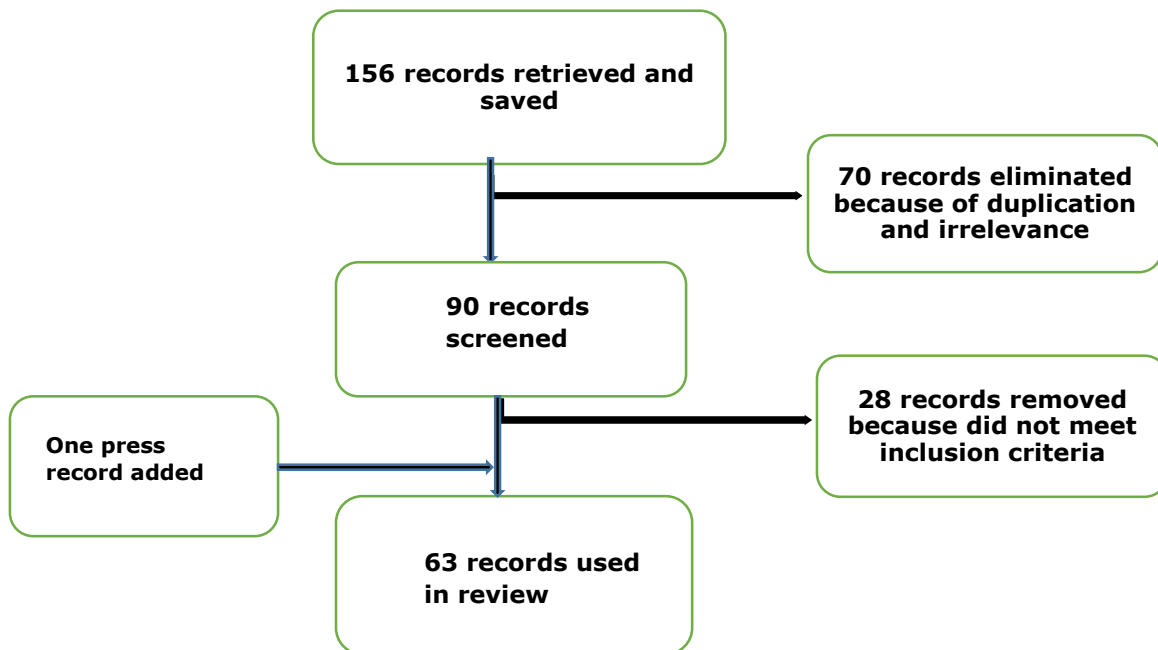
Step one: the search of databases retrieved 156 records with full text which were saved.

Step two: 70 records were eliminated because of duplication and irrelevance leaving 86 articles.

Step three: 90 records were screened and 28 records were removed because they did not meet the inclusion criteria. One press record was found to be relevant and was added.

Step four: 63 records were used in the review

Figure 1. Flow chart showing the process of literature search



Annex 2: Other Conceptual Frameworks considered

I settled on this framework after looking at three other frameworks namely; the framework integrating normative influences of stigma (FINIS) which is usually used in mental illness; the conceptual framework for factors determining HIV-related stigma (bearing in mind that the mechanisms of stigma are usually the same whether HIV, TB or Epilepsy); and the innovative care for chronic conditions framework (as epilepsy can be a chronic disease).

The FINIS was not used because this is a theoretical framework and concentrates on the social characteristic of stigma both of the individual and community. It is a good framework but it goes beyond the scope of this thesis incorporating a lot of concepts. Although it helped complement my understanding of the mechanisms of stigma.

The conceptual framework for factors determining HIV related stigma in Vietnam was not used because the emphasis is on the determinants of stigma and does not incorporate the other questions that are to be answered in this thesis.

The innovative care for chronic conditions framework is used usually when the main objective is to improve outcomes of a chronic condition which is not the case in this study. Although it was not picked as the main conceptual framework, it will be referred to during the discussion of the findings.

Annex 3: Table 1. Health system and mental health expenditure

	Total expenditure on health as % GDP	Per capita total expenditure on health (PPP int. \$)	External resources to health as % of total expenditure on health	Mental health budget as % total government health budget
Ghana	5.1	76	22.6	6
South Africa	8.0	715	0.9	1-8% (Provincial variation)
Uganda	7.0	71	31.2	4
Zambia	3.9	79	38.1	0.4%

Source Omar et al, 2010