

**Addis Ababa University**  
**School of Graduate Studies**  
**Department of Sociology**

**Socio-economic and Health situation of Epileptics and Attitude of the  
surrounding community towards epilepsy: A study in Mizan-Teferi town of  
Bench Maji zone, SNNP' Region**

**By**

**TadeleWorkineh Dabi**

**A Thesis Submitted to the School of Graduate Studies of Addis Ababa  
University in Partial Fulfillment of the Requirements for the Degree of Master  
of Arts in Sociology**

**May, 2017**

**Addis Ababa, Ethiopia**

**Addis Ababa University**  
**School of Graduate Studies**  
**Department of Sociology**

**Socio-economic and Health situation of Epileptics and Attitude of the  
surrounding community towards epilepsy: A study in Mizan-Teferi town of  
Bench Maji zone, SNNP' Region**

**A Thesis Submitted to the School of Graduate Studies of Addis Ababa  
University in Partial Fulfillment of the Requirements for the Degree of Master  
of Arts in Sociology**

**By: Tadele Workineh Dabi**

**Advisor: P.Murugan (PhD)**

**May, 2017**

**Addis Ababa, Ethiopia**

**Addis Ababa University**  
**School of Graduate Studies**  
**Department of Sociology**

**Declaration**

I, Tadele Workineh Dabi, hereby declare that the thesis entitled: “*Socio-economic and Health situation of Epileptics and Attitude of the surrounding community towards epilepsy: A study in Mizan-Teferi town of Bench Maji zone, SNNP’ Region*”, submitted by me to award of the Degree of **Master of Arts in Sociology at Addis Ababa University**, is a product of my original work and it hasn’t been presented for the award of any other Degree, Diploma, Fellowship of any other university or institution. This work has also accredited the views of the research participants. To the best of my knowledge, I have fully acknowledged the materials and pieces of information used in the study.

Name: Tadele Workineh Dabi

Signature\_\_\_\_\_

Date of Submission: June, 2017  
Department of Sociology, Addis Ababa University

**Addis Ababa University**  
**School of Graduate Studies**  
**Department of Sociology**

**Certification**

This is to certify that this thesis entitled: “*Socio-economic and Health situation of Epileptics and Attitude of the surrounding community towards epilepsy: A study in Mizan-Teferi town of Bench Maji zone, SNNP’ Region*”, prepared by Tadele Workineh and submitted in partial fulfillment of the requirements for the award of degree of **Master of Arts in Sociology** complies with the regulation of the University and meets the accepted standards with respect to originality and quality.

**Approved By Boards of Advisor and Examiners**

**Advisor**

**Signature**

**Date**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Internal Examiner**

**Signature**

**Date**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**External Examiner**

**Signature**

**Date**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Acknowledgments

First of all, I would like to thank the almighty, Alpha and Omega God for his countless help throughout my academic endeavors. Thank you Jesus for I am not epileptic who is living in Mizan-Teferi town. Next I would like to convey my cordial gratitude to my advisor Dr. P. Murugan for his constructive comments and guidance which help my paper take the current form. Above all, your fatherly approach made my ways easy to cooperate with you and learn a lot of lessons about research work from you. I am proud for being your advisee

My deeper gratitude goes to my grandmother who devoted her life for upbringing me. Mom, you take all my responsibility and spent your life to make me who I am now. However, you are not lucky to see me graduating. What if a grave be opened and let you see my success.

I am also indebted to the following *kebele* administrators Mr. Alemayehu Beyikede manager of *Kometekebele* and Mr. Shiferew Addisu, manager of *Addis ketemekebele* for providing me a sample frame of this study and cooperating me in any necessary circumstances.

I also extend my respect and gratitude to Addis Ababa University for providing me a financial help which was a pivotal for the successful accomplishment of this thesis work.

Finally, my sincere gratitude is also due to my field assistants, key informants, respondents and participants in in-depth interview and case study for allowing me to access all the necessary data.

## Table of contents

<b>Contents</b>	<b>pages</b>
Acknowledgments .....	I
Table of contents .....	II
Lists of Table .....	III
Lists of Figures .....	IV
Lists of Appendixes .....	V
Abbreviations.....	VI
Abstracts .....	VII
CHAPTER ONE: INTRODUCTION.....	1
1.1 Background of the Study.....	1
1.2 Statement of the Problem.....	5
1.3 Objectives of the Study.....	9
1.3.1 General Objective.....	9
1.3.2 Specific Objectives.....	9
1.4 Hypothesis.....	9
1.5 Significance of the Study.....	10
1.6 Scope of the Study.....	10
1.7 Conceptualization and Operationalization of terms.....	11
1.7.1 Conceptualization.....	11
1.7.2 Operationalization.....	14
1.8 Organization of the Paper .....	15

CHAPTER TWO: REVIEW OF LITERATURE.....	16
2.1 Historical overview of Epilepsy .....	16
2.2 Epilepsy in the African Region.....	17
2.3 Knowledge and attitude towards epilepsy and Epileptic patients.....	19
2.4 Treatment gaps in Epilepsy and influencing factors of access to Modern health care.....	21
2.5 Socio-economic and Health impacts of Epilepsy on Epileptic patients.....	23
2.6 Forms of Epilepsy Related Stigma.....	25
2.7 Theoretical Framework .....	26
2.7.1 Stigma Context .....	27
2.7.2 Disease Distribution and Health in-equality context.....	29
CHAPTER THREE: RESEARCH METHODS.....	31
3.1 Description of the Study Area.....	31
3.1.1 The Study Population.....	33
3.2 Research Approaches and Design.....	34
3.2.1 Quantitative Approach, Sampling technique and Sampling size.....	34
3.2.2 Qualitative Approach.....	36
3.3 Instruments of Qualitative data collection .....	36
3.3.1 In-depth interview .....	36
3.3.2 Key informants Interview .....	37
3.3.3 Case Study .....	37
3.4 Methodological Triangulation.....	38

3.5 Methods of Data Analysis and Interpretation.....	39
3.6 Field Challenges and Limitation of the Study.....	39
3.7 Ethical Consideration .....	40
CHAPTER FOUR: DATA ANALYSIS AND PRESENTATION .....	41
4.1 Socio-demographic Profiles of the Non-epileptic Respondents .....	42
4.1.1 Age distribution of Non-epileptic Respondents.....	43
4.1.2 Distribution of Non-epileptic Respondents by level of Education.....	44
4.1.3 Distribution of Non-epileptic Respondents by Religion .....	45
4.1.4 Distribution of Non-epileptic Respondents by Ethnic background .....	46
4.1.5 Distribution of Non-epileptic Respondents by level of Income .....	47
4.2 Knowledge of Non-epileptic Respondents about Epilepsy .....	49
4.2.1 Knowledge on the Causes of epilepsy .....	50
4.2.2 Knowledge on the ‘transmission’ of Epilepsy .....	51
4.2.3 Knowledge on the treatment of Epilepsy .....	53
4.2.4 Knowledge on the ‘heridetary’ of epilepsy .....	55
4.3 Attitude of Non-epileptic Respondents towards Epilepsy .....	56
4.3.1 Attitude of Respondents on Job recruitment of epileptics .....	57
4.3.2 Attitude of Respondents towards epileptics during active seizure .....	61
4.3.3 Attitude of Respondents towards epileptic students .....	62
4.3.4 Attitude of Respondents regarding marriage relationship with Epileptics .....	64
4.3.5 Attitude of Respondents about Epileptics’ participation at religious place .....	67

4.4 Determining factors of Attitude of Non-epileptic Respondents towards Epilepsy.....	68
4.4.1 Association between Education status of Respondent and their Attitude towards Epilepsy.....	71
4.4.2 Difference in Attitude of Non-epileptic Respondents based on Sex .....	72
4.4.3 Difference in Attitude of Respondents based on Age .....	73
4.4.4 Difference in Attitude among Respondents of different Educational Status.....	74
4.4.5 Difference in Attitude among Respondents of different Religious Group .....	74
4.4.6 Difference in Attitude of respondents based on Ethnic background .....	75
4.4.7 Difference in Attitude among Respondents in terms of Income level .....	76
4.4.8 Difference in Attitude among Respondents in terms of Marital Status.....	77
4.4.9 The Relationship between Age and Income and Attitude towards Epilepsy.....	78
4.5 Cultural Beliefs on the Causes, ‘Mode of transmission’ and Curability of Epilepsy .....	81
4.6 Effects of Epilepsy on Access to Basic Needs and Social services .....	84
4.6.1 Access to food, shelter, clothes and clean water.....	84
4.6.2 Access to education and health care services .....	86
4.6.3 Lack of Burial sites .....	88
4.6.4 Effects on Physical safety and Wellbeing .....	89
4.6.5 Gender Based Violence .....	91
4.6.6 Effects of the Problem on Psychosocial wellbeing of Epileptics .....	94

CHAPTER FIVE: DISCUSSION OF MAJOR FINDINGS AND CONCLUSION.....	96
5.1 Discussion .....	93
5.2 Conclusion.....	102
References	
Appendices	

## List of Tables

Table 1.1: Variables and their level of measurement .....	14
Table 3.1: Methodological Triangulation .....	38
Table 4.1: Distribution of Non-epileptic Respondents by Age .....	43
Table 4.2: Educational status of Non-epileptic respondents .....	44
Table 4.3: Distribution of Non-epileptic Respondents by Religion.....	45
Table 4.4: Ethnic background of the Non-epileptic Respondents .....	47
Table 4.5: The total annual income of the respondents.....	48
Table 4.6: Sources of information about epilepsy.....	49
Table 4.7: Non-epileptic Respondents' View on the Causes of Epilepsy .....	50
Table 4.8: Assumed ways of Epilepsy 'Transmission' .....	52
Table 4.9: Healing Options of Epilepsy.....	54
Table 4.10: Views of Non-epileptic Respondents on 'Heridetary' of epilepsy.....	55
Table 4.11: Attitude of Non-epileptic Respondents towards the banishment of Epileptics .....	56
Table 4.12: Attitude of non-epileptic respondents towards epileptics' competence to find.....	58
Table 4.13 Attitude of Non-epileptic Respondents towards Recruiting of Epileptics	
Table 4.14: The reaction of Non-epileptic towards epileptics during Seizure.....	61
Table 4.15: Attitude of non-epileptic respondents towards educational access of epileptic children.....	63
Table 4.16: Attitude of non-epileptic respondents regarding marriage relation with epileptics.....	65

Table 4.17:Attitude of non-epileptic respondents towards epileptics’ participation at religious place.....	67
Table 4.18:Attitude of the Non-epileptic head of households towards epileptics.....	68
Table 4.19:The Correlation between Age and Income and Respondents’ attitude towards epileptics.....	70
Table 4.20:Association between the educational levels of respondents and their attitude towards epileptics.....	71
Table 4.21:Difference in attitude based on sex of the respondents .....	72
Table 4.22:Difference in attitude towards epileptics based on age of the Respondents .....	73
Table 4.23:Difference in attitude among respondents of different educational level.....	74
Table 4.24: Difference in attitude based on religious type of the respondents.....	75
Table 4.25:Difference in attitude based on ethnic background of the respondents.....	76
Table 4.26:Difference in attitude towards epileptics based on income level.....	77
Table 4.27:Difference in attitude based on marital status.....	78
Table 4.28: Relationship between respondents’ attitude and their income level and age.....	79

## **List of Figures**

Figure 1.1: Relationship between independent and dependent variables.....	11
Figure 3.1: Map of Mizan-Teferi town.....	32
Figure 4: Photograph of the burned injury caused due to epilepsy .....	88

## **List of Appendices**

Appendix A: Survey Questionnaire.....	I
Appendix B: Guidelines for Key informant interview .....	II
Appendix C: Guidelines for In-depth interview .....	III

## **List of Abbreviations and Acronyms**

ANOVA	Analysis of Variance
PWE	People With epilepsy
WHO	World Health Organization
ADA	Americans with Disabilities Acts
ILAE	International League Against Epilepsy
GCAE	Global Campaign Against Epilepsy
CSA	Central Statistical Agency
NGO	Nongovernmental Organization
FGD	Focus Group Discussion
SPSS	Statistical Package for Social Sciences

## ***Abstract***

*Epilepsy is the most common chronic neurological disorder affecting people across the globe. Lack of knowledge and negative attitudes among non-epileptic people towards epilepsy causes stigmatization and discrimination of people diagnosed with epilepsy on a daily basis. In such away, the stigma and discrimination facing epileptics is affecting the victims more than the diseases itself. It is therefore, necessary to investigate this issue and disclose it. Thus, this study was conducted with the objective of examining the socio-economic and health situations of epileptics and the attitude of the surrounding non-epileptic community towards epileptics in Mizan-Teferi town of Benchimaji zone, SNNP's region, Ethiopia. Both quantitative and qualitative research approaches were employed in a triangulation form to address the objectives of this study. Two out of five kebeles in Mizan-Teferi town were purposefully selected. 353 households were selected from the two sampled kebeles for household survey using a Raosoft online sample size calculator randomly. In addition, key informant interview was conducted to investigate the attitude of the non-epileptic people towards epileptics in the study area. On the other hand, in-depth interview, case study and key informant interview were conducted to examine the socio-economic and health situations of epileptics in Mizan-Teferi town. The findings indicate that from demographic and socio-economic factors, sex, age, educational status, marital status, ethnic background and income found significantly affecting attitude towards epilepsy. 58.9% of the respondents thought epilepsy to be caused by evil spirit, 85.5% and 49% of the respondents thought epilepsy to be a transmittable and trans-generational disease respectively. Although 63.7% of the respondents reported affirmed to the idea epileptics can compete and be employed like non-epileptic counterparts, 66.3% of them were reluctant to hire an epileptic person to their business regardless of his/her qualification for the position. Besides, 92.1% of the respondents argued not to marry with somebody epileptic. Generally, 54.4% of the head of households reported to have unfavorable attitude towards epileptics. On the other hand, the socio-economic and health situations of epileptics are the direct reflection and result of the above negative attitude of the surrounding non-epileptic community in the study area. Finally, some of the problems facing epileptics in Mizan-Teferi town were lack of basic needs like food, shelter and clothes, lack of access to social services like education and health care services, lack of burial sites and gender based violence were among the most discussed problems by epileptics.*

## CHAPTER ONE: INTRODUCTION

### 1.1 Background of the study

Epilepsy refers to a group of chronic brain conditions characterized by recurrent epileptic seizures. Epileptic seizures are the clinical manifestations (signs and symptoms) of excessive and/or hyper-synchronous, usually self-limited, abnormal activity of neurons in the brain (Mula and Sander, 2016; WHO, 2004).

It affects more than fifty million people in the world and about one hundred million people will have at least one epileptic seizure at some time in their life (De Boer, 209; Scott et al. 2001).

If not treated, epileptic seizures lead to physical injury (wounding and bleeding), and frequent seizures have detrimental effects on education, employment and marital life whereby it may result in separation of the spouses, divorce and so forth (Shibru and Prevett, 2004). Besides, epileptic people experience negative psychosocial consequences of the disorder including social isolation, low self-esteem, and feeling of shame and guilty which resulted from people's assumption that epilepsy is caused by some insane act (being mad as a result of committing an act which is against the will of God) by epileptic individual (Atalay et al. 2006). People with epilepsy were viewed with fear, suspicion and misunderstanding, and were subject to enormous social stigma. As a result, they were treated as outcasts and punished in different forms like social exclusion and denial of job opportunity (Assefa, 2004).

On the other hand, poverty (lack of access to modern antiepileptic medicine, lack of adequate food and shelter and unsafe environment) plays an important role in influencing the socio-economic and health situation of epileptic people (GCAE, 2001). Not only this, but also, the level of education, unemployment, communication network, availability of resources within the health care system, among others, have a major influence on the management of epilepsy-related

burden (Reynolds, 2002). Furthermore, knowledge and attitude of people towards epilepsy is highly influenced by their understanding of how epilepsy is caused and the misconception on its transmission. People believe that epilepsy is contagious (Ghaydaa, 2016). For this reason, they hesitate to help or touch the person who has fallen during a seizure.

Therefore, those suffering from epilepsy are stigmatized and ostracized in the belief that their condition is a demonic possession and believed to be contagious consequently lead epileptic patients to develop different psycho-social problems such as stigma and discrimination, and psychiatric illness which affect epileptic patients more than the seizure itself (Birhanu et al.2015).

In the African continent, epilepsy affects about ten million people of all ages but, especially children, adolescents and the ageing population (WHO, 2004). In sub-Saharan African, active epilepsy was estimated to affect four million people and its prevalence is high among adults and children (Paul et al. 2012). In spite of global advances in diagnosis and treatment in recent years, about eight million people with epilepsy in Africa are not treated with modern antiepileptic drugs due to various reasons including; inability to afford, lack of awareness about epilepsy to be a treatable disease, inaccessibility of modern health care centers, and so forth (WHO,2004). Moreover, epilepsy is a treatable condition and relatively cheap and effective medication is available. However, the treatment gap in developing countries remains very high (GCAE, 2001). In Ethiopia, it is difficult to know how many people are affected by epilepsy, how many of them have accessed to modern antiepileptic drugs and how many of them have not been got any form of treatment or using other alternative medicine, as this issue was not adequately studied. However, there are a few studies so far conducted on epilepsy which tries to explain knowledge and attitude towards epilepsy and access to modern health care services by epileptic people.

For instance, Shibru and Prevett (2004) in Ethiopia, epilepsy affects an estimated 5.2 per 1000 of the population, but only 2–13% of people with epilepsy living in rural areas were received medical treatment. Accordingly, most of epileptic people in Ethiopia were not treated in a modern health care center due to various reasons like lack of awareness about the existence of modern antiepileptic drugs, inaccessibility of modern health care services, preference of traditional medicine and misconception of the causes of epilepsy (i.e. epilepsy resulted from some insane activity by epileptic individuals). Besides, in Ethiopia people with epilepsy have been marginalized within their societies, and have had reduced opportunities for education, employment, marriage and social relationships (Teshome, et al. 2006). As a result, having lower or no educational status, denied job opportunity and socially excluded, it's difficult for epileptic people to have a better understanding of epilepsy and access to modern health care.

As in the study by Zarihun (2009) there were fifty four epileptic people (17 males and 37 females) living in Mizan-Teferi town only in a temporary epileptics' camp. The number of epileptics living outside the camp is not known. In this manner, as it is indicated in this study, most of these patients migrated to Mizan-Teferi town from the nearby *weredas*, especially from *Menit wered* due to the banishment of epileptics by their community which includes killing of epileptics and throwing them to the forest. Epileptic people cannot continue living with non-epileptic family and community once they found epileptic (Zarihun, 2009). In this manner, epileptic people especially from nearby rural *weredas* where the stigma is high are forced to migrate to the town center including Mizan-Teferi town. Based on the researcher's own observation, most of the epileptic people in Mizan-Teferi town are living on the street under unfavorable condition whereby it's difficult for them to get even basic necessities like shelter, food and clothes. Very few of these epileptic people were provided communal houses by

municipality of Mizan-Teferi town. Only a few of them had access to modern health care services may be due to various reasons like; lack of awareness about epilepsy to be a treatable ill-health condition, lack of money to afford for health services, shortage of antiepileptic drugs with in the health care center and so forth.

In line with this, therefore, the current study was conducted in Mizan-Teferi town in particular emphasis on two *Kebeles* selected (i.e. *Addis Ketema and KometaKbebeles*) in order to investigate the socio-economic and health situations of epileptics and the attitude of the surrounding community towards epilepsy and epileptic patients.

## **1.2 Statement of the problem**

In Europe, the prevalence of epilepsy is 8.2 per 1000 people. As in the report of (GCAE, 2001), about 6,000,000 people since the year 2001 in Europe had epilepsy and were experiencing different forms of stigma and discrimination like, social isolation, difficulty to find job, lack of help during active seizures due to the assumption that ‘epilepsy is a contagious disease’ and also epileptics face health problem like injury and bleeding as a result of falling down during active seizure, shortage of modern antiepileptic drugs, inability to afford due to lack of money, so forth. Despite its high socio-economic and health burdens, little is studied and known about epilepsy in developing regions (WHO, 2004). In developing countries most of the evidence for the impacts of epilepsy has been drawn from studies in the developed countries. Consequently, little is known about the situation of people with epilepsy in developing countries (Baker, 2002). It is estimated that 80% of the global health burden represented by epilepsy is borne by the developing world, where 80% of people with epilepsy reside and did not receive modern treatment, or are not even identified (Mbuba and Newton, 2009). Poor infrastructure, insufficient availability of drugs and scarcity of trained medical personnel are all relevant factors for this situation (Meinardi, 2001).

Patients with epilepsy commonly have multiple psychological, social and health problems (Sharon, 2011). Some of the psychological problems faced by epileptics include; low self-esteem, fear, and feeling of shame and guilty. In addition to this, epileptic patients also experience different social problems like, social isolation, inability to get job, difficulty to find marriage partner, stigma and discrimination, and so forth due to their illness (GCAE, 2001). In addition, epileptics faced certain health related problems like in-adequate resources within the health care system, lack of skilled personnel on the area, patients’ attitude towards health care

services, inaccessibility of health care center and knowledge gap on epilepsy to be a treatable disease (Teshome et al. 2006). Furthermore, the biggest constraints which limit efforts aimed at reducing the burden of epilepsy in developing countries are sociocultural factors that not only maintain the negative attitudes about the cause and treatment of epilepsy, but reinforce negative discriminatory and stigmatization practices (WHO, 2004). Health seeking behaviors typically reflect the causation beliefs about epilepsy; when epilepsy is attributed to supernatural causes, care seeking does not typically include attendance at local medical clinics. For instance, in the study conducted by Angula (2016) in Namibia showed that while less than 4% of individuals identified as PWE sought care from medical personnel, all had been seen by at least one traditional healer. The study conducted by Kebir (2005) in Tanzania revealed that PWE had sought multiple types of care, including traditional healers, faith (prayer group) healers, in conjunction with Western medical health facilities.

In Ethiopia, epilepsy is a major health problem, which affects about 29.5% per 1000 population (Shibru, 2002). For instance in northern Gonder, epileptic people face different social, psychological and physical problems as a result of their illness which may include stigma and discrimination, inability to find marriage partner, problems with education, problems of employment, serious physical injuries like bleeding and be wounded during sudden falling as result of active seizure, and suffered from burns if an open-fire is around during active seizure (Shibru, 2002). With regard to the cause and forms of treatment of epilepsy, in Ethiopia there is a widespread belief that cause of epilepsy as demon possessions, bewitchment by evil spirits, ancestors' spirits or the evil eyes. As a result, affected individuals and/or their families often seek help from religious and traditional healers than modern antiepileptic drugs (Shibru and Prevet 2004).

Furthermore, by assessing knowledge, attitude and practice of epileptic patients towards their illness, Gizat, et al. (2013) explained that epileptic patients in Gonder have a knowledge gap about the causes and treatments of epilepsy so that only a few of them had access to modern health care services. Epilepsy is considered to be a transmittable disease caused by evil spirit or demon possession.

Similarly, study conducted on knowledge, attitudes and practices with respect to Epilepsy by Gedefa, et al. (2012), unveils the stigma and discrimination on epileptic people which resulted from misunderstanding of the causes of epilepsy, which is the thought that epilepsy is a result of some kind of insanity and due to the belief epilepsy cannot be treated by modern antiepileptic drugs. Hence, it becomes difficult for epileptic to find job, to get marriage partner, living together with their family and community, and continue their education.

Even though, the socio-economic and health situation of epileptic patients and the attitude and knowledge towards epilepsy deserves a profound empirical investigation, there are only a few studies on the issue at hand. Studies so far conducted on epilepsy in Ethiopia were almost all institutional (hospital) based survey research in which patients were interviewed about their socio-economic and health situation. For instance, Shibru and Prevett (2004) discussed epilepsy treatment in rural Ethiopia whereby the findings were devoted to discuss issues like seizure frequency, access to health care services and follow up of patients who begun using antiepileptic drugs. Similarly, Minale et al. (2014) discussed the quality of life and associated factors among epileptic people in Amanuel Mental Specialized Hospital in Addis Ababa and explained the impacts of felt stigma on the quality of life of epileptic patients and the influence of epileptic patients' socio-economic and demographic factors on their quality of life. Besides, Teshome et al. (2006) studied perceptions about epilepsy among epileptics and their relatives, and the

findings of this study explained how the cause and treatment of epilepsy were understood by the patients themselves. The available published study (e.g. Zarihun, 2009) indicated that epileptic children in Mizan-Teferi town were subjected to different forms of stigma and discrimination including banishment, child trafficking, child labor exploitation, identity crises, lack of educational and other basic social services and lack of basic needs. However, this study was delimited to epileptic child population and is not adequate to explain the socio-economic and health situations of epileptics in Mizan-teferi town and the study also overlooked the attitude of the surrounding community towards epileptics. In addition, this study has numbered some years since it was conducted, so that it cannot adequately explain the current situations of epileptic people in this town as there were some changing dimension. For instance, it was reported in the above study that epileptics in Mizan-Teferi town were living in a camp. However, during data collection in the current study, epileptics' camp was no more existing and epileptics were living on the street. Besides, the previous studies on epilepsy have often focused on a separate investigation of attitude and knowledge of both epileptic and non-epileptic people towards epilepsy and targeted epileptics who were attending the medical care services. To the knowledge of the researcher, no such a research which incorporates the attitude of the surrounding non-epileptic community towards epileptics and the socio-economic and health situations of PWE has been done in Mizan-teferi town. Therefore, this study was conducted to fill the identified knowledge gap concerning the issue at hand.

### **1.3. Objectives of the study**

**1.3.1 General objective:** The general objective of this study was to assess the socio-economic and health situation of epileptics and the attitude of the surrounding community towards epileptics in Mizan-Teferi town.

#### **1.3.2 Specific objectives**

- To assess the knowledge and attitude of the surrounding community towards epileptics living in Mizan-Teferi town
- To examine the socio-economic consequences of epilepsy on epileptics
- To examine the relationships between certain demographic and socio-economic characteristics of household heads and the household heads' attitude towards epileptics

### **1.4 Hypothesis**

Based on the literature reviewed, the following hypotheses were formulated regarding the socio-economic situation of epileptic people and the attitude of the public towards epileptic people.

Hypothesis 1: People of lower socio-economic and educational status have poorer understanding of epilepsy and negative attitude towards people with epilepsy.

Hypothesis2: People with epilepsy are perceived by the public as having mental illness and antisocial.

Hypothesis 3: People who are older in age have tended to have unfavourable attitude towards epileptics.

### **1.5 Significance of the study**

A study on the socio-economic and health situation of epileptic people and the attitude of the surrounding community towards epilepsy is very important. Different studies so far conducted on epilepsy in Ethiopia were institutional/hospital based cross-sectional survey in which data were gathered from epileptic patients under treatment via questionnaire. However, by this research, both qualitative and quantitative data were collected from the respondents at their natural setting (i.e. the community of the town were sampled for collecting attitudinal data and qualitative data also collected from epileptic people in Mizan-Teferi town who were living in the community). Such an inclusive study which employs mixed approach helps to understand the attitude of the surrounding community towards epilepsy and at the same time, its impacts on the socio-economic and health situation of epileptics. Moreover, the findings of this study will attract a policy formulation to have adequate health policy which can solve the socio-economic problems faced by epileptic people.

Furthermore, this study furnished data which expose the socio-economic and health conditions of epileptics in Mizan-Teferi town for an appropriate intervention like creating awareness for the surrounding community about this disease and rehabilitating the victims. Finally, the findings of this investigation will serve as a stepping stone for any further studies by interested researchers.

### **1.6 Scope of the study.**

This study was confined to investigate the socio-economic and health situations of epileptic people and the attitude of surrounding community towards epileptic patients in Mizan-Teferi town. In this manner, the study was devoted to investigate and describe the socio-economic and health burdens of epilepsy on epileptics. In addition to this, the access and utilization of health

care services by epileptic people and the treatment gap in epilepsy were also covered under this particular investigation. In addition to this, the stigma and discrimination faced by epileptic people due to the banishment by the surrounding community as a result of their epileptic situation were examined. However, the attitude of epileptic patients towards epilepsy was not covered under the current study, because it has been adequately studied in past researches.

## **1.7 Conceptualization and operationalization of concepts**

### **1.7.1 Conceptualization of basic terms**

**Epilepsy:** Epilepsy is a chronic neurological disease characterized by an enduring predisposition to generate epileptic seizures (ILAE, 2014)

**Epileptic seizures:** is a brief episode of signs or symptoms due to abnormal excessive or synchronous activity in the brain (WHO, 2005)

**Active epilepsy:** has been defined by WHO (2004) as epilepsy that has caused two or more unprovoked seizure on different days in the year prior to the assessment date

**Demon possession:** is the belief that individuals can be possessed by malevolent preternatural beings, commonly referred to as demons or devils (WWW. Wikipedia encyclopedia)

**Stigma:** Goffman (1963) in his seminal work, defined stigma as “an attribute that is deeply discrediting” and proposed that the stigmatized person is reduced “from a whole and usual person to a tainted, discounted one

**Traditional Medicine:** According to the definition by WHO (2004) traditional medicine is the sum total of the knowledge, skills, and practices based on the theories, beliefs, and experience of

different cultures, whether explicable or not, used in the maintenances of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness.

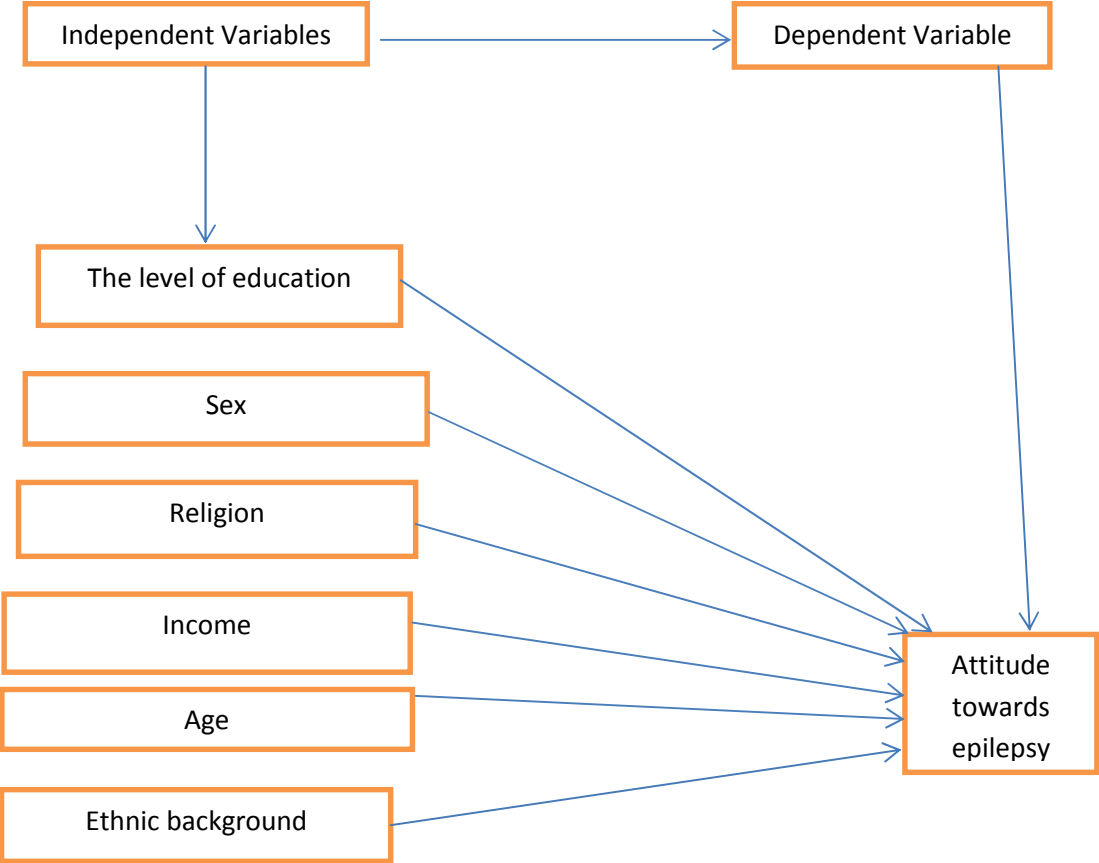
**Perceived/Felt Stigma:** it has been defined by Scamber (1989) as the shame associated with being an epileptic and the fear of encountering stigma by other people.

**Enacted/Social Stigma:** Enacted stigma has been defined by Scamber (1989) as actual episodes of discrimination against an epileptic solely on the ground of his/her disease.

**Household:** Constitutes of a person or group of persons, irrespective of whether related or not who normally live together in the same housing unit and who have common cooking arrangements (CSA 2012).

**Head of Household:** is a person who economically supports or manages the household or for reasons of age or respect, is considered as head by members of the household or declares himself as head of a household (CSA 2012)

**Figure1:** A diagram showing the Relationship between in-dependent and dependent variables which explains influencing factors of attitude of non-epileptic people towards epilepsy



## 1.7.2 Operationalization of concepts

In this sub-section the researcher will discuss the independent and dependent variables; the indicators used to measure the variables and their level of measurement as indicated in the table below.

Table: 1.1 Variables and their level of measurement

<b>Concept</b>	<b>Variable</b>	<b>Indicator</b>	<b>Measurement</b>
Income	Income	The total annual income gained from all sources	Interval/Ratio
Demographic factors	Age	The number of years a respondent lived	Scale/ratio
	Sex	Sex of the respondent (Male, Female)	Nominal
	Religion	The type of religion the respondents follow	Nominal
	Ethnicity	The kind of ethnic group respondent belongs to.	Nominal
	Marital status	The marriage status of the respondents during data collection	Nominal
Social factors	Level of education	The maximum grade the respondent has completed	Ordinal
Attitude towards epilepsy	Knowledge and attitude of non-epileptic respondent towards epilepsy	Total test scores on certain statements reflecting the attitude of the respondent towards epilepsy (Likert scale)	Interval/ ratio

## **1.8 Organization of the paper**

This research paper has been divided into five chapters. The first chapter deals with the introductory part which states the background of the study, statement of the research problem, research objectives and hypothesis, significance of the study, definition of basic terms and operationalization of concepts . In the second chapter, the researcher presents review of empirical literature on the socio-economic and health impacts of epilepsy, the attitude and knowledge of the surrounding community towards epilepsy and epileptic patients and, finally, theoretical framework of this study.

The third chapter deals with the description of the study area, research approach and design and the methods that were employed to collect data. The fourth chapter presents the findings in line with the specific objectives of the study. The final chapter provides discussion of the findings, conclusions and recommendations.

## CHAPTER TWO: REVIEW OF LITERATURE

This chapter deals with review of literature related to the historical overview of epilepsy, attitude and knowledge of the surrounding community towards epilepsy and epileptic patients, socio-economic and health situations of PWE, treatment gaps and other related issues that are reviewed from different empirical studies so far conducted on the issue at hand. In addition to this, theoretical and conceptual frameworks regarding the issue at hand were also included in this chapter.

### 2.1 Historical overview of epilepsy

Among ancient people in different parts of the world, the causes and treatment of epilepsy took different forms. For instance, Babylonians had no concept of pathology; however, they associated each seizure type with invasion of the body by a particular name evil spirit, so that treatment was not medical but spiritual (Reynolds, 2005).

The concept of epilepsy in history has been changing over a period of time. For instance, as in De Boer, et al. (1994), in ancient Christian world (70 A.C), epilepsy was explained based on the Gospel of Mark (9:14-29) as “epileptics demoniacs and cause by unclean and deaf sprit” On the other hand in ancient China (100 A.C), epilepsy was considered as a “disease of the head”. Yet again, in the ancient Arab-Persian manuscripts called *Zoroaster* (600 A.C) epilepsy was explained as sickness caused by “demons scarce” or non-exist. However, in the 17<sup>th</sup> and 18<sup>th</sup> c, in the western world, epilepsy was explained as the consequence of fight against supernatural power.

This supernatural view has dominated thinking about epilepsy until quite recently and even now remains a deep rooted negative social influence in some parts of the world (De Toledo et al. 1999). In this manner, despite scientific advances in the 19th century, epilepsy remained a

profound social problem compounded by deeply rooted historical concepts of a supernatural or sacred disorder which resulted in widespread ignorance, fear, misunderstanding and stigma of epileptic patients (Reynolds, 2005).

People with epilepsy have themselves used terminology such as their epilepsy being an unclean spirit, evil, a craziness or mental illness (Schneider and Conrad 1981). Studies examining social attitudes towards epilepsy globally uncovered generalizations and beliefs about the condition including epilepsy being a punishment for sinning, involving possession or bewitchment, connotations of contagion persist and that it is a brain disease (Andermann 2000).

It has been discussed in Guerreiro et al. (2006) that people in Brazil found to perceive epilepsy as more stigmatizing a condition than, asthma, diabetes, arthritis, migraine, leukemia and even HIV, and they believe that epilepsy can be 'caught' by bystanders, causes mental handicap and can lead to death not altogether unfounded beliefs.

Epilepsy is not a condition which a person can take personal responsibility for having it (Galvin 2002). Ancient English law has only been recently reviewed in terms of the ramifications caused should people with epilepsy commit a crime as they come out of a seizure, but which they do not remember committing (Dekkers and van Domburg 2000).

## **2.2 Epilepsy in the African region**

Epilepsy is well known in Africa, and as in many other societies, people with epilepsy, particularly those who have active seizures, experience discrimination in several areas of life, even from some health professionals.

According to WHO (2004), epilepsy is often perceived as a mental illness or contagious disease and involuntary behavior associated with some seizures, such as incontinence, tends to invoke fear and misunderstanding among the public.

In some African societies, the breath, blood, sperm and genital secretion of people with epilepsy are also considered to be highly contagious and this in turn leads to unacceptable responses such as rushing from a person experiencing a seizure without offering any help, due to irrational fears of contamination from bodily fluids (Ghaydaa, 2016). As a result, death, drowning, burning and other injuries may result from such situations.

Discrimination and exclusion are daily frustrations for people living with epilepsy. Thus, on the grounds of epilepsy, discrimination manifests itself in all spheres of life, including health care and educational systems, employment, and social and family life. For instance, Nubukpo (2000), in Côte d'Ivoire (the Ivory Coast), people with epilepsy have to wash their clothes separately and ladies are not allowed to cook meals for the group. Besides, workers must use their own tools and may not mix them with the group.

Furthermore, as it was explained in Nubukpo, (2000), in Burkina Faso's *Nankara* ethnic group, people with epilepsy are not allowed to make speeches during traditional assemblies. When they die, they are not buried, but were thrown into the mountains or the sacred bush. People with epilepsy cannot marry, although this is not specific to *Nankara* ethnic group but, have been practiced in many parts of African countries. Besides, epileptic people may also not be permitted to participate in traditional ceremonies celebrating the passage to adulthood.

People with epilepsy often face discrimination and isolation at school and work place. This results in low self-esteem and under-achievement at school. Surveys conducted in schools revealed a high rate of social withdrawal among people with epilepsy (Agbohoui, 1994). Consequently, in certain instances children with epilepsy are denied access to education out of shame on the part of the family or the school's refusal to accommodate them for fear of

“contaminating” other pupils, so that children experience cognitive difficulties due to the severity of this condition.

As discussed in WHO, (2004), ignorance about epilepsy and its effects on the part of teachers often leads to misinterpretation of certain behaviors of epileptic students, such as drowsiness, memory impairment and attention deficits being mistaken for laziness and lack of interest.

### **2.3 Knowledge and attitude towards epilepsy and epileptic patients**

Attitudes towards epilepsy can be influenced by the individual’s socioeconomic background, knowledge, and the illness perceptions of epilepsy and demographic factors like age and residential areas. For example, as in Lim (2011), people from rural areas with lower educational level and socioeconomic status have been found to have more negative attitudes towards epilepsy. In addition to this, people with less knowledge about epilepsy, or without personal contact with someone epileptic, have poorer attitudes.

The magnitude of the negative attitudes seems to be aggravated by the presence of misconception of epilepsy, which include the perception of epilepsy as a form of being untreatable, contagious, hereditary, or a form of mental retardation (Thomas and Nair, 2011).

Wrong perceptions and beliefs about epilepsy create serious negative social and psychological consequences for people with epilepsy such as fear, humiliation, and limitations in social interactions (Gedefa, et al. 2012). As a result, the challenges facing the optimal management of epilepsy is stigma and discrimination against epileptic patients due to a gap in knowledge of epilepsy and the negative attitude towards people with epilepsy. Incorrect information about the causes and inheritability of epilepsy increase the stigma and make the lives of people with epilepsy more difficult (Aydemir. 2011). Many communities in Africa believe that epilepsy results from insanity, witchcraft or possession by evil spirit. Persons with epilepsy are shunned

and discriminated against education, employment and marriage because epilepsy is seen as a highly contagious and shameful disease in the eyes of the public (Nubukpo 2003). Thus, discrimination against epileptic patients could also be due to lack of knowledge and understanding about epilepsy. On the other hand Assefa (2004) explained how people develop certain attitudes towards epilepsy and epileptics based on the information they get from different sources like, folklores, own experiences media and religious teachings and practices. In such away, the current study addresses how people's source of information about epilepsy shapes and influences their knowledge and attitude towards epilepsy and epileptic people.

Stigma was defined in Goffman (1993), as any social attribute that is deeply discrediting for an individual and, in the case of epilepsy; it can significantly affect the quality of a patient's life in many everyday activities such as going to school, working, driving, creating a family, and obtaining insurance. The social stigma has been classified in Scambler (1989) as felt and enacted. Felt stigma is defined as the shame associated with being an epileptic and the fear of encountering stigma by other people while enacted stigma is defined as actual episodes of discrimination against an epileptic, solely on the ground of his/her disease. The stigma associated with any disorder is determined not only by the actual characteristics of the disorder but also by social stereotypes concerning it created by lack of information, misconceptions, and unfounded fears. In the case of epilepsy, stigma seems to be largely based on the public perception of epilepsy as a disease that can unpredictably cause a violent and frightening attack on the patient's mental faculties, that is incurable, that affects the patient's personality, and that may be transmitted to their offspring and perceptions about epilepsy or misconceptions, when become social stereotypes, obviously cause prejudice and rejection toward anyone with epilepsy (Diamantopoulos et al. 2006; Kabir, 2005).

## **2.4 Treatment gaps in epilepsy and influencing factors of access to modern health care**

Epilepsy is a treatable condition and relatively cheap medication is available, however, Professionals who treat people with epilepsy often do not have sufficient specialized knowledge of the condition, and, in some countries, antiepileptic drugs are not always available or are not affordable and diagnostic facilities are lacking or are inadequate (WHO, 2004).

Factors such as lack of infrastructure, shortage of skilled medical personnel in the area, inadequacy of modern antiepileptic drugs, in ability to afford for treatment and so forth were some of the factors hindering access to medical care by epileptic patients (Scottt, et al. 2001).Furthermore, as in Kabir (2005), religious and socio-cultural beliefs influence the nature of treatment and care received byPeople with Epilepsy. Besides, wrong perceptions and beliefs about epilepsy create serious negative social and psychological consequences for PWE such as fear, humiliation, and limitations in social interactions. One of the greatest challenges facing the optimal management of epilepsy is stigma and discrimination whereby, incorrect information about the causes and inheritability of epilepsy increase the stigma and make the lives of PWE more difficult. For instance, Nubukpo (2003) argued that many communities in Africa believe that epilepsy results from insanity, witchcraft or possession by evil spirits. So that such misunderstanding hinders epileptic patients to be treated in a modern health care center.

Throughout history epilepsy was and is plagued by misinformation and misconception. For example, in Shibru and Prevett (2004), if someone touched a person with this kind of illness common belief assumed that you might catch the disease. Thus, epileptic people are limited in their interaction with non-epileptic people.

Therefore, despite being a common neurological disorder, epilepsy seems to be the least understood and most feared disorder in most parts of the world (Teshome, et al. 2006). This is further complicated in developing countries by its traditional attribution to demonic possession, and the perception that it is transmissible by physical contact, and these misperceptions might explain why epilepsy carries more stigma than other disorders, including mental illnesses.

The dimension of epilepsy treatment gap in the African continent is due to the general economic crisis experienced by African countries which leads to a gradual decline in the provision of health services (WHO, 2004). In this socioeconomic context, mental illness in general and epilepsy in particular are not prioritized in the national health policies of the majority of governments. In Africa, epilepsy is not considered as a common disease by the general population and this leads to stigmatization, rejection, and discrimination in many aspects of life. For example as in GCAE (2001), the major problems in epilepsy treatment are the lack of knowledge about epilepsy and the absence of collaboration between traditional and modern approaches. Moreover, treatment gaps are exacerbated by the lack of affordable, accessible and available care, so that people with epilepsy can spend years from the moment of their first seizure before they consult modern medical services and benefit from the progress achieved (Meinardi H et al. 2001). As part of new visions in health policies and sustainable development approaches WHO (2004), there is an opportunity for patients in Africa through the actions that can be taken to dramatically reduce many secondary and preventable causes of seizures, including infectious diseases and perinatal factors.

Cultural factors may not often represent as obstacles to adequate delivery of care and management of epilepsy. For instance as in GCAE (2001), cultural factors might encourage adequate management of epilepsy, like when religious beliefs support help-seeking or when

ideologies of human rights or widely shared social norms protect people with illness and disabilities from social exclusion and discrimination. On the other hand, cultural factors may be representing as an obstacle to care and management of epilepsy when people's ideas cause a delay in seeking treatment or lead to stigmatization and isolation.

## **2.5 Socio-economic and health impacts of epilepsy on the epileptic patients**

Epilepsy is highly associated with so many social problems (Tai, 2011). The negative impact of this disease on all social aspects (work, driving, interpersonal relations, education) results in low financial status, limited mobility, isolation, disturbed social inclusion and discrimination as result, it is rarely that the patients with epilepsy marry and have children.

One of the most significant impacts of epilepsy on adult patients is employment opportunities (Baker, 2002). The severity of seizure activities, educational attainment and social skills will largely determine their vocational opportunities, and so that they need to avoid employment with potential risk to their own lives and the public such as driving buses.

For those who are working, patients are inclined to conceal their illness lest they will not be employed or even lose their jobs (Viteva, 2013). Keeping this 'spoiled identity' (covered identity due to fear of losing job) and 'hidden disability' from colleagues and employers is a very stressful and prolonged process. On top of coping with the normal work stress, they are also suffering from the stress of managing their epilepsy identity.

Furthermore, those who have seizures at the workplace, feeling of embarrassment and guilt would be very strong (Hung, 2009). As a result, they will feel more helpless, rejected and frustrated in the midst of misunderstanding and gossips, and some patients may even lose their jobs directly or indirectly after seizures.

Another major impact of epilepsy on epileptic patients is the interpersonal relationship, embracing friendship, courtship and marriage, withdrawal from social lives, fear of rejection and worry over inheritance and pregnancy limit their social support network and establishment of new family support system in the long run (Hung, 2009). Both patients and their family members tend to conceal their epilepsy due to their fear of being stigmatized and discriminated (Hills, 2007). This felt stigma will further exert stress and restrict normal participation in society and patients inclined to perceive job discrimination as normal.

Although the Americans with Disabilities Act (ADA) was initially thought to address many of the discriminatory employment practices adversely impacting persons with epilepsy, Ghaydaa (2016) said that recent judicial rulings suggest that persons with epilepsy have little protection against unreasonable employment practices.

Stigma may also affect patient's health by impacting access to care and by contributing psychosocial stress to the physiological burden of disease. It is common that people with epilepsy are not a priority and the organization of their health care is inadequate, as patients are not adequately referred from primary to higher levels of care. For instance, WHO (2004) has discussed the commonest problems of PWE which includes, lack of or under-use of epilepsy surgery, lack of comprehensive care, stigma and social problems, the high cost of (especially the newer) antiepileptic drugs, lack of specialists and of specialized epilepsy care; lack of financing, equipment and resource allocation; insufficient professional education and knowledge about epilepsy and lack of epidemiological data, violation of patients' rights and employment problems.

## **2.6 Forms of epilepsy related stigma**

This section explores the ways in which stigma related to epilepsy manifests itself among people living with this condition, at the individual, family, social and structural levels. The multiple levels along which stigma can be experienced contribute to the burden of epilepsy in ways that cannot necessarily be quantified using traditional measures such as mortality and morbidity measures. Epilepsy related stigmas were explained in Hung(2009) as individual level, larger social unit, and finally, structural related stigma as follows:

*At the individual level, stigma can manifest itself in the form of diminished self-confidence, withdrawal, self-imposed isolation, financial losses and tendencies to internalize shame as well as negative perceptions of the self and of epilepsy, all of which have numerous trickle-down effects on practically all aspects of an individual's life.*

At the level of the larger social units, stigma is manifested in multitudinous ways. For instance, epilepsy-related stigma has the potential to influence social variables such as social integration, extent of interaction with social networks and peer -group activities. A young child with epilepsy may be refused continued access to education because social attitudes in educational institutions are prejudicial and discriminatory. In a country where the majority of marriages remain arranged, families of people with epilepsy may confront stigma when they try to arrange marriages. Employers may refuse employment to potential employees with epilepsy, or refuse advancement to existing employees with epilepsy.

Structural stigma can be perceived in the policies of private and state institutions, which systematically discriminate against or restrict the opportunities available to stigmatized groups. One of the most important of these state institutions is the marriage law (Corrigan *et al.* 2013). For instance, the Hindu Marriage Act of 1955 and the Special Marriage Act of 1954 both

rendered a marriage null if a partner was subject to “recurrent attacks of insanity and epilepsy.” Several years of legal struggle by the Indian Epilepsy Association resulted in the removal of epilepsy as a criterion for annulment almost at the end of the twentieth century. A brief overview of the twentieth century judicial records revealed that this particular provision was used extensively to discriminate against People with epilepsy. Even after marriage laws caught up with medical advances and understandings of epilepsy, it remains a contentious issue in family courts across India and the common practice of concealment of epilepsy from spouses is often constructed as fraud and cruelty, and the condition is still offered as spurious evidence that people with epilepsy are incapable of sustaining marital lives (Thomas and Nair, 2011). A recent data from United States had shown that seizures accounted for fatal car accidents less often (0.2%) than drunken driving (31%) (Mula and Sander, 2016). Unlike in the USA and other several countries, the Motor Vehicles Act in India does not permit issue of license to drive a motor vehicle, if the applicant has epilepsy (Thomas and Nair, 2011). In this manner, despite the petition to the Indian government by interest groups to legally permit people with epilepsy to drive, there has been little progress on this front.

## **2.7 Theoretical framework**

Under this sub topic, two theories which can better explain the current study were included. The first theory was a stigma theory of Erving Goffman. This theory explains the socio-economic consequences of illness related stigma and the potential influences of stigma on the health care provisions. The second theory is the theory of political economy of health. The analysis of this theory addresses the health consequences of social in-equalities involving race/ethnicity, gender and sexuality as they play out within and across socio-economic position in diverse societies.

### **2.7.1 Stigma context (Goffman’s theory)**

Since the emergence of stigma's definition proposed by Erving Goffman (1993), widely different models and frameworks for stigma analysis have been extended by a number of authors and have been adapted to fulfill variety of purposes to explain the stigma and discrimination which resulted from illness related problem in general and epilepsy in particular. Before going further to discuss the theoretical framework of stigma and discrimination, let us see some of the relevance of dealing with stigma to the socio-economic and health situation of patients. Stigma, as a phenomenon and an analytical framework, is relevant to both the epileptic patients and health policy makers for several reasons. First, illness-related stigma had powerful effects on economic status, psychological wellbeing, social interactions and overall health, even greater than the effects of the illness itself. Second, stigma can interfere with timely access to healthcare, early diagnosis, treatment and adherence to treatment and lifestyle recommendations. Third, stigma is linked to a broad range of psychosocial consequences, including a loss of self-esteem, social withdrawal and isolation, often influencing others within the social network. Fourth, stigma has the potential to influence the provision of care to people with epilepsy. The negative perceptions of epilepsy among medical professionals and structural discrimination resulting from stigma can impair the service utilization, particularly when there is scarcity of resources for treatment and rehabilitation. In order to better understand stigma and discrimination faced by PWE, this paper presents a systematic overview of the theoretical framework of stigma.

Accordingly, for the present study, the framework that has been forwarded first, by Erving Goffman on how stigmatizing traits can be created by the society and become applicable on patients and later more elaborated by different scholars was used. In addition to this, the framework forwarded by social psychologists based on the idea of Goffman also briefly

explained. In such away, it elaborated why there is a difference in responding to the stigmatizing traits by epileptic patients.

One of the first clearest articulations of a theory of stigma came from the sociologist Erving Goffman, who defined stigma as an attribute that has the potential to discredit an individual, and the possession of which results in the “tainting” of social identity. Those who bear a stigmatizing trait become targets for stereotypes built around that trait, prejudicial attitudes and discriminatory behavior such as shunning, exclusion and punishment. Not all individuals who possess potentially stigmatizing traits are faced with stigma. Stigmatization can be conditional upon the process of ‘labelling’ individuals with potentially stigmatizing traits are either “discredited” because the attribute is obvious or visible or “discreditable,” which means the attribute is concealed or “secret.” Persons with epilepsy can therefore be perceived as “normal” as long as they do not have public seizures. Once this occurs, the label of epilepsy is assigned; usually by an individual in a position of power most often this figure is a medical professional. Goffman (1993) also pointed out that stigma casts a long shadow that has the potential to impact those who are associated with stigmatized subgroups, including family members and friends.

Further work from social psychology has highlighted that stigma processes are part of the everyday psychological processing, cognitive schema and ordering of the world. The tendency to stigmatize is considered universal and omnipresent, but this tendency can be altered by conscious thought, changes in social policies, cultural perceptions, individual attitudes and behavior. Social psychologists also explain why different individuals respond to the same stigmatizing trait in different ways. Stigmatization is one among a large and varied set of stressors that individuals must confront. Therefore, the ability to withstand stress imposed by stigma will vary according to the intellectual, psychosocial, social and economic resources available.

### **2.7.2 The theory of political economy of health (Disease distribution and health inequality context)**

The theory of political economy of health was selected for the study at hand based on its emphasis on different aspects of social and psychological conditions in shaping population's health, how they integrate social and psychological explanations and its recommendations for action. This theory was devoted to discuss contemporary social inequalities in health and disease distribution.

The underlying hypothesis in this theory is that, economic and political institution and decision that create, enforce and perpetuate economic and social privilege and inequality are root or fundamental causes of social inequalities in health. Revisiting issues of agency and structure, theoretical analysis examine interdependence of institutional and interpersonal manifestations of unjust power relations within and between countries.

The analysis of this theory addresses social inequalities involving race/ethnicity, gender and sexuality as they play out within and across socio-economic position in diverse societies. The theory raises relevant questions like, what are the health consequences of experiencing economic and non-economic discrimination for men and women. For the aged and children? Finally, the call for action promised on this theory is thus, minimally, for public health policy, especially redistributive policies to reduce poverty and income inequality.

## CHAPTER THREE: RESEARCH METHODS

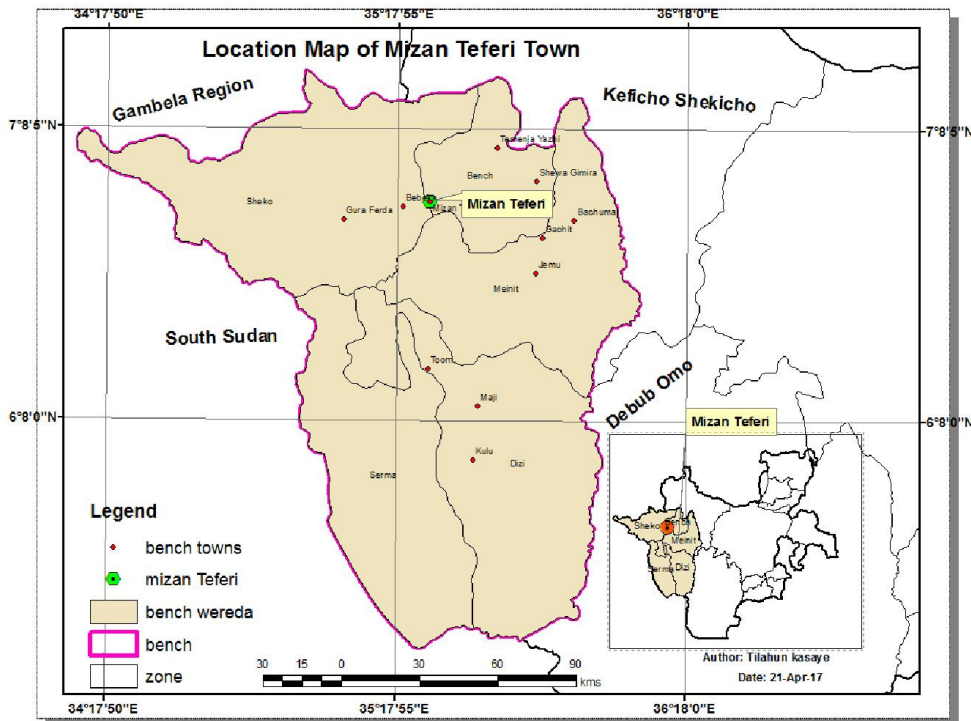
### 3.1 Description of the Study Area

Bench Maji Zone is one of the twelve zones and eight special *woredas* in the SNNPR of Federal Democratic Republic of Ethiopia. It is found 562 KMs away from Addis Ababa to the south west. The Zone is the house for about six ethno-linguistic groups, namely, Bench, Me'enit, Surma, Dizzi, Sheko and Zilmamu. The Zone is divided into ten *woredas*, the administrative level of division below the zone. These ten *woredas* include: North Bench, South Bench, She Bench, Sheko, GurraFerda, Me'enitGoldeya, Me'enitShasha, BerroSurma, and Maji. Bench Maji Zone is one of the zones in the Region which is rich in bio-diversity and mineral resources (CSA, 2007). However, the Zone is relatively poorer than the other areas in the Region in terms of infrastructural development. Of the ten *woredas* in the Zone has only three all-weather road system and five *woredas* get hydroelectric power. As far as telephone service is concerned, only the Zonal center, MizanAman is a beneficiary of the automatic telephone system (CSA, 2007).

Regarding the educational service coverage of the Zone, the Zonal data for the 2007-2008 Ethiopian calendar shows that, there were 176 first and second cycle school (1 to 8th grade), seven high schools, two preparatory schools and one University. A university was built before some ten years ago in the Zone which houses one of the Campuses (the other Campus being located in Sheka Zone, Teppi Town). With regard to the distribution of health care centers in the zone, there were one hospital, sixteen mid-level health centers, and 131 health posts in the Zone in the 2006/2007 calendar (Zarihun, 2007). Bench Maji has 142 kilometers of dry-weather roads, for an average road density of 22 kilometers per 1000 square kilometers. The main food crops in this zone include maize, godere (taro root), and enset, while sorghum, teff, wheat and barley are cultivated to a significant extent. Although cattle, goats and poultry are produced in limited

numbers, meat and milk are very much appreciated. Cash crops include fruits (bananas, pineapples, oranges) and spices (e.g. coriander and ginger) are grown in the zone. Honey is also an important local source of income. However, coffee is the primary cash crop.

Figure 3.1: Map of Mizan-Teferi town



Based on the 2007 Census conducted by the central statistical authority (CSA) of Ethiopia, this Zone has a total population of 652,531, of whom 323,348 are men and 329,183 women; with an area of 19,252.00 square kilometers, Bench Maji has a population density of 33.89. While 75,241 or 11.53% are urban inhabitants, a further 398 or 0.06% are pastoralists. A total of 157,598 households were counted in this Zone, which results in an average of 4.14 persons to a household, and 151,940 housing units. The seven largest ethnic groups reported in this Zone were the Bench, the Me'enit, the Amhara, the Kafficho, the Dizi, the Sheko, and the Suri.

Benchis spoken as a first language by 44.54%, 21.36% spoke Me'enit, 12.5% Amharic, 5.09% Dizin, 5.03% spoke Kafa, 4.31% spoke Sheko, and 3.88% Suri; the remaining 3.29% spoke all other primary languages. With regard to religion, 49.27% were Protestants, 18.12% of the population is followers of Ethiopian Orthodox Christianity, 26.34% practiced traditional beliefs, and 3.47% are Muslim (Zarihun, 2009). On the other hand, it is very difficult to know the exact figure of the population size of epileptic people in Mizan-Teferi town. However, the study by Zarihun Doda (2009) revealed, crude statistical profile of epileptics living in Mizan-Teferi town as follows:

The total banished population living in the temporary shelter was 80 (30 Males and 50 Females) Out of this, the number of epileptics was 54 (17 males and 37 females). However, the number of epileptics living outside the camp was not known.

### **3.1.1 The study population**

Mizan-Teferi town has two sub-cities (*Mizan* and *Aman* sub-cities) and a total of five *kebeles* (*Addis ketema, Ibrat, Edget, Kometa and Sheshakebeles*). The first three *Kebeles* (*Addis ketema, Ibrat and Edget*) are found in Mizan sub-city in which large population of the town is living. This is because, even if the two sub-cities have been governed under Mizan-Teferi town administration, Aman sub-city is a little bit far (7km) away from Mizan sub-city. So many epileptic people were living in Mizan sub-city as it is found in the central area of the town.

In this manner, the subjects of this study included epileptic people in Mizan-Teferi town, health professionals, religious leaders, and head of zonal social affairs office, community elders and sample of non-epileptic households.

### **3.2 Research Approach and Design**

The study employed a cross-sectional research design in order to obtain data concerning the issue under study. A cross sectional design entails a collection of data at a single point in time from a sample selected to describe some large population at that time (Bryman, 2004). Since the aim of this study is a single-time description of the issue under investigation (i.e. assessing the socio-economic and health situations of epileptic people and the attitude of the surrounding community towards epileptic patients in Mizan-Teferi town), a cross-sectional survey has been found to be the most important research design for this study.

On the other hand, both quantitative and qualitative research approaches were employed to gather the necessary quantitative and qualitative data as this study was a mixed type research. Recently, employing the combination of quantitative and qualitative approaches has gained popularity (Creswell, 2009). This popularity is because research methodology continues to evolve and develop, and mixed method is another step forward to utilizing the strengths of both qualitative and quantitative research. According to Neuman (2006) the logic of triangulation is based on the idea that looking at something from multiple points of view can improve accuracy. There is more insight to be gained from the combination of both qualitative and quantitative research than either form separately. Their combined use provides an expanded understanding of research problems. In such away, the analyses of quantitative and qualitative data were made concurrently and also there was also a separate thematic analysis used for the analysis of qualitative data.

#### **3.2.1 Quantitative approach, Sampling techniques and Sample size**

Quantitative research was used to understand the attitude and knowledge of the surrounding community towards epilepsy and epileptic people. Therefore, sample Survey was conducted to collect quantitative data regarding the attitude of the head of households among the study community.

Sample survey is the best way to collect a large amount of data from a large number of people in a short period of time and peculiar to ask for people's self-reported behavior or attitudes (Neuman 2006; Vanderstoep and Johnstone, 2009). Surveys are very robust and can be used in investigating many life domains. In developing countries, where information recording and keeping is very fragile and unreliable, sample survey is a standard tool to collect quantitative data (Ansah and Jackson 2013).

In this case, probability sampling techniques were employed in the sample survey for quantitative data collection from sampled households. The type of sampling technique employed in survey part under the current study was a multistage stage (two stage sampling). In this manner, first, two *kebeles* (Addis ketema and Kometa), out of the five kebelesexisting under Mizan-Teferi town admiration were selected via lottery method. The reason behind selecting only two of the five *Kebeles* in Mizan-Teferi town was because of shortage of time and cost, it was impossible to cover the whole five *kebeles*. In the second stage sampling, households in the two selected *kebeles* in the first stage were sampled as follows: First, sample size was determined by computer at 95% confidence interval for the total population of 4236 households. Then, Rao soft online sample size calculator resulted in a sample size of 353 households. Then, a sample interval (K) was computed as,  $n/N \times 100, = 353/4236 \times 100 = 8.33$  Accordingly, a semi-structured questionnaire which includes both open-ended and closed ended, and items of likert scale were

prepared and distributed among non-epileptic sampled households whereby heads of each household were filled the questionnaire with the help of the researcher.

Head of household is a person who economically supports or manages the household or for reasons of age or respect, is considered as head by members of the household or declares himself as head of a household (CSA, 2012). Based on the above definition by CSA, head of household in the current study were decided by the rest members of the family with the help of the researcher taking into account the issues of who is currently living together with the family and has an authority to control them, on whom the rest members of the family assumed to be dependant generally, who the family members were considering as their representative.

### **3.2.2 Qualitative approach**

Qualitative research was used in this study, to assess the socio-economic and health situations of PWE and the stigma and discrimination faced by them. In addition to this, the access and utilization of health care services by PWE to recover from their illness were discussed in a profound manner. With regard to the selection of respondents under the qualitative approach, samples were selected through non-probability (purposive) sampling techniques based on availability, and the assumption that they can better explain the issue at hand.

To this end, the following methods of qualitative data collection were applied in this study to gather the required qualitative data.

### **3.3 Methods of Qualitative data Collection**

**3.3.1 In-depth interview:** According to Vanderstoep and Johnstone (2009) this technique of face to face interview helps to come up with very thorough data, and allows for probes and follow-up questions to tailor interviews based on respondents' unique knowledge or experience.

First, about twenty informants from epileptic people living in Mizan-Teferi town were purposively and conveniently selected based on availability and the assumption that they can provide sufficient information. Then, the researcher continued interviewing the respondents until reaching on a saturation point in which necessary data that can adequately addresses the objectives of the this study were collected.

In this manner, their relationship with the other non-epileptic people in the town, their access to basic need, availability and access to basic social services like education, health care and clean water, and opportunity to participate in different form of social gathering, availability of burial sites for died epileptic, marriage and job opportunity issues were discussed in a profound manner. In-depth interview guide was used to conduct the in-depth interview. Tape recorder and note taking techniques were used to capture the information acquired from interviewees. Based on this, rough notes were prepared in Amharic, developed and transcribed to English.

**3.3.2 Key informant interview:** In this regard, some knowledgeable individuals who can best explain the issue under this study were purposively selected by snowball technique to generate data concerning epileptic people living in their town. Generally six key informants were contacted including one key informant from Mizan-Tepi University teaching hospital, one community elder, one from epileptics, three religious leaders (including), one from protestant, one from orthodox and the rest one from Muslim) were selected and interviewed on their views about epilepsy, epileptic people, and generally on how epileptic people should be treated in the community. Then, key informant interview guideline was prepared in line with the objective of this study and used by the researcher during key informant interview. Note taking was used for recording data during the interview process and the average duration of the interview was 35 minutes.

### 3.3.3 Case Study

Case study is the most flexible of all research designs, allowing the researcher to retain the holistic characteristics of real-life events while investigating empirical events. Moreover, a case study is an empirical inquiry which investigates a contemporary phenomenon within its real-life context: when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used (Yin, 1984).

A more rigorous application of case study may try to isolate selected social factors or processes within the real-life context to provide a test of the existing explanations using how and why questions. Accordingly, in the current study, a case study approach was conducted by selecting two female cases from epileptic patients via snow ball non-probability sampling technique based on different grounds like length of the year since they got epileptic, availability and capability to respond to the interview questions raised by the enumerator or the researcher. Besides, issues like gender based violence which has a significant impact on female than their male counterparts forced the researcher to take a case from epileptic female. In such away, the selected cases were interviewed and discussed their socio-economic and health situations in profound manner. During the interview, data were recorded using a tape recorder and also note taking was conducted.

### 3.4 Methodological triangulation

Table 3. 1: Methodological triangulation

Objectives of the study	Unit of analysis	Observation unit	Method of data collection
To examine the socio-economic and health consequences of epilepsy on epileptics	Epileptic people	sample of epileptic people in Mizan-Teferi town	In-depth interview Case study

			Key informant interview
To assess the knowledge and attitude of the surrounding community towards epileptics living in Mizan-Teferi town	The study community/ Sampled <i>Kebeles</i>	community elders and Religious leaders Sampled heads of households	Key informant interview Survey-questionnaire
To examine the stigma and discrimination faced by epileptics in Mizan-Teferi town.	Epileptic people	sample of epileptic people in Mizan-Teferi town	In-depth interview

### 3.5 Methods of data analysis and presentation

The qualitative data were first rearranged and organized. Finally it was thematically analyzed. On the other hand, the data obtained via sample survey were coded and interred into a statistical package for social science (SPSS version 20.0) for appropriate analysis. Then, quantitative description and explanations was followed by the qualitative data for the profound explanation of the subject under this study.

### 3.6 Field challenges and Limitations of the Study

As a beginner, the researcher has encountered different challenges during data collection process. To list a few, it was first went difficult for the researcher to convince the respondents that the information they were providing could not be affecting them and only used for academic work because they were very suspicious of the researcher. However, the researcher further assured the

respondents that the information they provide will be kept confidential and in no way affect them.

The other challenging situation that faced the researcher in this study was inability to get routinely listed names (sample frame) of households of both sampled *kebeles*. In each *kebele*, only separate files of individual households were found. Therefore, the researcher was forced to rewrite and list the name of 4236 total households of the two sampled *kebeles* in order to have a sample frame.

With regard to the limitations of this study, although Mizan-Teferi has five *Kebele* administrations, this was confined to only two *Kebeles* which may not fully represent the study town and it was due to resource constraints. Consequently, it has its own impacts on generalization.

Finally, the other limitation of this study was, the Researcher's inability to sufficiently review literature on epilepsy particularly concerning Ethiopian context due to lack of published studies on the issue.

### **3.7 Ethical consideration**

Before going to the data collection activity, the researcher took a supporting letter from Department of Sociology, Ababa University and submits to the concerned body. After getting the recognition of all concerned body, data collection process took place. Respondents gave their response totally based on their own consent and free willing and any idea raised by the respondents were never undermined by the researcher. Data were collected and analyzed in a way it does not affect the respondents in every aspect. The actual names of respondents were used as it is. Generally, any data expected to affect the respondents were handled carefully and confidentially.

## **CHAPTER FOUR: DATA ANALYSIS AND PRESENTATION**

In this chapter, the major findings of the study, based on the data obtained through survey method, in-depth interview, key-informant interview and case study were coded, analyzed and presented. The data were organized and analyzed in a sequential order taking into account of the stated objectives of the study. Accordingly, descriptive statistics like frequency tables, percentages and cross tabulation were employed for the analysis of quantitative data. Besides, inferential statistics like chi-square, T-test, ANOVA, correlation and multiple regressions were also conducted for the analysis of quantitative data whereas, qualitative data were presented alongside quantitative data analysis. Besides, thematic presentation was made for the qualitative data. The chapter consists of two major sections. The first section dealt with the analysis of quantitative data regarding the attitude of the surrounding community towards epileptics. In this manner, first quantitative data were coded and described using frequency tables and percentage of responses. Then, test statistics like T-test and ANOVA were conducted to see difference occurred as a result of socio-demographic factors influencing community's attitude towards epileptics. A statistical test chi-square was also conducted to see association between respondents' educational status and their attitude towards epileptics. In addition to this, correlation and multiple regressions were also used to see the relationship between socio-demographic factors and the attitude of non-epileptic respondents towards epileptics

The second section was devoted to discuss the socio-economic and health situation of epileptics in Mizan-Teferi town. Different themes were used to present the qualitative data taking into

account the objectives of this study. Data collected regarding socio-economic and health situation of epileptics in Mizan-Teferi town were all qualitative and presented qualitatively.

#### **4 Section One: Analysis of quantitative data collected from non-epileptic respondents**

Under this section, quantitative data collected via sample survey regarding the attitude of the non-epileptic respondents (head of households) towards epileptics were analyzed using descriptive statistics like frequency table and percentage. Moreover, test statistics like T-test, ANOVA, correlation and multiple regressions were conducted to see difference and relationship between variables tested in this investigation. Hence, the section begins with a simple description of socio-demographic profile of the respondents using frequency table and percentage.

##### **4.1 Socio-demographic profile of non-epileptic respondents**

Under this sub-topic, respondents' socio-economic and demographic profiles were described. In this manner, the sexes, ages, educational status, marital status, income level, religious type and ethnic group were described using a frequency tables and percentages. With regard to sex distribution of the respondents, the study involved a total sample of 353 heads of households, out of which 78% were male and the rest 22% were female respondents. The overwhelming majority of household heads that participated in this study were male. This was perhaps due to the fact that household headship is culturally vested in male (husband) as in most parts of Ethiopia.

#### 4.1.1 The age distribution of non-epileptic respondents

Here below is the distribution of non-epileptic respondents by age where by each of the age of individual respondents was collected and later coded in to the following age category.

The minimum age score was used as the initial point in grouping the ages of respondents and the interval 10 was decided by the researcher based on the age distribution of the respondents.

**Table 4.1: Distribution of the respondents by Age**

Age category	Frequency	Percent	mean	S2
26-35	10	2.8	55.5	9.19
36-45	98	27.5		
46-55	101	28.6		
56-65	80	22.7		
66-75	61	17.3		
76-85	3	.8		
Total	353	100.0		

---

Source: Field data (March-April, 2017)

The age distribution of the respondents ranges from 26 to 85 with most of the respondents (28.6%) falling in the age category of 46-55 and followed by 27.5.6% respondents falling in the age category of 36-45. Only a few respondents (2.8% and 0.8) respondents were constituted in the first and the last age categories respectively. Last, about 22.7% of the respondents were falling in the age category of 56-65. The mean age of the respondents was 55.5. To understand

how much age scores of the respondents were deviated from the mean, standard deviation was computed. Thus, the standard deviation of the above age distribution was 9.19. The numbers of respondents become less as the age group increases, especially after the age group of 56-65. This shows that life expectancy was short.

#### 4.1.2 Distribution of non-epileptic respondents by their level of education

One of the hypotheses of this study stated that, people of lower socio-economic and educational status have less favourable attitude towards epileptics. Hence, under this sub-topic the distribution of non-epileptic respondents by their level of education was discussed and this paves the way for testing the above hypothesis later in the other portion using correlation.

**Table 4.2: Educational status of the respondents**

Level of education(category)	Frequency	Percent
Illiterate	140	39.7
Can read and write	62	17.6
Primary School completed	58	16.4
Secondary school	30	8.5
College diploma and above	63	17.8
Total	353	100.0

Source: Field data (March-April, 2017)

Table 4.2 unveiled that, majority of the respondents (39.7%) were illiterate which is not surprising because of the inadequate educational expansion in the rural parts of the country. About 17.6% of the respondents were found to be able to read and write. Church education was the base for most of the respondents who can only read and write. The least portions of

respondents 8.5% and 16.4% were reported to complete primary and secondary education respectively. Finally, about 17.8% respondents were reported to earn college diploma and above.

Respondents who were illiterate and those who only can read and write constitute large numbers due to the low school coverage in the zone. Regarding the school coverage of the zone, as in Zarihun (2009), there were only 176 first and second cycle (1-8 grades), six high schools and one University in this zone. However, the Zonal data for the year 2007-2008 Ethiopian calendar shows that, there were 179 first and second cycle school (1 to 8th grade), seven high schools, two preparatory schools and one University. Therefore, the inadequacy of educational services in Bench Maji zone in general and Mizan-Teferi town in particular resulted in lower educational status by the community of the town which can in turn influence the attitude towards epileptics.

#### **4.1.3 Distribution of non-epileptic respondents by religion**

In the table 4.3 below different religious categories to which the respondents belonging were identified and analyzed by frequency table. The three major religious types (Orthodox Christianity, Protestantism and Islam) constitute large numbers of respondents as in different parts of the country. In addition to this, there were also some respondents who were practicing their own tradition beliefs.

**Table 4.3 Religion of the respondents**

	Frequency	Percent
Orthodox Christianity	115	32.6
Protestantism	158	44.8
Islam	76	21.5

traditional religion	4	1.1
Total	353	100.0

Source: Field data (March-April, 2017)

Table 4.3 unveiled that, majority of the respondents (44.8%) were protestant Christians. This finding confirms with the report of CSA (2007) which revealed that about 49.27% of population of the zone were followers of Protestantism. Respondents who were followers of orthodox Christians and Muslims constitute 32.6% and 21.5% respectively. The least portions (1.1%) were followers of different traditional religious practice like *Tobo* (A person who is considered as having supernatural power and doing different miracles). However, in the report of CSA (2007) the percentage of population of the zone who were practiced traditional beliefs was found to be 26.34% which is contrary to the finding of the current study in which respondents who were practiced traditional beliefs were reported to be only 1.1%. This is because the current study was conducted among urban dwellers of Mizan-Teferi town where traditional beliefs were rarely practiced.

#### **4.1.4 Distribution of non-epileptic respondents by ethnic background**

Here below on table 4.4, the ethnic backgrounds of non-epileptic respondents were discussed using frequency and percentage. It was reported in CSA (2007) that the zone is the house for six ethno-linguistic groups namely; Bench, Me'init, Surma, Dizzi, Shekko and Zilmamu. However, only Bench ethnic group were predominantly living in Mizan-Teferi town together with other ethnic groups coming from other zones and regions like Kaffa and Amhara.

**Table 4.4: Ethnic background of the respondents**

	Frequency	Percent
Bench	154	43.6
Kaffa	109	30.9
Menit	25	7.1
Amhara	63	17.8
Others	2	.6
Total	353	100.0

Source: Field data (March-April, 2017)

With regard to the ethnic composition of the respondents, table 4.4 shows that the majorities (43.6%) of the respondents were belonging to Bench ethnic group. About 30.9% were from Kaffa ethnic group while respondents from Me'init and Amhara ethnic background constitutes 7.1% and 17.8% respectively. Finally, about 0.6% respondents came one from Oromo ethnic group and the second respondent from Dawuro.

#### **4.1.5 Distribution of the non-epileptic respondents by their level of income**

It is important to see first the income distribution of the respondents before testing one of the hypotheses of this study which says, people of lower socio-economic and educational status tend to have unfavorable attitude towards epileptics. In this manner, the following income categories

were made to see the total annual income of the respondents, from all sources since the year 2008 E.C

**Table 4.5: The total annual income of the respondents (since 2008 E.C)**

	Frequency	Percent
10,000-20,000	54	15.3
20,001- 30,000	101	28.6
30,001-40,000	87	24.6
40,001-50,000	54	15.3
50,001-60,000	33	9.3
60,001-700	24	6.8
Total	353	100.0

Source: Field data (March-April, 2017)

Respondents were asked to furnish data regarding their total annual income since the year 2008 E.C from all sources in Ethiopian Birr. Accordingly, as shown on table 4.5 above, about 15.3% of the respondents were falling in the income category of 10,000-20,000 Birr. Majority of the respondents (28.6%) were falling in the income category of 20,001-30,000 Birr followed by 24.6% respondents falling in the income category of 30,001-40,000 Birr. The least portion (6.8%) of the respondents was falling in the income category of 60,001-70,000 Birr. The last 15.3% and 9.3% of the respondents were falling in the income categories of 40,001-50,000 Birr and 50,001-

60,000 Birr respectively. Hence, as the income category increases, the percentages of respondents become decline. The average annual income of the respondents was 40,000 Birr.

#### 4.2 Knowledge of non-epileptic respondents about epilepsy

Under this specific sub-topic, data related to the knowledge of non-epileptic respondents about the causes of epilepsy, sources of information about epilepsy, its transmittability, and forms of epilepsy treatment were analyzed using frequency tables and percentages.

**Table 4.6 Sources of information about epilepsy**

Multiple responses		Responses		Percent of Cases
		N	Percent	
sources of information about epilepsy	Family and friends	345	62.3%	97.7%
	Religious teachings	97	17.5%	27.5%
	Media	58	10.5%	16.4%
	Health workers	54	9.7%	15.3%
Total		554	100.0%	156.9%

a. Dichotomy group tabulated at value 1.

With regard to the information about epilepsy, all respondents were reported to have heard about epilepsy from different sources. Accordingly, majority of the respondents (97.7%) reported to have heard about epilepsy from their family and friends whereas religious teaching was found to be a source of information for 27.5% respondents. About 16.4% and 15.3% respondents were reported to have heard about epilepsy from media and health workers respectively. The sources of information from which people hear about certain disease have impact on the way people understanding it. The framework developed by Assefa (2004) and used in the current study with

a simple modification explains how people develop certain attitudes towards epilepsy based on the information they get from different sources like, folklores, own experiences, religious teachings and medical information.

#### 4.2.1 Knowledge of non-epileptic respondents on causes of epilepsy

Epilepsy is defined by WHO (2005) as the most common serious chronic neurological condition which can be resulted from brain damage. However, how the cause of epilepsy understood by the general public across the globe is different from place to place and people to people. The table 4.7 below shows the understanding of non-epileptic respondents of the current study regarding the cause of epilepsy.

Table 4.7 Respondents view on the cause of epilepsy

	Frequency	Percent
God's curse	19	5.4
Devil spirit	208	58.9
Brain damage	108	30.6
I don't know	18	5.1
Total	353	100.0

Source: (Field data from March-April, 2017)

The above table 4.7 depicts, majority of the respondents (58.9%) were reported to consider the cause of epilepsy as evil spirit which possesses the mind of epileptics. The idea of demon possession regarding to the cause of epilepsy was similarly discussed by Reynolds (2005) among ancient Babylonians. Ancient Babylonians had no concept of pathology; however, they

associated each seizure type with invasion of the body by a particular name evil spirit, so that treatment was not medical but spiritual. About 30.6% respondents were reported to think brain damage as the cause of epilepsy and followed by 5.4% respondents who were thought God's curse as the cause of epilepsy. The rest 5.1% of the respondents were reported that they didn't know the cause of epilepsy. The qualitative data collected regarding the cause of epilepsy via key informant interview further strengthen the above findings. The following data from the horse mouth were taken from the respondent in key informant interview with religious leaders of

A 41 year religious leader of Protestantism who was participated in key informant interview explained this as follows:

*“The science can say this and that about the causes of epilepsy, I know that, but as far as I am concerned and based on the Bible, epilepsy is caused by demon possession. I have seen in many occasions practically, when such kinds of people come to our church and become free from this evil spirit. It caused to some people when the demon spirit takes over their mind and finally makes them fall down sometimes.”*

Thus, the above explanation by one of the key informant interviewees indicates the thought that epilepsy is caused by evil spirit and praying as healing option. Similarly, the findings of the study by Fanta et. al (2015) in Addis Ababa confirm with the finding of the current study in this regard whereby 42.5% and 26% of the study respondents reported to think the cause of epilepsy as evil spirit and supernatural force respectively. However, in the study by Nicholas (2005) in Greece, about 57.5% of the study respondents were reported to consider epilepsy as a risk of inheriting from family and 15% of the respondents reported to understood epilepsy as a kind of insanity.

#### **4.2.2 Knowledge of non-epileptic respondents on the transmittability of epilepsy**

Under this specific sub-topic the views of respondents regarding transmissibility of epilepsy (whether epilepsy is a contagious disease) was discussed. In this manner, majority of the respondents (85.8%) thought that epilepsy is a transmittable disease while 14.2% respondents were viewing epilepsy as a non-infectious disease. The following table 4.8 shows some of the means of epilepsy transmission discussed by the respondents.

Table 4.8 Assumed ways of epilepsy ‘transmission’ (Multiple responses)

ways of epilepsy transmission	Responses		Percent of Cases
	N	Percent	
Through breathing	251	35.5%	83.1%
Touching the body of epileptic during active seizure	282	39.9%	93.4%
Sharing same objects used by epileptic	90	12.7%	29.8%
Sharing same home with epileptic.	84	11.9%	27.8%
Total	707	100.0%	234.1%

a. Dichotomy group tabulated at value 1.

As shown on the above table 4.8, respondents who considered epilepsy as a transmittable disease was asked to rate some of the ways of epilepsy transmission. Hence, the majority (93.4%) of the respondents were found to think epilepsy can be transmitted by touching the body of epileptic during active seizure. About 83.1% respondents were found to consider epilepsy as transmittable through breathing. The rest 12.7% and 11.9% respondents were reported to have considered epilepsy as transmittable via sharing same objects used by epileptics and sharing one home with epileptics respectively.

Therefore, the banishment of epileptics by their family and community was emanated from such belief whereby people are considering epilepsy as a contagious disease which can be transmitted through breathing, sharing same home and objects with epileptics and touching any parts of the body of epileptic during active seizure. The following raw data forwarded during a key informant interview with community elder can elaborate how the belief by non-epileptic people that epilepsy is a contagious disease make epileptics to be subject of different form of stigma and discrimination like social isolation and denial of opportunities.

A 58 year old community elder participated in key informant interview explained this as follows:

*“You know, before some years ago, there were few epileptics in this town. Now days the number of epileptics is highly increasing. Here and there you can find them alongside the street especially around the churches. This disease is highly expanding in our town. Therefore, people should not approach the patients. I advised all people I know not to approach these people. They (epileptics) should have to live in a separate village away from this town”*

Thus, the increasing number of epileptics who were coming to Mizan-Teferi town from the nearby towns and *weredes* resulted in the wrong understanding among the community as if the disease is wide spreading in town.

#### **4.2.3 Knowledge of non-epileptic respondents on epilepsy treatment**

With regard to the treatability of epilepsy, majority of the respondents in the current study (89.8%) were reported to have believed that epilepsy can be treated whereas 10.2% thought epilepsy as untreatable disease. Table 4.9 below brought the different epilepsy healing options assumed by the respondents

**Table 4.9 Healing options of epilepsy**

Multiple responses		Responses		
		N	Percent	Percent of Cases
Healing options	Antiepileptic drugs	249	33.3%	77.6%
	Using Holy water	103	13.8%	32.1%
	Fasting and praying	233	31.1%	72.6%
	Going to traditional healers	163	21.8%	50.8%
Total		748	100.0%	233.0%

a. Dichotomy group tabulated at value 1.

Source: Field data (March- April, 2017)

The above table 4.9 unveils respondents thought on the healing options through which epilepsy can be treated. Accordingly, 77.6% respondents were suggested using modern antiepileptic drugs as an effective practice of epilepsy treatment. About 72.6% respondents were thought fasting and praying as an effective healing option for epilepsy. The rest 32.1% and 50.8% respondents were thought effective epilepsy treatment as using holy water and going to traditional healers respectively. Thus, by splitting these responses into two categories as using modern antiepileptic drugs and traditional medicine, by summing all responses all together except modern antiepileptic drug as a tradition healing practices, about 155.4% respondents believed that traditional medicines is the effective means of treating epilepsy.

Similar to the finding of the current study with regard to forms of treatment of epilepsy, the finding of the study by Gedefa et .al (2012) in Mekelle town, northern Ethiopia revealed that majority of the study respondents (195%) were suggested non-western medicine whereas only 64% of the study respondents reported to have suggested modern anti-epileptic drugs. This is not surprising as most of the respondents perceived the cause of epilepsy as opposed to the scientific explanation.

#### 4.2.4 Knowledge of non-epileptic respondents on ‘heridetary’ of epilepsy

Among some community epilepsy is considered as a trans-generational disease. For instance, the study by Aydemir (2011) in Turkey revealed that about 57% of the study respondents were considering epilepsy as a trans-generational disease. The following table 4.10 shows the view of respondents in the current study regarding heridetary of epilepsy.

Table 4.10 Views of respondents on ‘heriderity’ of epilepsy

	Frequency	Percent
Yes	173	49.0
No	180	51.0
Total	353	100.0

Source: Field data (March-April, 2017)

As shown on table 4.10 above, respondents were asked whether they thought epilepsy as hereditary disease. Accordingly, 49% respondents were argued epilepsy as a transgenerational disease while the majority 51% responded epilepsy as not a transgenerational disease. The understanding of epilepsy as a transgenerational disease by the community has its own impact on epileptics, especially to make marriage relationship with non-epileptic people. The following explanation by one of the epileptic key informant interviewees can supplement this idea:

A 36 year old epileptic man participated in in-depth interview explained this as follows:

*“Except amongst ourselves, we cannot marry any non-epileptic woman, because they thought the disease will be transmitted to them and in the future, the child they are going to bear will also be born with the disease. However, since there are many epileptic women who are living with us, we can find a wife from among ourselves”.*

### **4.3 Attitude of non-epileptic respondents towards epileptics**

Under this sub-topic, the attitude of non-epileptic respondents towards epileptics based on different grounds like job and marriage situation, relationship of epileptics with family community and participation in different forms of social gatherings were analyzed.

Table 4.11: Attitude of respondents towards the banishment of epileptics.

	Frequency	Percent
Yes	279	79.0
No	74	21.0
Total	353	100.0

Source: Field data (March-April, 2017)

During the time of this study, majority (79%) of the respondents were thought, once somebody found epileptic, he/she should continue to live with the other family members. Even though, majority of the respondents in the current study believe that epileptics should live with family members after affected by epilepsy, it was not because of they believe epilepsy is not a

transmittable disease, rather due to the immorality of banishing one's family member. This idea was further explained by one of the participants during

A 45 year old religious leader of Muslim during key informant interviews explained this as follows:

*“Of course this disease can be transmitted, but how could you let your beloved son and daughter go? It's not our culture. It is unacceptable. Even, it's better if we die together. Rather you can prepare special room for them in the house”*

Hence, even if respondents believed that epilepsy is a transmittable disease, due to various reasons like their cultural and religious values, they were considering the banishment of epileptics as unacceptable.

The rest 21% of the respondents reported to be agreeing with the idea that epileptics must leave home as soon as possible after suffered from epilepsy to avoid further transmission of the disease to the other family members.

A 58 year old community elder during key informant interview elaborated this as below:

*“Let me tell you what our fathers' say, if one of your fingers got sick and you realize that it can't be cured, you should cut it down before the disease affects the other fingers.”*

Therefore, as it is indicated in the above data from the horse mouth, for the respondents who were skeptical towards the idea of living with epileptics, fearing of the transmission of the disease was the main reason to abandon the patients.

#### **4.3.1 Attitude of non-epileptic respondents on job recruitment of epileptics**

In different communities epileptics are considered as mentally retarded so that they can't compete for job equally with non-epileptic people. For instance, in the study by Nicholas (2005) in Greece, among the study respondents 47.8% were skeptical about recruitment of epileptics. Similarly Assefa (2004) explained that People with epilepsy were viewed with fear, suspicion and misunderstanding, and were subject to enormous social stigma. As a result, they were treated as outcasts and punished in different forms like social exclusion and denial of job opportunity. The views of respondents in the current study regarding job situations of epileptics were discussed in the following two tables (table 4.12 and 4.13).

Table 4.12: Attitude of non-epileptic respondents towards epileptics' competence to find a job

	Frequency	Percent
Yes	225	63.7
No	128	36.3
Total	353	100.0

*Source: Field data (March-April, 2017)*

Table 4.12 presents respondents attitude towards epileptics based on employment issue. Accordingly, significant number (63.7%) of the respondents responded that epileptics could compete and employed like non-epileptic people, while 36.3% respondents were responded that epileptics could not be compete and employed like non epileptic people. Some of the reasons forwarded by the respondents on this regard were; first during the recruitment, epileptics cannot perform as non-epileptic people because they are mentally weak. The second is, if they will be hired to certain positions, they cannot effectively perform their duty. Finally, in the institution

where epileptics will be hired, it is difficult for colleagues and customers to work together because they will be infected by the disease.

The following table 4.13 below brought a cross tabulation of respondents view on hiring epileptic people with respect to their educational status. This enables us to easily analyze the difference in attitude towards hiring epileptics among non-epileptic respondents of different educational level.

Table 4.13. A crosstabulation of views on Recruitment of Epileptics and educational level of the respondents

Would you hire an epileptic person to your own business, provided that she/he has the skill or qualification for it?	educational level of the respondents					Total
	Illiterate	Can read and write	Primary School completed	Secondary school	College diploma and above	
Yes	36 24.8%	8 5.5%	34 23.4%	20 11%	51 35.2%	149 100%
No	104 51%	54 26.5%	24 12%	10 6%	12 6.2%	204 100%
Total	140 39.7%	62 17.6%	58 16.4%	30 8.5%	63 17.8%	353 100%

Source: Field data (March-April, 2017)

People with epilepsy not only have to cope with the complex demands of a chronic illness, but also have to deal with social stigma and prejudice in physical activities and job opportunity.

One of the grounds on which disadvantaged segment of population discriminated is job opportunity. In this regard, under the current study, respondents were asked if they would hire epileptics in to their business given that the epileptics have the skill or qualification for it. Thus, the majority (57.8%) of the respondents were reported that they will not hire epileptics to their business even if he/she has necessary qualification for it whereas 42.2% of the respondents in the current study reported that they would hire epileptics to their business if they have the needed qualification. As we can understand from the above cross tabulation table, the number of respondents reported to have agreeing with hiring epileptics to their business increase with the increasing in the level of education. On the other hand, the number of respondents who were skeptical of hiring epileptics to their business decreases with the increase in the level of education.

Furthermore, respondents who were reported to have not agreeing with hiring epileptics to their business were asked to mention some of their reasons. Thus, some of the reasons mentioned by the respondents were summarized into two as the fear of stigma from the surrounding society and the second reason was the idea that epilepsy is infectious disease. The following idea which was explained by one of the key informant interviewee can supplement the above finding regarding job discrimination against epileptics in the study area:

A 33 year old head of zonal social affairs explained this during key informant interview as follows:

*Personally, I believe that epilepsy is not a transmittable disease and I have no problem to hire epileptics to my business but you know that you are not an island, you are living in the community and your customers are people of the town. So, who will come to your business? Who will use your services?*

Therefore, as we can understand from the above explanation by the key informant interviewee, even if some respondents personally have no problem to hire epileptics to their business, fear of the stigma and discrimination they will face from the community was the reason why they were unwilling to hire epileptics to their business. Moreover, the study by, Gedefa, et al. (2012) similarly revealed the job discrimination faced by epileptics inMekelle, Ethiopia.However, only

### 4.3.2 Attitude of non-epileptic respondents towards epileptics during active seizure

Under this specific sub-topic, the reaction of non-epileptic respondents when for the first time heard that their friend has suffered from epilepsy was described using a frequency table. Hence, the result is shown on the following table 4.14 below.

Table4.14. The reaction of non-epileptic towards epileptics

	Frequency	Percent
I would continue to treat him/her as before	96	27.2
I would feel a little awkward and afraid.	183	51.8
I would feel very awkward and stop contacting him/her	74	21.0
Total	353	100.0

*Source: Field data (March-April, 2017)*

As depicted on table 4.14 above, respondents were asked how they react if they learnt somebody they know has epilepsy. In this manner, 27.2% of the respondents were responded that they would continue to treat him/her. The majority (51.8%) of the respondents responded that they

would feel a little awkward and afraid. About 21% of the respondents reported that they would feel very awkward and stop contacting him/her. In this manner, the knowledge gaps about epilepsy among the study community lead them to the mistreatment of epileptics. Thus, epileptics were subjected for banishment and discrimination by both family and community.

A 26 year old epileptic boy who participated in in-depth interview explained this as follows:

*“Biriyo (epilepsy) is a bad disease, it makes you lose everything; your family, friends and property. I have brothers and sisters, but none of them approach me due to this disease. All people I know before are passing me as if they didn’t know me”*

The above explanation by the informant shows, once someone found epileptic, family members and other friends will no longer treat the victim as before and the patients are subjected to social isolation.

#### **4.3.3 Attitude of non-epileptic respondents towards epileptic children learning at same school with non-epileptic children.**

Educational status of individuals is an important component of human capital. It plays a pivotal role in determining individuals’ socio-economic positions in their society. Therefore, the consequences of lacking education opportunity for individuals are not only limited to lack of skill and knowledge. However it transcends to affect individuals’ psychosocial and economic aspects. In the current study, it was reported that, since epileptics were banished by family and community, epileptic children were not attending schools. This was due to different reasons among which fear of stigma and economic problems were major problems. Thus, the following table describes the attitude of non-epileptic respondents towards the school participation of epileptic children together with their non-epileptic children counterparts.

Table 4.15: Attitude of non-epileptic respondents towards educational access of epileptic children

	Frequency	Percent
Yes	262	74.2
No	91	25.8
Total	353	100.0

Source: Field data (March-April)

As shown on table 4.15, respondents were asked whether they believed that epileptic children should learn at same school together with non-epileptic children. In this regard, majority (74.2%) of the respondents were responded that epileptic children should learn together with non-epileptic children at same school whereas, about 25.8% of the respondents were responded that epileptic children should not sit and learn together with non-epileptic children at same school. Obviously, those respondents who thought epileptic children should learn at separate school reason out their position that the disease will be transmitted to the other non-epileptic children if they sit and learn together at same school. Therefore, due to this fact it was difficult for epileptic children to continue their education once they face even a single seizure. This was not only because of the disease itself, but also due to the stigma they faced at school because of their epileptic situation. The zonal administration took different measures to intervene this problem by establishing school outside the town where epileptic people were taken to resettle and teach their children.

A 33 year old head of zonal social affairs explained this during key informant interview as follows:

*“There were many epileptic children who were dropped out from school and live on the street in this town. We tried to resettle them in one separate village in Me’entwereda at a place called khat. We have opened one elementary school there and currently about 40 epileptic students are on their learning activity.”*

However, this intervention can further perpetuate the stigma and segregations against epileptics as the zone is establishing a separate village and school for epileptics who were banished by their family and community.

#### **4.3.4 Attitude of non-epileptic respondents towards marriage relationship with epileptics**

Epileptics have been facing different forms of discriminations which can affect them than the disease itself. Epileptics encounter different problems in their marriage relationship. Finding marriage partner among non-epileptic people is not easy task for epileptics. Due to the fact that, epilepsy is considered among the public as infectious and transgenerational disease, it was difficult for them to marry epileptics. Table 4.16 below shows the view of non-epileptic respondent regarding marriage relationship with epileptics in relation to their religious background using a cross tabulation.

Table 4.16: Attitude of non-epileptic respondents regarding marriage relation with epileptics

Religion of the respondents	Will you marry an epileptic?		Total
	Yes	No	
Orthodox Christianity	4(3.5%)	111(96.5%)	115(100.0%)
Protestantism	23(14.6%)	135(85.4%)	158(100.0%)
Islam	1(1.3%)	75(98.7%)	76(100.0%)
Traditional religion	0(0.0%)	4(100.0%)	4(100.0%)
Total	28(7.9%)	325(92.1%)	353(100.0%)

Source: Field data (March-April, 2017)

As displayed in the table 4.16 above, respondents from different religious background were asked whether they would marry epileptic. Accordingly, only out of the total 353 respondents, only 7.9% were thought that they can make epileptic their marriage partner while the majority 92.1% of the respondents reported that they never make an epileptic their marriage partner. In relation to respondents' religious background, about 96.5% respondents from Orthodox Christianity were reported that they would not marry with someone epileptic whereas only 3.5% affirm that they can marry epileptic. On the other hand, among followers of Protestantism, about 84.5% respondents were reported to not agree having a marriage relationship with epileptics while 14.6% of the respondents from Protestantism were reported that they can possibly marry to someone epileptic.

Among the followers of Islam, 98.7% were reported that they didn't agree to marry an epileptic whereas only 1.3% of respondents from Islam religious background affirm that they can marry epileptic. Finally, all respondents from traditional religious background were reported to not agreeing to marry epileptic.

There were different reasons mentioned by respondents who didn't agree a marriage with epileptics. One of the reasons mentioned by the respondents was the fear that the disease will transmit to them. The second reason discussed by the respondents was the assumption that 'epilepsy istransgenerational disease' so that the child they are going to bear will also affected by the disease.

A 38 year old divorced epileptic woman participated in in-depth interview explained is follows:

*“Emm, Yeah! Just I have two daughters from my first husband and they never got married; all of my community knew when my partner banned me out of my home due to this disease. All people considering them that they will give birth to infected”*

The third reason was fear of stigma and discrimination they will face if married an epileptic. Even if they personally believe that they can marry epileptic, they fear the stigma and discrimination they will face by the surrounding community. Not only epileptics, but also people approaching them will also be a subject of different forms of stigma and discrimination like social isolation.

A 24 year old epileptic boy living in Mizan-Teferi town was described this idea during an in-depth interview as follows:

*“Look! This man is non- epileptic but married with epileptic woman; for this reason he is banned and isolated from his family; now, he is living with us on the street”*

### 4.3.5 Participation of epileptics at religious worshipping places

The other form of social relationship in which people come together, share their ideas and strengthen their togetherness is a religious worshipping place. In this case, under the current study, regarding epileptics' opportunity of participation at religious place was discussed by non-epileptic respondents and described by crosstabulation.

Table 4.17 Attitude of non-epileptic respondents towards epileptics' participation at religious place.

Educational level of the respondents	Do you think epileptic people should participate at religious place together with other non-epileptic persons?		
	Yes	No	
<b>Illiterate</b>	106(75.7%)	34(24.3%)	140 (100%)
<b>Can read and write</b>	55(88.7)	7(11.3%)	62 (100%)
<b>Primary school completed</b>	54(93.1)	4(6.9%)	58(100%)
<b>Secondary school completed</b>	30(100)	0(0.0%)	30 (100%)
<b>College diploma and above</b>	59(93.7%)	4(6.3%)	63 (100%)
<b>Total</b>	304(86.1%)	49(13.9%)	353 (100%)

Source: field data (March-April, 2017)

Table 4.17 unveils, majority (86.1%) of the respondents reported that they would agree that epileptics should participate at same religious places together with non-epileptic people. This figure may contradict with the above idea whereby many respondents took the position of social exclusion of epileptics on different circumstances. There were different reasons why majority of the respondents responded that epileptics should participate at religious place together with non-epileptic people. One thing is that, even if they believe epilepsy to be a transmittable disease, they hope that God will keep them safe and also due to the fear of God, they would not prohibit

epileptics from coming to churches/mosques. The rest 13.9% of the respondents responded that epileptics should not participate at same church/mosque together with non-epileptic people. Hence, some of the obvious reasons repeatedly explained by this group of respondents were the thinking that epilepsy as infectious. In relation to level of the education of the respondents, as educational level increases, the percentage of respondents who didn't accept the participation of epileptics at same religious place with non-epileptic people become decreases and vice versa.

Table 4.18: Attitude of the Non-epileptic head of households towards epileptics

	Frequency	Percent
<30	192	54.4
>30	161	45.6
=30	0	0
Total	353	100.0

---

Source: Field data (March-April)

Data from likert scale were organized and entered into the statistical package (SPSS, version 20). Accordingly, the result was summed up out of 50 score for each cases. Given the population distribution of this study is normal or not skewed, a mean point was used as cut off point in order to categorize attitude of the respondents as favorable and unfavorable attitude towards epilepsy. Besides, based on the procedure of likert scale analysis suggested by Kothari (1990), the following cut off points were decided.

According to Kothari (2004), if the instrument consists 10 items and 5 degrees

$10 \times 5 = 50$ , Most favourable response possible

$10 \times 3 = 30$ , A neutral attitude

$10 \times 1 = 10$ , Most unfavourable attitude

Accordingly, the scores happen to be above 30 shows favourable attitude while the scores below 30 would mean unfavourable attitude.

Therefore, based on the above two points (using mean as cut off point and based on Kothari's technique of classifying likert scale data, it was concluded that the majority (54.4%) of the respondents had unfavourable attitude towards epileptics while 45.6% of the respondents had favourable attitude towards epilepsy.

#### **4.4 Determining factors of communities' Attitude towards epileptics**

This sub-section of the chapter examines if there is a relationship between certain demographic and socio-economic characteristics of the respondents/their households and the attitude of respondents towards the forest. In order to see if there is a relationship between variables measured at ratio level (such as age and income level of the respondents, and their attitude towards epileptic patients, Pearson's product moment correlation coefficient was computed and the following results were obtained. On the other hand, chi-square was computed to see the association between educational level of the respondents and their attitude towards epilepsy.

Table 4.19: The Correlation between Age and Income and Respondents' attitude towards epileptics

**Correlations**

		Age of the respondents	Annual income of the respondents since 2008 E.C	Respondents' attitude towards epileptics
Age of the respondents	Pearson Correlation	1	-.020	-.244**
	Sig. (2-tailed)		.702	.000
	N	353	353	353
Annual income of the respondents since 2008 E.C	Pearson Correlation	-.020	1	.298**
	Sig. (2-tailed)	.702		.000
	N	353	353	353
Respondents' attitude towards epileptics	Pearson Correlation	-.244**	.298**	1
	Sig. (2-tailed)	.000	.000	
	N	353	353	353

\*\* . Correlation is significant at the 0.01 level (2-tailed).

From table 4.19 above, we can see that there was a statistically significant weak negative correlation between age of the respondents and their attitude towards epileptics ( $r = -.224$  at  $p < 0.01$ ). The finding supports the hypothesis which states that respondents older in age tend to have less favorable attitude towards epileptic patients. Nevertheless, there was only a weak negative correlation between the two variables as the value of correlation coefficient lies between 0 and -0.3. Finally, with regard to the relationship between income level of the respondents and their attitude towards epileptics, there was weak positive correlation as  $r = .298$  at  $p < 0.01$ . Therefore, the test result supports the initial hypothesis of this study which states that people who have a better income level tend to have a favorable attitude towards

epileptics. However, since the value of correlation coefficient is less and only lies between 0 and 0.3, the correlation between income level of the respondents and their attitude towards epileptics was positively weak.

#### 4.4.1 Association between educational level of respondents and attitude towards epilepsy

Educational status of individuals is an important component of human capital. On top of that, it influences the way people think and explain the world in general and how they understand certain phenomena in particular. Thus, the influence of educational status of heads of household towards epilepsy was considered in this study. Hence, to test the assumption that there is no association between respondents' educational status and their attitude towards epilepsy, a statistical test chi-square was employed. The following table 4.20 unveils the result of chi-square on the association between respondents' educational status and their attitude towards epilepsy.

Table 4.20: Association between the educational levels of respondents and their attitude towards epileptics

#### Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	49.667 <sup>a</sup>	4	.000
Likelihood Ratio	52.781	4	.000
Linear-by-Linear Association	42.365	1	.000
N of Valid Cases	353		

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 13.68.

As we can see from table 4.19, the Pearson chi-square value is 49.667 with a probability (P) value of .000. This means, according to the chi-square calculation, the probability of this distribution to be occurred by chance is less than .05 or 0 probability in 100 for the association to

be appeared by chance, since probability (p) = .000. Therefore, we would accept these odds as statistically significant and conclude that there is a significant relationship between the educational level of the respondents and their attitude towards epileptics.

#### 4.4.2 Difference in attitude between respondents of different sex groups

Under this sub-topic, a test statistics which is T-test was computed to see if there was a difference occurred between respondents of different sex group. The T-test statistical test was selected due to the dichotomous nature of the variable sex. Hence, the result of the test statistics was explained in the following table 4.20.

Table 4.21: Difference in attitude based on sex of the respondents

#### One-Sample Test

	Test Value = 0					
	T	Df	Sig. (2-tailed)	Mean Difference	95% Confidence Interval of the Difference	
					Lower	Upper
sex of the respondents	54.971	352	.000	1.227	1.18	1.27
Respondents' attitude towards epileptics	99.934	352	.000	30.89235	30.2844	31.5003

SPSS out come on one sample T-test

The above t-test result shown on table 25 was computed to see whether the attitude of the respondents towards epileptics was differed based on their sex. In this manner, the test statistics t-test shows there was a significant difference in attitude towards epileptics between respondents of different sex group at P-value = .000. Therefore, since the result of p- value = .000 is <0.05,

we can conclude that there is statistically significant difference in attitude towards epilepsy based on the sex of the respondents.

#### 4.4.3 Difference in attitude among respondents of different age groups

To examine the difference in attitude among respondents of different age groups and their attitude towards epileptic patients, one-way ANOVA was computed and presented in the following table. A statistical test one way ANOVA was selected because the variable age has more than three categories.

Table 4.22: Difference in attitude towards epileptics based on age of the Respondents

#### ANOVA

	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	1137.174	5	227.435	7.350	.000
Within Groups	10736.735	347	30.942		
Total	11873.909	352			

Source: Field data (March-April)

The above table 4.22 examines if there is a significant difference in attitude of respondents of different age category. There is statistically significant difference among respondents in this regard as determined by one way ANOVA ( $F(5, 347) = 7.350$ ). Since the p-value (0.000) is less than 0.05, it can be concluded that there is statistically significant difference in attitude towards epilepsy based on the age category of the respondents. Similarly, the correlation result shown on page 72 in table 4.19 unveils the negative relationship between age of the respondents and the

attitude towards epilepsy as r- value was -0.224 which implies respondents older in age tend to have less favorable attitude towards epileptic patients.

**4.4.4 Difference in attitude among respondents of different educational level**

In this regard, one way ANOVA was computed to see the difference in attitude towards epileptics among respondents of different educational status and the result was discussed in the table below.

Table 4.23: Difference in attitude among respondents of different educational level

**ANOVA**

Respondents' attitude towards epileptics

	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	2128.883	4	532.221	19.006	.000
Within Groups	9745.026	348	28.003		
Total	11873.909	352			

The above table examines if there is significant difference among respondents of different educational level. Accordingly, one way ANOVA was computed to determine whether there is significant difference among respondents of different educational level. The result shows, there is significant difference at ANOVA (F (4, 348) = 19.006 at P=000, (P<0.05).

**4.4.5 Difference in attitude among respondents of different religious group**

The religion of the respondents were categorized into more than three categories so that one way ANOVA was computed if there was any difference in attitude based on the type of

Table 4.24 Difference in attitude based on religious type of the respondents

	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	332.459	3	110.820	3.351	.019
Within Groups	11541.451	349	33.070		
Total	11873.909	352			

religion the respondent was belonging to. The following table shows the one way

ANOVA result on this regard.

Source: Field data (March-April, 2017)

As shown on the above table 28, the one way ANOVA result computed to see difference in attitude towards epileptics among respondents of different religious type was one way ANOVA (F(3, 349) = 3.351 at P = 0.19). Therefore, the test statistics one way ANOVA depicts that there is no statistically significant difference in attitude towards epileptics among respondents of different religious background as the P-value = 0.19 > 0.05.

#### 4.4.6 Difference in attitude of the respondents of different ethnic background towards epileptics

Under this sub-topic, the difference in attitude among respondents of different ethnic background was discussed using a test statistics one way ANOVA and the result was brought in the following

table. This was aimed at testing if there appeared a difference at least in one category of respondents' ethnic background.

Table 4.25: Difference in attitude based on ethnic background of the respondents

ANOVA  
Respondents' attitude towards epileptics

	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	814.366	4	203.592	6.406	.000
Within Groups	11059.543	348	31.780		
Total	11873.909	352			

Table 4.25 unveils the result of a test statistics one way ANOVA to determine whether there is statistically significant difference among respondents of different ethnic background. In this manner, one way ANOVA ( $F(4, 348) = 6.406$  at  $P = .000$ , ( $P < 0.05$ ). Therefore, the result of the test statistics one way ANOVA depicts that there is statistically significant difference in attitude of the respondents of different ethnic background towards epileptics.

#### **4.4.7 Difference in attitude towards epileptics among respondents of different income level**

In order to see whether attitude of the respondents towards epileptics varies among respondents of different income level, a test statistics one way ANOVA was computed as this variable as more than three categories. Here below is the result of ANOVA table.

Table 4.26: Difference in attitude towards epileptics based on income level

ANOVA  
Respondents' attitude towards epileptics

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	1857.924	5	371.585	12.873	.000
Within Groups	10015.986	347	28.865		
Total	11873.909	352			

As shown in the above table 30, the result of a test statistics one way ANOVA was computed to see the difference in non-epileptic respondents' attitude towards epileptics based on their income level and the result one way ANOVA was  $(F(5, 347) = 12.873$  at  $P = .000$ ,  $(P < 0.05)$ . Therefore, based on this result, we can conclude that there is statistically significant difference in attitude towards epileptics among respondents of different income category.

#### 4.4.8 Difference in attitude of the respondents towards epileptics in terms of marital status of the respondents

In order to see whether there is a difference in attitude of respondents towards epileptics based on their marital status, a one way ANOVA was computed. The result was discussed in the table 31 below

Table 4.27: Difference in attitude based on marital status

Respondents' attitude towards epileptics		ANOVA			
	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	1099.081	4	274.770	8.874	.000
Within Groups	10774.829	348	30.962		
Total	11873.909	352			

There was statistically significant difference in attitude towards epileptics among respondents of different marital status as determined by one way ANOVA ( $F(4, 348) = 8.874, P = .000, (P < 0.05)$ ). Therefore, the attitudes of the respondents differ at least among the respondents of one category of marital status.

In addition to correlation analysis presented above, a multiple regression was run in order to check for spuriousness of the associations and differences found out by the tests used in the foregoing section.

**4.4.9 The relationship between Age and income level of the respondents and their attitude towards epileptics**

In order to see the relationship between the variables age and income level of the respondents and their attitude towards epilepsy, multiple regression were conducted. The levels of measurements of all variables analyzed by this statistical test were interval. The ANOVA model decides whether the model as a whole was significant to make prediction. Hence, the following table 4.28 describes the result of the test statistics regression and the result was explained as follows:

Table 4.28: Relationship between respondents’ attitude and their income level and age

**ANOVA**

Model		Sum of Squares	Df	Mean Square	F	Sig.
1	Regression	1730.177	2	865.088	29.849	.000 <sup>b</sup>
	Residual	10143.732	350	28.982		
	Total	11873.909	352			

a. Dependent Variable: Respondents' attitude towards epileptics

b. Predictors: (Constant), Annual income of the respondents since 2008 E.C.

**Coefficients<sup>a</sup>**

Model	Unstandardized Coefficients		Standardized Coefficients	T	Sig.	95.0% Confidence Interval for B	
	B	Std. Error	Beta			Lower Bound	Upper Bound
(Constant)	30.027	1.112		27.000	.000	27.840	32.214
1 age of the respondents	1.002	.208	.238	4.825	.000	.594	1.411
Annual income of the respondents since 2008 E.C	-1.156	.195	-.293	-5.935	.000	-1.539	-.773

a. Dependent Variable: Respondents' attitude towards epileptics

A multiple regression was computed to predict respondents' attitude towards epileptics from age and income level of the respondents. As F ratio in ANOVA table above shows, the independent variables statistically significantly predict the dependent variable,  $F(2, 350) = 29.849$ ,  $P\text{-value} < 0.05$ ,  $R\text{-value} = 0.850$ . On the other hand, the model fit was quite strong as  $(R^2) = 0.722$ . Therefore, based on the above regression result it can be concluded that, age and income level of respondents were found to be statistically significant to predict and explain the attitude of the respondents towards epileptic patients. Model summary ( $R^2$ ) value shows the proportion of the variation in the dependent variable which is explained by the model. It varies from 0 to 1, but is usually reported as percentage. Thus, when the result of  $R^2 = 0.722$  changed into percentage, it became 72.2%. On the other hand, the value of  $R^2 > 70\%$  is generally considered to be good for prediction (Elleni, 2005). Finally, based on the above regression calculation, it can be concluded

that there was an overwhelming evidence (72.2%) to say attitude of the respondents towards epilepsy can be explained or predicted by their age and level of income.

## **Section two: Socio-economic and health situation of epileptics**

Under this section, the qualitative data collected regarding the socio-economic and health situation of epileptics were organized and thematically presented under different sub-topics. In this manner, the cultural beliefs on the causes, mode of transmissions and curability of epilepsy among the study community were examined. Besides, the multiple effects of epilepsy on epileptic people which include banishment by family and community, lack of basic needs, lack of access to social services like, educational and health care services, lack of access to clean water and lack of burial site were identified and described. Moreover, effects of the disease on the physical and psychosocial wellbeing of the epileptic patients were also described under this section. Finally, gender based violence among epileptic people in the study area was also examined under this section.

### **4.5.Cultural beliefs on the causes, ‘mode of transmission’ and curability of epilepsy**

It's commonly accepted by many respondents, as verified from data collected from different sources by different instruments, defined epilepsy as a sort of the ‘evil spirit disease’. Under the current study majority of the respondents related the cause of epilepsy to evil spirit. “*Ehe ye kifumenfessira new*” in Amharic (meant, this is the work of evil spirit). Its causes were not exactly known to most of the respondents. As discussed by the respondents, the other cause of epilepsy was the unknown fateful decision of the supernatural power descendent up on some individuals whom it chooses. Besides, epileptic is the one who is meted out divine punishment

for his/her “sin” or may also due to God’s curse on ancestors which transcends to children the thought that epilepsy is a trans-generational disease. The following idea was discussed by an informant during key informant interview with 58 years old community elder:

*“You can’t question what God did, look we are in his hand, if we do not adhere to his words, such a bad thing will happen to us. We have to be careful for ourselves and for our children”*

Regarding the mode of transmission, the overwhelming number of informants believed the disease as infectious, except for some who were influenced by modern information which provided them basic facts of epilepsy. Accordingly, the very underlining reason for the stigmatization and discrimination of epileptics emanated from such beliefs that epilepsy is transmitted via eating and drinking together, physical contact with the patient, living in one home with the patients, through breathing and touching the saliva and stepping on the urine of the patients to list some. During a key informant interview, a 58 year old a community elder was further strengthens this idea as follows:

*“Let me tell you true things happened; there is one grave of man with epilepsy and on his grave; trees have grown well; unknowingly, daughter of other non-epileptic family collected firewood from that tomb’s area; When girl’s mother asked her as to where the firewood came from, the daughter responded that around that grave; Oh, that is the grave of that man with the disease, the mother replied; On spot, the daughter fell down to the ground and developed the disease; So this indicates that it is contagious. So, if a grave of dead man did this, you can guess how much we have to fear living man with the disease.”*

Therefore, as one can understand from the above raw data, it was strongly believed that epilepsy is a transmittable disease. Therefore, let alone having a physical contact or any relationship with living epileptics, stepping on the grave of the dyed epileptics was frightening among the study community. As a result, epileptic were stigmatized by shameful remarks put on them by the

surrounding community. Thus, they were banished by their families & community, so that they would die in alongside street without any help or forced to migrate to unknown places.

The inferiority attitude among the epileptic outcasts is probably a function of this belief that they themselves consider themselves as “a *briyam*” (in Amharic meaning, ‘one who is epileptic) and this considered as a lifetime, shameful tag which they cannot avoid. Some even seem to justify the banishers’ action by sharing this inimical belief.

A 37 yearold married epileptic man who has tried to commit suicide three times was further explained the impacts of the stigma as follow:

*“Look this! This is a sign when I tried to strangulate myself; I attempted three times to kill myself, thanks to my wife she protected me from this. I thought I am a bad person, because I couldn’t do what other people do and I couldn’t make money. I couldn’t, do all sorts of different things, so that I always hate myself.”*

In this manner, epileptic people tend to accept and internalize the social stigma they were facing which resulted in devaluation of themselves. Most of the epileptics in Mizan-Teferi town were spending their time by simply sitting alongside the street in the town.

Epileptic children were barely attending school. For most of the respondents, waiting for the day of their death is the only future plan. However, one association which consists (5 epileptic males) was formed by the municipality of Mizan-Teferi town and assigned to collect garbage in the town. Among these epileptic men, four of them were married to epileptic women and able to manage their family. This has helped others who had been considering themselves as incapable to manage their life, look forward and decide to improve their life.

Finally, with regard to the treatment options and curability of the disease, respondents were divided in their opinions. The idea that epilepsy is a treatable disease was harbored among majority of the study respondents. However, only a few respondents believed that epilepsy could

be treated by modern antiepileptic drugs while the majority believed it could only be treated by traditional healing practices like sprinkle holy water, fasting and praying and going to traditional medical practitioners.

Scientifically, there are different causes and treatment of different diseases, so that knowing the causes for any diseases plays great role and helps for seeking a proper care and treatment. As it can be concluded from the quantitative data in section one of this study, most of the study respondents were reported to have believed the causes of epilepsy as evil spirit. The following idea which was forwarded by a 51 year old priest of Orthodox Christianity during key informant interview can further elaborate the above explanation.

*“I couldn’t imagine epilepsy to be caused by anything else rather; it can be either the will of God or evil spirit. God can do whatever he wants to show his grace in the life of human. Let me ask you one question: do you think the people on this earth can adhere to God’s words and believe in his existence if there is always peace? And if there is no disease and death? Do you think man can fear his creator God? Have you seen how far God is wise! Therefore, he may sometimes punish people this way (by making them epileptic).*

*The other thing is, what the father of darkness or (in Amharic; ‘ye cheleme abet’) doing on some people. You can see many epileptic people healed in our church by fasting and praying, and drinking and washing holy water.”*

Generally, all religious leaders were used as key informants in the current study in one way or another traced the cause of epilepsy to evil spirit which takes over the mind of some individuals who are “weak in their spiritual life”. Some of the indicators of weakness in spiritual life discussed by key informants were, not regularly attending churches/mosques, not reading Bible/Qur’an and not obeying the word of God/Allah and finally lack of fasting and prayer. Even though all the religious leaders selected from different religion in this study explained the cause of epilepsy in relation to evil spirit and God’s punishments, none of them support their argument

with any verses from the Bible/Qur'an. However, According to De Boer, et al. (1994), in the ancient Christian world, epilepsy was explained based on the Gospel of Mark (9:14-29).

#### **4.6 Effect of epilepsy on epileptics' access to basic needs and social services**

##### **4.6.1 Access to food, shelter and clean water**

Getting basic needs like food, shelter and clothes are not options for human survival, but compulsory things which must be fulfilled to sustain alive. In this regard, epileptics in Mizan-Teferi were affected by lack of food and exposed to hunger. Being unemployed and having no any sources of income, it went difficult for this people to afford their basic needs. Hotels' remaining was the only means to get food for epileptics in this town. Even if they got money by begging, it was difficult for them to access to hotels and restaurants to buy foods. This was due to the stigma and discriminations they were facing from the surrounding non-epileptic people of the town including owners of hotels, café and restaurants.

A 43 year old epileptic man who participated in in-depth interview explained this as follows:

*“Whatever I have a lot of money in my pocket, I can't go hotels and restaurants to buy food. Immediately as you approach to their get, they said no, no go back, there is no food!”*

Moreover, there was no access to clean water (both drinking and washing) for epileptics in Mizan-Teferi town. During interview sessions with epileptics, the researcher had to endure the horrid, festering smells emanating from the victims. It looked as if they had never washed their bodies and clothes. There was thus no drinking water supply; they had to fetch it from a distant river.

A 24 years old epileptic girl who participated in in-depth interview further elaborated this as follows:

*“There is a river called shonga at the outskirts of this town. People throw garbage in to it and we draw water from this river. We use this water for drinking and washing. Even sometimes when I beg water for my daughter, nobody is willing to give me water for my kid. You know if I approach them they fear that the disease may transmit to them”*

Furthermore, victims of epilepsy in Mizan-teferi town were facing an alarming crisis in access to shelter and clothes. Before some years ago, it was reported that the town administration of Mizan-Teferi town built them a camp and large numbers of epileptics were used to live in it. However, at the time of data collection of the current study, this epileptics’ camp was totally destructed and another private building was constructed instead. Hence, epileptics were forced to live alongside streets, under verandas and the walls of churches.

A 37 year old epileptic man who participated in in-depth interview stated this as follows:

*We used to live in a camp. More than 60 epileptic people including children and women were living in that camp. Even if living in the camp has some its own problem, it was better. Look, you can see that building? Our camp was there; it got old and finally falls down. Since then, we have no shelter. As you can see all of us are living on the street.”*

In addition to this, epileptics; including small children, women and men were sufferings from lack of clothes. Clothes used during days are again worn during night when they sleep. Children were walking their bare body. Epileptic informants discussed that they are unable to afford for buying clothes and only they wait for others providing them some used clothes. The other thing is lack of toilet. Epileptics didn’t have their own home or toilet, and they are not allowed to use other people’s toilet.

A 26 years old epileptic girl who participated in in-depth interview explained this as follows:

*Look I have no job so that I can't earn money and to rent a house. Therefore, I am living on the street. Lack of toilet is a big problem. I usually go to the forest outside the town to use an open field to defecate. If people see you that time, they will shout at you and insult you. I always feel ashamed about this thing."*

Small children and women are particularly vulnerable in this regard as they defecate in open field in the town whereby this resulted in verbal abuses like insulting by the nearby community.

#### **4.6.2 Access to education and health care services**

With regard to the educational service coverage of the Zone, the Zonal data for the 2008-2009 calendar shows that, there were one hundred seventy nine first and second cycle schools (1 to 8th grades), nine high schools and two preparatory schools. From these, four primary and secondary cycle schools (1-8 grades), two high schools (9-10) and one preparatory (11-12) school were found in Mizan-Teferi town administration. However, it is not common to see epileptic children attending schools in Mizan-Teferi town. Due to the fear of stigma they may face at schools and out of schools, students who were victims of epilepsy never come back school once they faced seizure. They drop out from school and soon begin street life as they are also in one way or another forced to leave their family.

A 23 years epileptic boy who participated in in-depth interview further explains this as follows:

*"I have stopped my education by the time I was in grade three due to this disease. One day at school while was learning, I suddenly fall down and wentunconscious. Blood was poured out of my mouth when I became conscious and I got myself on the ground. Both students and the teacher left me alone and nobody approached and helped me. Really I cannot explain how much I became ashamed that time. I went home and toldmy mother all what happened to me in the class. Then, my mother advised me to leave the home before father heard what happened to me and otherwise he (My father) will kill me. Then, I immediately left the home and begun street life. Now, I do not want think about education, of course, I was a clever student"*

Consequently, due to the stigma and discrimination they faced and lack of support, epileptic children were dropping out of school. As none of the epileptic informants raised epilepsy as a direct cause for their lack of education, the stigma and discrimination they were experiencing was more affecting them than the disease itself.

Another major issues explained by participants during data collection were about access and utilization of health care services. Most of the epilepsy victims did not consider modern antiepileptic drugs as an effective means of epilepsy treatment. Here, lower educational status among most epileptics is highly affecting their access and utilization of modern antiepileptic drugs. Antiepileptic drugs have been provided for epileptics by the zonal health office at free charge with the help of different nongovernmental organizations, but there were gaps in creating awareness and distributing these drugs for the patients. In addition to this, there is also a gap in follow up of those epileptics who already begun using antiepileptic drugs. Drugs are not reaching the patients timely and epileptics are not fairly treated by health workers. This force the patients to rely on traditional healing practices like using holy water, fasting and praying, going to traditional healers and so forth.

A 38 year old epileptic man explained this during in-depth interview as follows:

*“This disease never likes hungry and anxiety; for this, if you are taking drugs properly and eat well, the seizure may not regularly happen. However, there is no drug distribution timely. Once they came and disappear for more than three months. No access to it regularly”*

Similarly, this idea was repeated and further strengthened by one of the key informant from health professionals whereby gaps in distributing antiepileptic drugs and lack of different reproductive health services for epileptics were discussed.

A 34 year medical doctor who participated in a key informant interview stated as follows:

*“We have observed the problem, there are adequate drugs in different health care centers; Drugs are there, but not distributed timely for patients. Not only antiepileptic drugs, but also family planning issues should have been addressed as well”*

Therefore, as data from different sources verifying, in addressing health problems of people of the town, epileptics were clearly overlooked. Not only lack of antiepileptic drugs, but also there were no reproductive health care services for epileptics. Most of the epileptic respondents have no clue on using contraceptive methods and unwanted pregnancy is common among epileptic community.

#### **4.6.3 Lack of Burial Site**

Problems facing epileptics in Mizan-Teferi town were not limited to those who are alive, but extends to after death. Being out of the social networks like *Idir* and *Ekub* in which people help each other in time of danger like death, epileptics in Mizan-Teferi town were exposed to lack of cemetery. Regardless of the existence of different cemetery places for followers of Christianity and Islam religion of the residents of the town, epileptics were not allowed to use these places when one of their members died.

A 32 year old epileptic woman who participated in in-depth interview states this as follows:

*“That day is the most disgusting of my life, I always try to forget, but I can’t. My daughter was seriously crying that night. I couldn’t understand what was wrong with her. I love her very much; she was my everything, in the early morning when I woke up from my sleep I found her died. She left me alone. I told what happened to every epileptic around me, and we all reduced to tears. The other non-epileptic people were watching us from some distant and none of them approached us. However, where the funeral service of my daughter would take place was unanswered question. We stayed all the day with the body of my daughter. I asked people what was wrong, and then I heard that epileptics can’t engrave in the cemetery of both Christians and Muslims. Finally, two guys whom I we don’t know came from the municipality of the town and*

*took the body of my daughter and the funeral service took place in an open field outskirts of the town.”*

As a beginner researcher and as human, it was very difficult for me to hear this. At least after death, epileptics should have been treated fairly. However, discrimination against epileptics continues even against died epileptics.

#### **4.6.4 Effects of epilepsy on physical safety and wellbeing of the victims**

Epileptics are forcibly banished from their home and family to live on the street due to their epileptic situation. Most of them were physically disabled. Physical injuries and deformities were common. The salient source of this danger included: falling down onto open fire and getting burnt during epileptic seizure, falling down onto hard surfaces like stones and other objects causing physical harm and getting physically punished such as being stabbed by the surrounding community. They were living on the street which makes them feel completely unsafe and exposed to lots of hazards, harms and harassments. They were exposed to all manners of challenges: chilly colds, rain, heat and harassments from passersby who throw stones and oftentimes make rape attempts.

Dekita is a 36 years epileptic woman and a mother of one daughter. She was living in small plastic ‘home’ together with her child under the wall of St. Mary church. She was surviving her life and her kid by begging. The researcher interviewed her in the early morning before she went to the street for begging. The following was how she had discussed her situation:

##### **Case1: Regarding physical safety and wellbeing**

*My name is Dekita Marugn. I come from Jammu town, Gorrikebele. I came to Mizan before 7 years ago due to Biriyo (epilepsy). One day I suddenly felt down as I was preparing a dinner for my family. My parents were not at home that time, but my younger brother had told them all what happened to me by the time parents back home. Then, my father was rush to tell me that I*

*must leave his home to anywhere which even he did not tell me the direction and otherwise he is going to kill me. I feared that father will kill me and I immediately left to a place called Zozo on my foot without having money for transportation. Then, after four days, I and another epileptic woman whom we met at Zozzo decided left to Mizan where we are now living.*

*“Biriyo” (epilepsy) is bad disease, you know, if you suffered from any other disease, you can live with your parents and get treatment, but this disease makes me lose everything, my parent, sister, brother and my friends. For me life is better in Mizan, because here nobody will kill me. I can move anywhere in the town. I gave birth to a daughter for a man whom we met in Mizan. He has committed a crime and sentenced to two years in a prison. He cannot help me and my child. I earn some money from begging and by washing clothes and fetching water for other people. However, it cannot buy even food for me and my daughter. Look my daughter; she has no clothes to wear. She cries day and night due to lack of food. The money I earn can't buy anything. I can't rent a home. There is no place for me to hide myself from harsh climates including coldness and hotness. I and my kid live on the street and there is no one to help us. Even, some people do not let me wash clothes and fetch water for them because; they think I cannot perform the task they are going to provide me effectively.*

The other thing with regard to physical safety and wellbeing is secondary disability (subsequent risks) as a result of epilepsy. With regard to the physical injuries caused during active seizure, fire burn was the main source. An open fire is used by epileptics during night as a means to escape from cold climate. As a result, most of the epileptics have at least some parts of their body burnt in an open fire. Most informants argue that, if an open fire is around during active seizure, the victim may run into and fall in an open fire. However, none of the respondent including, health workers were unable to explain the connection between the disease and the fire.

#### **4.6.5. Gender based violence**

As data from different sources verifying, the banishment of epileptics by their family and community exposed them to gender based violence. The fact that epileptics of different sexes living together along side streets and sleeping together during night exposes especially epileptic women to sexual abuses. The perpetrators come from both epileptic and non-epileptic men. Most of the epileptic men spent the money they got from begging for drinking alcohol especially *teji* (a local beer) during night. They frequently drink *teji*. Then, they went to the place where epileptic women slept and rape them. As epileptic women and men were living together on the street, women do have no chance to escape themselves nor do they have the power to resist and protect themselves. Not only epileptic men are rapping epileptic women, but also some drunken men from the town during night, hunt for epileptic women and rape them. During rape, even if the raped woman shouts, people come out from their home and once they checked that it is an epileptic woman, nobody approach and help her. This is because; it is assumed by the surrounding community that, fighting is common among epileptic population.

A 28 year old epileptic woman who participated in in-depth interview explained her experience regarding raping as follows:

*Being a female is difficult in this situation. I always fear when night comes. I have been raped by drunkenmen more than four times. The first time I was raped, I became pregnant and give birth to a son.*

Above all, even if the raped women reported the case to the police, the police will never give a due regard to the issue. The reason behind this was asked discussed by the epileptic respondents. Accordingly, the major reason why police most of the time overlooked the rape issue among epileptic women is the believe that epileptics are abnormal and what they talk is always doubted and considered as false claim.

The study by Zarihun (2009) revealed a similar situation facing epileptic women in this town. Accordingly, epileptic women were subjected for gender based violence including rape and beating by epileptic and non-epileptic drunken men in Mizan-Teferi town.

***Case 2: Regarding gender based violence***

*My name is DennoDelech. Now it is more than 12 years since I got epileptic. Before that I married and give birth to one child. My child is now living with my former husband somewhere in north Benchiwerede. I and my former husband were leading a good and stable life before this thing happened to me. Suddenly, I suffered from this disease and my husband forced me to leave home. Now I am living on the street with another epileptic people. You know life is difficult here, I do not know why God kept me alive. Many times I have been attacked by some drunken men in this town. As you can see, I am living on the street and there is no place to escape from them and nobody is here to help me. I beg on the street and during night I go around St. marry church. I always sleep under the wall of this church. One day, in the mid-night after I slept two drunken men who I couldn't identify their identity came to rape me. First, they came to the place where I slept and step on my legs. I was shocked and woke up from sleep. I tried to shout, but they shut my mouth with cloth and raped me. Both of them raped me one by one. Why they did all things to me? Am I their enemy? Why they did this evil thing to me? That night after they raped me, I couldn't remember what they did to me next. During rape they didn't use any condom, but thanks God I didn't got pregnant. In the morning, I couldn't wake up; I got sick due to the physical force they used during rape. After that time, I am facing a frequent seizure whenever I remember it. I didn't report this to anybody, because I fear for my life. What if they kill me the other time if I report the case to*

*the police?*

#### **4.6.6. Effects on the psycho-social wellbeing of epileptics**

Stigma and discrimination affect epilepsy patients in a variety of ways. Stigma worries the patients more than the disease itself. It makes them feel guilty, mental status impairment and depression. This stigma is a result of unpredictability of seizure and social exclusion due to the negative attitude of the society, including difficulties in access to education, lack of job opportunity, difficulty of finding a marriage partner and having a family.

The phrase ‘psycho-social’ can be broken into two: social and psychological. However, the two aspects are intertwined together. The different stages through which the epileptic patients pass due to abolishment each brings on them a complex sets of psycho-social problems. For instance, for the first time when an epileptic patients learn that family is about to chase him/her and people stop approaching him/her, the most likely psycho-social response is fear, stress, confusion, crying and losing hope.

Lack of knowledge about the basic facts of epilepsy coupled with the deep rooted sense of rejection by their family and community; lead them to consider themselves as the scapegoats, being possessed by evil spirit. Hence, epileptics were not confident enough to resist the stigma

and discrimination, except accepting the problem as their fate.

A 27 year old epileptic boy participated in in-depth interview explained this as follows:

*“I have been living here in Mizan since my childhood. I become epileptic when I was a grade six student since 2002. My families are also living here, but I am not living with them, because of their bad attitude towards me. Even if they didn’t explicitly tell me to leave their home, I know they do not feel good whenever I go home and even I fear that, one day they will kill me. So, I left home two days after I face seizure. I lost all of my friends after I became ill. People where withdrawing from me and cutting me out from their life. This was really confusing to me, that it was happening, because I thought they were good friends.”*

Therefore, as we can understand from the above explanation by one of the victims of epilepsy during in-depth interview, once somebody found epileptic, he/she is no more wanted by neither family nor friends. Hence, epileptic patients were subjected to different forms of stigma and discrimination including lack of social support, isolation and so forth.

On the other hand, after epileptic patients banished and begin another stage of life they tend to experience other psycho-social problems including the above discussed problems.

More social oriented problems like, lack of social support/helplessness, social isolation, lack of love and affection, insult and embarrassment, risky drinking behavior and lack of opportunity to share family and community properties lead the patients to some more psychological oriented problems like inferiority feeling, hopelessness, frustration, fatalistic thinking, depression, loneliness and aggressiveness.

## **Chapter five: Discussion of major findings and Conclusion**

### **5.1 Discussion**

This study was conducted on the socio-economic and health situations of epileptics and the attitude of the surrounding community towards epilepsy in Mizan-Teferi town. In such away the study tried to see the stigma and discriminations faced by epileptics in relation to the attitude of the surrounding community which is an inclusive technique to dig out data from both epileptic patients and the surrounding community. Accordingly, the attitude of the surrounding community towards epilepticsand the actual living conditions of the victims of epilepsy was explained. This paves the way to see the impacts of community's attitude on socio-economic situations of epileptic patients. Most of the previous studies were devoted to discuss the knowledge and attitude of non-epileptic people towards epilepsy and unable to link their findings to the socio-economic and health situations of epileptics.However, the current study was conducted in a way to triangulate data from both the surrounding community and epileptics.

In this manner, in the current study, respondents were asked to state their opinion on what cause epilepsy; the majority (58.9%) of the respondents thought epilepsy to be caused by evil spirit. About 30.6% of the respondents reported epilepsy to be caused by brain damage followed by 5.4% and 5.1% respondents who thought epilepsy as a result of God's curse and those who didn't know what causes epilepsy respectively. Concerning the treatment of epilepsy, majority (89.8%) of the study respondents thought epilepsy as a treatable disease.

Similarly, in the study by Andualem and Tefesse (2017) in Me'entworeda, south western Ethiopia, 85% and 49.3% of the study respondents reported that, they thought epilepsy as a mental disease and God's curse respectively. However, only 30.7% of the respondents were thought epilepsy as a treatable disease. This difference may be due to the difference in level of education among the study respondents whereby, the educational statuses of the respondents of the present study were relatively better than that of the respondents in the above study.

Furthermore, the study by Gedefa et al. (2012) in Mekelle, Ethiopia revealed that, 33.24% of the study respondents thought epilepsy to be caused by evil spirit and about 51.6% respondents believed epilepsy as a kind of insanity. Another study conducted by Nicholas Diamantopoulos (2006) in Greece revealed 91% of the study respondents believed epilepsy as a nervous system disorder, 19% of the respondents consider epilepsy as a mental retardation and 15% of the respondents argued epilepsy as a kind of insanity. The rest 57.5% and 5.2% of the respondents thought epilepsy as a risk of inheriting from family and supernatural phenomenon respectively. Moreover, in the study by Fanta et al. (2015) in Addis Ababa, Ethiopia respondents were asked their opinion on what cause epilepsy. In this manner, 26% respondents thought epilepsy as a result of supernatural force and about 42.5% of the respondents thought epilepsy to be caused by evil spirit. The rest 31.5% of the respondents didn't know the cause of epilepsy.

However, the recent study conducted by Angula (2016) in Namibia unveiled that, 39% of the study respondents thought epilepsy as an inherited disease and 12% respondents argued epilepsy to be caused by accidents. About 14% and 13% respondents thought epilepsy as a brain tumors and birth deficits respectively. Besides, in the other recent study conducted by Ghaydaa (2016) in Egypt, 46% of the study respondents consider epilepsy as abnormality (madness).

Moreover, Nubukpo, (2002) revealed that Epilepsy is perceived as an “African” ailment, a manifestation of supernatural forces, traditionally looked upon as caused by ancestral spirits or attributed to possession by evil spirits. In most instances traditional healing is the first treatment sought. In some countries, the traditional belief systems endorse discrimination against people with the condition, leading to their exclusion from mainstream society and restrictions on their access to basic human and civil rights. (Global Campaign Against Epilepsy, 2001).

On the other hand, with regard to curability and treatment options of epilepsy, in the present study, about 89% of the respondents were argued epilepsy is a curable/treatable disease and they were mentioned different epilepsy treatment options they thought effective and efficient to cure epilepsy. In such away, about 33.3% of the respondents suggested modern antiepileptic drugs as effective treatment of epilepsy. Hence, this idea confirms what the science says regarding treatment of epilepsy. The other 13.8% and 31.1% of the respondents thought using holy water and fasting and prayer as an effective means of epilepsy treatment respectively. The rest 21.8% of the respondents believed going to traditional healers and using traditional medicines as options of epilepsy treatment. The findings of the study by Gedefa et al. (2012) in Ethiopia with regard to assumed treatment options of epilepsy confirm with the above finding of the current study whereby majority (53%) of the study respondents were believed epilepsy is a treatable disease. Hence, concerning the different treatment options, the majority (70.33%) of the

respondents suggested using holy water as an effective means of epilepsy treatment likewise, 64% and 44.8% of the respondents thought antiepileptic drugs and traditional medicines as treatment options of epilepsy respectively. Finally, 32.14% of the respondents argued fasting and prayer as effective means of epilepsy treatment.

Epilepsy leads to a multiple interacting psychosocial, health and economic repercussions, all of which need to be considered. Fear, misunderstanding, and the social stigma and discrimination surrounding epilepsy are more difficult than the seizure itself. Together with the social stigma and discrimination that persists in the society, people with epilepsy often feel a sense of social isolation and have an overall reduced quality of life. Some of the grounds on which the epileptic patients in Mizan-Teferi town stigmatized and discriminated were; inability to find a job, inability to find marriage partner, exclusion from social networks, lack of access to education and health services and so forth. With regard to marriage and job situations of epileptics in the current study, respondents were first asked if they would marry to someone epileptic and only 7.9% were reported no objection while the majority (92.1%) were hesitant about it and clearly rejected to make someone epileptic their marriage partner. The findings of the study by Nicholas Diamantopoulos (2006) in Greece confirms with the finding of the present study in such a way that 43.8% of the respondents were not in a position to make an epileptic patients their marriage partner and only 9% were argued that they can make someone epileptic their marriage partner. Besides, in the very recent study conducted in Me'entweweredede south western Ethiopia by Andualemand Tefesse (2017), respondents were asked their opinion on whether epileptics can marry and able to manage their family. Then, (61.8%) of the participants did not think that epileptics can marry and able to manage their family. Among the study participants, 75% of the respondents were not agreeing to recruit epileptics to their business. About 38.2% and 39.3% of

the study participants reported that they did not agree to work with epileptics to have close relation with them respectively.

In the same way, under the study at hand, respondents were first asked if they thought epileptics were competent and able to work. Thus, the majority (63.7%) of the respondents gave an affirmative answer and 36.3% were skeptical about it. However, asked if they would hire an epileptic patient to their business, given that he/she has the quality for that position, majority respondents (66.3%) were reluctant about it. One of the major reason behind their argument were, even if they thought epileptics can be hired and work, their customers will never approach the epileptic employee and their business will be endangered. Only 33.7% of the respondents argued they can hire an epileptic to their business if he/she has the quality for it.

Regarding to recruitment of epileptic patients, a study carried out in Greece by Nicholas Diamantopoulos (2006) also came up with similar findings in which 47.8% of the respondents were hesitant to hire epileptics to their business while only 37.7% gave affirmative answer.

Asked how they would react to the announcement that someone they knew is suffering from epilepsy, in the present study, the majority (27.2%) of the respondents reported a neutral type of reaction and the majority (51.8%) reported feelings of little awkward or fear and rather avoid him. Finally, about 21% of the respondents reported to feel very awkward or afraid and desire to stop associating with this person.

Hence, the stigma and discrimination facing epileptically banished population in Mizan-Teferi town which may include isolation on living quarters, eating, sharing common resources like water sources, burial sites, firewood, employment opportunity, access to health and educational services and marriage were discussed as some of the major problems facing epileptics of the town. These findings confirm with argument of Erving Goffman's theory of stigma.

Erving Goffman, (1993) who defined stigma as an attribute that has the potential to discredit an individual, and the possession of which results in the ‘tainting’ of social identity. Those who bear a stigmatizing trait become targets for stereotypes built around that trait, prejudicial attitudes and discriminatory behavior such as shunning, exclusion and punishment. According to Goffman, not all individuals who possess potentially stigmatizing traits are faced with stigma. Stigmatization can be conditional upon the process of labelling: individuals with potentially stigmatizing traits are either ‘discredited’ because the attribute is obvious or visible or ‘discreditable, which means the attribute is concealed or ‘secret.’ Persons with epilepsy can therefore be perceived as ‘normal’ as long as they do not have public seizures. Once this occurs, the label of epilepsy is assigned; usually by an individual in a position of power most often this figure is a medical professional. Consequently, the findings of the current study regarding the stigmatization and discrimination which includes exclusion from any form of social gathering, job discrimination, difficulty to find marriage partner, inability to access to educational and other basic social services against epileptics in Mizan-Teferi town confirms the stigma theory of Goffman. However, with regard to hiding epileptic’s seizure attribute, there is a rare chance for epileptics in Mizan-teferi town. This is because; even a single sudden seizure may cause banishment by the other family members themselves. Due this, epileptics can no way make their epileptic trait a secret. Besides, with regard to the claim that not all individuals who possess potentially stigmatizing traits are faced with stigma, findings of the current study unveils, there was no boundary in labeling and discriminating individuals who possess epilepsy attribute in the study area. Every individual with epilepsy trait, regardless of their gender, age, and socio-economic status were subjected to stigma and discrimination by the surrounding community. Hence, the success probability of the labeling process was high for all epileptic patients.

Moreover, in order to see how the decisions by economic and political institutions affect individuals' health and the health consequences of experiencing economic and non-economic discriminations, the theory of political economy of health was selected. In this manner, this theory explained how economic and political institutions and decision that create, enforce and perpetuate economic and social privilege and in-equality becomes the root or fundamental causes of social in-equalities in health. The findings of this study go hand in hand with the argument of the theory of political economy of health in its analysis of the health consequences of experiencing economic and non-economic discrimination for certain segments of a given population. In this regard, under the current study, the different economic and non-economic discriminations faced by epileptic people were affecting the victims more than the disease itself. Economic discrimination like lack of job opportunity, inability to share property like land and social discrimination like isolation, lack of opportunity to participate in different forms of social gathering, difficulty to find marriage partner were highly affecting the lives of epileptics.

## **5.2 Conclusion**

This study was intended to investigate the socio-economic and health situations of epileptic patients in Mizan-Teferi town and the attitude of non-epileptic sampled head of households towards epilepsy and epileptic patients.

To conduct the study, data were collected from sample households randomly selected from two kebeles namely addisketema and kometakebeles. The total number of respondents was 353 of which 275(78%) were males and 78(22%) were females. The survey questionnaire by which the data was collected from the respondents was composed of three parts: namely demographic and

socioeconomic profile of the respondents', their knowledge towards epilepsy and the attitude of the respondents towards epileptic patients.

In addition, six key informant interviews were carried out in order to identify the attitude of the non-epileptic head of households towards epilepsy and epileptic patients. The quantitative data were analyzed using descriptive statistics, bivariate correlation analysis, ANOVA (one way) and a multiple regression whereas the qualitative data were thematically analyzed and partly alongside quantitative data analysis. On the other hand with regard to the socio-economic and health situations of epileptic patients in Mizan-Teferi town, data were gathered via in-depth interview, key informant interview and case study methods.

The result of this study uncovers the knowledge gap and misunderstanding about epilepsy by the surrounding community and how this resulted in stigma and discrimination of epileptic patients. Epilepsy was understood by majority of the surrounding community as a contagious and trans-generational disease caused by the possession of evil spirit. Hence, once found epileptic, it was difficult for epileptic patients to carry on living with the rest non-epileptic family members and the community, and thus subjected to banishment.

The ancient, deep rooted belief of the people regarding the nature, cause, mode of transmission and curability of the disease has been at dissonance with the scientific facts about the disease and still continue to enjoy widespread acceptance among the people of the study area, even including the epileptic themselves whereby they internalized the shameful tag attached to them due to their epileptic situation. Such beliefs have put an aura of supernatural uniqueness to the disease locating its origins in the works of evil spirits. The disease has been understood by people of the study area as one which has no scientific remedy, and thus the only solution to the disease has been to do away with the patient.

The practice of quarantining the epileptic patient has been shrouded in antiquity: it has been in practice for time immemorial. The method of quarantine has been until recently to put the patient in complete isolation at a faraway location from the home and neighborhood and let him live there until he died, out of lack of care and support and the workings of nature (cold, rain, heat, wild animals, etc.).

There was no preferential treatment offered to the patients irrespective of age, sex, and socio-economic status or otherwise. Whoever it might be, even if it is the only child of a parent must be put to abolishment if he/she got epilepsy.

To wind up, the findings of this study unveils lack of knowledge and awareness about the nature, cause and modes of treatments of epilepsy were the major reasons for the unfavorable attitude of the non-epileptic surrounding community towards epileptic patients. This in turn result in the stigma and discrimination of epileptics like social exclusion, lack of access to basic social services including education services, health care services, lack of access to clean water (i.e. water for drinking and washing) and burial sites for died epileptics. However, there were some beginning work for the intervening the problem by Mizan-Teferi town municipality in collaboration with the zonal social affairs department. In such away, they provided the epileptic patients with some job opportunities by forming an association of five members of epileptic men. The tasks to which they were recruited and assigned includes; street cleaning, ditch clearing and the like) and they were earning about a 500 birr per month. This was serving as a good example for both epileptics and non-epileptic people of the study area in changing the wrong perception that epileptic are incapable to work and improve their lives.



- Abigal Paul, Davis Adeloye, Rihannon George, Ivana Kolcic, Liz Grant and Kit Yee  
 chan(2012). An estimated provenance of epilepsy in Sub-Saharan African: A  
 systematic analysis. Centre for Population Health Sciences and Global Health  
 Academy. The University of Edinburgh Medical School, Edinburgh, Scotland,  
 UK. Vol. 2 No. 6 . 020405 doi: 10.7189/jogh.02.020405
- Anchor TF Hung, (2009). Psycho-social impacts of epilepsy and issues of stigma; the Hong  
 Kong society for rehabilitation
- Andermann, L. F. (2000). "Epilepsy in Our World: An Ethnographic view." *Epilepsy and  
 Behavior* 1: 169 -175
- Andualem Henok and Tafesse Lamaro. (2017). Knowledge about and Attitude towards Epilepsy  
 among Menit Community, Southwest Ethiopia. *Ethiop Journal of  
 Health Scie* 2017; 27(1):47 58. <http://dx.doi.org/10.4314/ejhs.v27i1.7>
- Ansah, Evenly, and Timothy Powell-Jackson. (2013). "Can we trust measures of healthcare?  
 utilization from household surveys?"
- Assefa Mulu (2004). Perception of epilepsy among Ethiopian immigrants in the Netherlands.  
 Master's thesis in medical anthropology, University of Amsterdam, the  
 Netherlands.
- Aydemir N. (2011). Familiarity with, knowledge of, and attitudes toward epilepsy in Turkey.  
*Epilepsy Behave.*
- Birhanu B, Berihun A, and Bewket T. (2015). Perceived stigma and associated factors among  
 People with epilepsy at Gonder University hospital, North West Ethiopia:  
 A cross-sectional institution based study. University of Gonder, college of  
 medicine and health sciences
- Bruce G. Link and Jo C. Phelan, (2005). *Conceptualizing Stigma: an annual review of sociology.*  
 Columbia University and New York State Psychiatric Institute, Department of

Sociology, New York.

Bryman, Alan. (2004). *Social Research Methods*. 2nd ed. Oxford, UK: Oxford University Press.

Charles Schell, (1992). *The value of case study as a research strategy*. Manchester business school.

Corrigan PW, Watson AC, Heyrman ML, Warpinski A, Gracia G, Slopen N, et al. Structural stigma in state legislation. *Psychiatr Serv*. 2005;56:557–64. PubMed

Creswell, John. (2009). *Research design: A qualitative, quantitative, and mixed method approaches*. United States of America: SAGE Publications, Inc.

De Boer H. (1994). *Horizan: the trans-national epilepsy training project*. *International Journal of Adolescent medicine and health*.

Dekkers, W. and P. van Domburg (2000). "The role of doctor and patient in the construction of the pseudo-epileptic attack disorder." *Medicine, Health Care and Philosophy* 3: 29 - 38.

De Toledo, Carrazana, J. Tatum, Rivas-Vasquez, Rey G. and Wheeler S. (1999). *Epilepsy and religious experiences. Voodoo possession*. Neurologic Center of South Florida, University of Miami School of Medicine, and University of South Florida-Tampa General Hospital, Miami, Florida, U.S.A.

Edward Reynolds. (2005). *Epilepsy: the disorder. Milestones in the history of epilepsy*. *Epilepsy Atlas*

Ellen Marshal. (2005). *The statistics: Tutors' quick guide to commonly used statistical tests*.

University of Sheffield, England

Ekaterina Viteva. (2013). *Impact of social factors on the quality of Life of Patients with refractory epilepsy*. University of Medicine –Plovdiv: Department of Neurology, Bulgaria

Fanta T, Azale T, Assefa D, Getachew M. (2015). *Prevalence and Factors Associated with*

Perceived Stigma among Patients with Epilepsy in Ethiopia. J Psychiatry 18:  
324 doi:10.4172/2378-5756.1000324

Fernandes R and Sander JW. (2013). Stigma and attitudes on epilepsy. A study on  
Secondary school students, epilepsy institute of the Netherlands

Galvin, R. (2002). Disturbing notions of chronic illness and individual responsibility: towards a  
genealogy of morals. Health 6(2): 107 – 137

Gedefa M, Wolde T, Solomon G.(2012). Knowledge, Attitudes and Practices with  
respect to Epilepsy among Preparatory School Students in Mekelle city,  
Ethiopia.

Retrieved from: <http://iomeworld.com/ijcrimph/ijcrimph-v04-n03-04.htm>

Ghaydaa Ahmad. (2016). A Review of Epilepsy Stigma in Egypt. Assiut University Hospital,  
Egypt

Gizat M, Tsegaye M, and Bogale K. (2014). Knowledge, attitude and practices of epileptic  
Patients towards their illness and treatment in Jimma University specialized  
Hospital, south west Ethiopia.

Global Campaign against Epilepsy.(2001). Out of the Shadows: an introduction to the Global  
Campaign and its demonstration projects. Hempstead: Global Campaign  
against Epilepsy. Retrieved from <http://www.who.int>

Goffman, E. (1993). *Stigma: Notes on the Management of Spoiled  
Identity*. Englewood Cliffs, NJ: Prentice Hall,

Graham Scambler. (1989).Epilepsy and quality of life research. Journal of the royal society of  
medicine, Volume 86. Academic Department of Psychiatry,  
College and Middlesex School of Medicine, London W1N 8AA,UK

Guerreiro Marilisa M., Guimarães Catarina A., Gagliardi Isabella C., Souza Elisabete A.P. and  
Kátia M.R. Schmutzler Katia M.R. (2011). Quality of life and epilepsy  
surgery in childhood and adolescence

- Gus A. Baker. (2002). The psychological burden of epilepsy. University department of Neurosciences, Liverpool, UK.
- Hills MD. (2007). The psychological and social impacts of epilepsy. Department of psychology, University of Waikato, New Zealand.
- Kabir M (2005) Knowledge attitude and beliefs about epilepsy among adults in a northern Nigerian urban community. *Annals of African Medicine*.
- Kheng Seang Lim. (2011). Attitude towards epilepsy, a systematic overview. Division of Neurology, faculty of medicine, University of Malaya, Kuala Lumpur, Malaysia
- Kothari, C.R. (2004). *Research Methodology: Methods and Techniques*. New Delhi: New Age International (P) Limited, Publishers.
- Mbuba CK, Newton CR.(2009). Packages of Care for Epilepsy in Low and Middle-Income Countries. *PLoS Med* 6(10): e1000162. Doi: 10.1371/ journal.pmed.1000162
- Meinardi H. (2001). The treatment gap in epilepsy: the current situation and ways forward. Report of the ILAE commission on the developing world. *Epilepsia*, 42:136-149.
- Mula M and Sander JW. (2016). Psychosocial aspects of epilepsy: a wider approach. The royal College of psychiatrists, UK.
- Neuman, Lawrence.( 2006). *Social Research Methods: Qualitative and quantitative approaches*. Delhi, India: Pearson Education, Inc.
- Nicholas D. (2005). Knowledge and attitude of the Greek educational community toward epilepsy and the epileptic student. *Epilepsy behavior*.
- Nubukpo, P, Preux, P.M, Clement, J.P.etal (2003). Comparison of sociocultural attitudes towards epilepsy in Limousin(France), in Togo and in Benin(Africa) *Med Trop(Mars)*.
- Nunes MG, Geib L, and Apego G. (2011). Incidence of epilepsy and seizure disorders in childhood and association with social determinants: a birth cohort study.
- Sarason, I. G., Levine. (1983). Assessing social support: the social support questionnaire. *Journal of Personality and Social Psychology*, Vol.44.
- Schneider, J. W. and P. Conrad (1981). "Medical and sociological typologies: the case of

- epilepsy." *Social Science and Medicine*.15A: 211 -219.
- Scott RA, Lhatoo SD, and Sander JW. (2001). The treatment of epilepsy in developing countries: Where we go from here? *Bulletin of the WHO*, 79:344-351.
- Shibru Birhanu and Prevett M. (2004).Treatment of epilepsy in rural Ethiopia; two years follow up. Department of internal medicine, Gonder College of medical sciences.
- Shibru Berhanu, Shitaye Alemu, Jilalu Asmera and Martin Prevett,(2002). Primary care treatment of epilepsy in rural Ethiopia; Gonder, college of medicine science. Ethiopian Journal of health, Dev. 2002:16(3); 235-240
- Tai Sharon. (2011). Social and Psychological Issues in Patients with Epilepsy, Novel Aspects on Epilepsy, Prof. Humberto Foyaca-Sibat (Ed.), ISBN: 978-953-307-678-2, InTech, Available from: <http://www.intechopen.com/books/novel-aspects-on-epilepsy/social>
- Teshoma Sh, Atalay A, Redda T/H, Girmay M, and Jacobsson L.(2006). Perceptions of stigma in people with epilepsy and their relatives in Butajira, Ethiopia.
- Thomas Sv. And Nair A. (2011). Confronting the stigma of epilepsy. *Official journal of Indian academy of Neurology*. Vol. 14 (13): (pp. 158-163).
- Vanderstroep, Scott, and Johnston, Dreidre. (2009). *Research methods for everyday life: blending qualitative and quantitative approaches*. San Francisco: Jossey Bass.
- World Health Organization (WHO). (2005). *Atlas: epilepsy care in the world*. Geneva: WHO.
- World Health Organization (WHO). (2004). *Epilepsy in the WHO African region: Bridging the Gap: The Global Campaign against Epilepsy: "Out of the Shadows"*
- Yin, R. (1994).*Case study research: design and methods*. (2nd edition). Thousand Oaks, CA: Sag

Zarihun Doda. (2009). Participatory child protection concerns assessment. Learning for action consult: Mizan-Bachuma-Jemmu epileptic children study. Commissioned by agency of labour and social affairs, SNNP and UNICEF, Hawassa University, Ethiopia.

**Addis Ababa University**  
**College of Social Science**  
**Department of Sociology**

**Title of the study: Socio-economic and health situations of PWE and the attitude of the surrounding community towards epilepsy in Mizan-Teferi town**

Dear respondent, I am Tadele Workineh, MA student in the field of Sociology at Addis Ababa University. Currently, I am conducting my MA thesis entitled as “*Socio-economic and health situation of epileptics and the attitude of the surrounding community towards epilepsy in Mizan-Teferi town*” for the partial fulfillment of MA degree in sociology. Therefore, you are one, from among the different respondents selected to provide necessary information about knowledge and attitude towards epilepsy. In such away, this study will help to provide an empirical data on the knowledge and attitude of the surrounding community about epilepsy. Participation in this survey is voluntary and the responses you give will be extremely confidential. For the results of the research project are dependent on your genuine answers, I kindly request you to carefully respond to all questions.

**I thank you in advance for your cooperation!**

**Addis Ababa University**  
**College of Social Science**  
**Department of Sociology**

**Appendix I: Questionnaire for head of households**

**Introductory remarks**

Dear respondent, this questionnaire is designed to collect information for the study titled as *Socio-economic and health impacts of epilepsy and the knowledge and attitude of the surrounding community towards epilepsy in Mizan-Teferi town*. The purpose of this study is to collect information on the socio-economic and health situation of PWE, and knowledge and attitude of the surrounding community towards epileptic patients in Mizan-Teferi town. Accordingly, this questionnaire paper has four sections: **section I** comprises questions related to household's demographic and socio-economic profile, **section II** deals with household's head knowledge about epilepsy, **section III** comprises questions related to the view of household head towards PWE and finally, **section IV** deals with the attitude of house hold heads towards PWE. For the results of the research project are dependent on your genuine answers, I kindly request you to respond to all the questions. I thank you in advance for your cooperation!

**Certification and identification**

Interviewer's Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date Western (D-M-Y): \_\_\_\_\_

Field Supervisor's Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Respondent's *Kebele* \_\_\_\_\_

Questionnaire ID Number \_\_\_\_\_

## Part I. Survey Questionnaire for head of households

**Direction for enumerators:** *Please, encircle the number which holds the correct response of respondent for the following questions, or write the answer in the space provided if it is 'other'.*

### **Section one: Households' Demographic and Socio-economic Profile**

1. Sex of the respondent

1. Male                      2. Female

2. Age of the respondent: \_\_\_\_\_

3. Educational status of the respondent: 1). Illiterate

2). Can read and write

3). Primary School completed

4). Secondary school

5). College diploma and above

4. Thetype of religion the respondent follows:

1. Orthodox Christianity      2. Protestantism      3. Islam

4. Traditional religion      5. Other \_\_\_\_\_

5. Current occupation of the respondent:

1. Merchant      2. Daily laborer      3. Government employee      4. NGO Worker

5. Unemployed      6. Others \_\_\_\_\_

6. Ethnic background: 1. Bench      2. Kaffa      3. Menit 4. Amhara

5. Others: \_\_\_\_\_

7. Marital status: 1). Married 3). Divorced  
2). Never married 4). Separated 5). Widow
8. Family size: \_\_\_\_\_

9. What are your main sources of income? (You can have more than one answer for this question)
- 1). Salary 3). Agriculture 5). Pension  
2). Trade 4). Remittance 6). Others \_\_\_\_\_

11. How much is your total annual income from all sources in the year 2008 E.C (in Ethiopian birr)? \_\_\_\_\_

### **Section two: Questions related to the knowledge of epilepsy**

Under this sub-section, items are designed to know the attitude and knowledge of non-epileptic people from the study area about epilepsy. Accordingly, questions related to what epilepsy is, what causes epilepsy, whether epilepsy is a contagious disease and also whether epilepsy is a treatable disease are included. Finally, questions related to some of the healing options which have been practiced by epileptics are involved.

12. Have you ever heard or read about epilepsy?
- 1). Yes 2). No

- 12.1. If “Yes” what were the sources of your information about epilepsy? (You can have more than one answer)

- 1). Family and friends 3). Media  
2). Religious teachings 4). Health workers  
5). Others: \_\_\_\_\_

13. What do you think is the cause of epilepsy?

1. God’s curse  
2. Devil spirit  
3. Brain damage  
4. I don’t know  
5. Others \_\_\_\_\_



1). Yes

2) No

18.1 If “No”, what are your reasons?

---

---

---

19. Do you think epileptics could be employed like non-epileptic people?

1). Yes

2). No

19.1 If “No” what are your reasons?

---

---

---

20. How would you react if you learned that someone you know has epilepsy?

1). I would continue to treat him as before

2). I would feel a little awkward and afraid and I would rather avoid him

3). I would feel very awkward and afraid and I would stop contacting him

4). I do not know

21. Would you become a close friend with an epileptic person?

1). Yes

2). No

21.1 If “No” what are your reasons?

---

---

---

22. Do you think epileptic children should learn at one school with other non-epileptic children?

1). Yes

B). No

22.1 If “No” what are your reasons?

---

---

---

23. Will you marry an epileptic?

1). Yes

2). No

23.1 If “No”, what are your reasons?

---

---

---

24. Would you let your son/daughter marry with an epileptic?

1). Yes

2). No

24.1 If “No”, what are your reasons?

---

---

---

25. Do you think epileptic people can marry and bear children?

1). Yes

2). No

25.1 If “No”, what are your reasons?

---

---

---

26. Would you hire an epileptic person to your own business, provided that she/he has the skill or qualification for it?

1). Yes

2). No

26.1. If “No”, what are your reasons?

---

---

---

27. Do you think epileptic persons can equally compete and find a job like any other non-epileptic persons?

1). Yes

2). No

27.1. If “**No**”, what are your reasons?

---

---

---

28. Do you think epileptic people should participate at religious place together with other non-epileptic persons?

1). Yes

2). No

28.1. If “**No**”, what are your reasons?

---

---

---

29. Assume that, if you got epileptic, would you easily talk about it with other people?

1). Yes

2).No

29.1 If “**No**”, what are your reasons?

---

---

---

30. What do you think that epileptic people should do to recover from their illness?

---

---

---

**Section four: Household head's attitude towards epileptic people**

This part of the questionnaire is prepared to know the attitude of non-epileptic respondents regarding epilepsy and epileptic people. To this end, respondents are expected to state their level of agreement or disagreement to each item presented as follows.

<b>(INSTRUCTION: Circle for each item the answer that most closely expresses the respondent's attitude towards epilepsy)</b>				
1. I know epilepsy as a contagious disease.				
1	2	3	4	5
Strongly agree	Agree	I don't know	Disagree	Strongly disagree
2. Epilepsy is a frightening condition.				
1	2	3	4	5
Strongly agree	Agree	I don't know	Disagree	Strongly disagree
3. I think touching the saliva of epileptics during active seizure can expose to epilepsy.				
1	2	3	4	5
Strongly agree	Agree	I don't know	Disagree	Strongly disagree
4. I regard PWE as different from others so that they have to live separately from other family members.				
1	2	3	4	5
Strongly agree	Agree	I don't know	Disagree	Strongly disagree
5. PWE should learn in different schools from non-epileptic people.				
1	2	3	4	5
Strongly agree	Agree	I don't know	Disagree	Strongly disagree
6. I do not give help for epileptic people during seizure because I fear it will be transmitted to me.				
1	2	3	4	5



**Addis Ababa University**  
**College of Social Science**  
**Department of Sociology**

**Appendix II: Key informant interview Guide for Key Informants**

This Key Informant Interview Guide is prepared for the purpose of collecting information on the study titled *socio-economic and health situation of PWE and attitude of the surrounding community towards epilepsy in Mizan-Teferi town*. The main objective of the study is to investigate the socio-economic and health situations of PWE and attitude of the surrounding community towards epilepsy. The information you provide will be used only for research purpose and you are guaranteed that the researcher has no any other hidden agenda. Accordingly, Key Informants are cordially requested to freely respond to the questions presented by the interviewer. I would like to thank you in advance for your cooperation and patience in the interview session since your participation is invaluable to the success of this study.

**I. Key informant interview guideline for the sampled community elders**

1. Sex: \_\_\_\_\_
2. Age: \_\_\_\_\_
3. Educational background: \_\_\_\_\_
4. Occupation: \_\_\_\_\_
5. Religious background: \_\_\_\_\_
6. What is epilepsy and how it can be caused?
7. Is epilepsy a transmittable disease?
8. Is epilepsy a treatable condition? If not, why?
9. Can you touch epileptic persons during active seizure?
8. Do you think epileptics can live together with non-epileptic people?

9. The social impacts of epilepsy on epileptic patients
10. The health impacts of epilepsy on epileptic patients
11. The economic impacts of epilepsy on epileptic patients
12. Access of PWE to health care services including modern and alternative medicines
13. The stigma and discrimination facing epileptic patients
14. What should epileptic persons do to recover from their illness?
15. How could you explain the social interactions of PWE and non-epileptic people?
16. How it is possible to improve the socio-economic situations of epileptic people?
17. How do you explain the participation of epileptic people participate in different form of social gathering like *Idir* and *Ekubin* your town?
18. Do you think epileptic children can learn at same school with non-epileptic children? If No, why?

## **II.Key informant interview guidelines for health professionals**

1. Sex: \_\_\_\_\_
2. Age: \_\_\_\_\_
3. Educational background: \_\_\_\_\_
3. Role in the institution: \_\_\_\_\_
4. Religious background: \_\_\_\_\_
5. What is epilepsy?
6. What is the cause of epilepsy?
7. Is epilepsy a treatable disease?
8. What are the forms of treatment of epilepsy?

9. Is epilepsy a contagious disease?
10. What should be done as a first aid during active seizure?
11. What are the major health impacts of epilepsy?
12. How do you explain the access of PWE to health care services including modern and traditional medicines?
13. What are the major socio-economic impacts of epilepsy on epileptics?
14. What should have epileptic persons do to recover from their illness?
15. How do you explain the treatment gap in epilepsy?
17. What do you think should be done to improve the attitude of non-epileptic people towards PWE?
18. How do you explain the sanitation issue in epileptic camps?
19. What hinders epileptics from accessing to health care services?

### **III. Key informant interview guidelines for religious leaders?**

1. Sex: \_\_\_\_\_
2. Age: \_\_\_\_\_
3. Religious type: \_\_\_\_\_
4. Educational background: \_\_\_\_\_
5. Role/position in the church/ mosque: \_\_\_\_\_
6. What is your understanding of epilepsy?
7. How epilepsy can be explained from your religious point of view?
8. What causes epilepsy?

9. What should PWE do to recover from their epileptic situation?
10. Can epileptic people be allowed to attend one church/mosque with non-epileptic people? If not, why?
11. Can epilepsy be treated by modern health services? If not, why?
12. Is epilepsy a treatable disease? If yes how?
13. Is epilepsy a contagious disease? If yes how?
14. Can epileptic children share similar school with their non-epileptic counterparts? If not, why?
15. Can PWE marry with non-epileptic persons? If not, why?
16. Can epileptic people be hired to some formal organizations?
17. What are the major socio-economic consequences of epilepsy?
18. What do you think is the role of your church/mosque, to improve the socio-economic and health situation of PWE?

**Addis Ababa University**  
**College of Social Science**  
**Department of Sociology**

**Appendix III: In-depth interview guidelines for PWE**

This in-depth interview Guide is prepared for the purpose of eliciting information on the study titled *socio-economic and health situation of PWE and attitude of the surrounding community towards epilepsy in Mizan-Teferi town*. The main objective of the study is to investigate the socio-economic and health situations of PWE and attitude of the surrounding community towards epilepsy. The information you provide will be used only for research purpose and you are guaranteed that the researcher has no any other hidden agenda. Accordingly, Informants (sampled epileptics) are cordially requested to freely respond to the questions presented by the interviewer. I would like to thank you in advance for your cooperation and patience in the interview session since your participation is invaluable to the success of this study.

1. Sex \_\_\_\_\_
2. Age \_\_\_\_\_
3. Level of education \_\_\_\_\_
4. Religion \_\_\_\_\_
5. Ethnic background: \_\_\_\_\_
6. Marriage status:
7. Number of children: \_\_\_\_\_
8. Currently, with whom are you living?
9. For how long since you become epileptic?
10. How you disclose your epileptic situation for the first time you face seizure?
11. What happen to your relation with your family after you become epileptic?
12. How is your job situation after you got epileptic
13. What do you think is the cause of epilepsy?
14. How do you explain about your living conditions with regard to food, shelter, clothes, education and health care services,

15. What healing measurement you have took so far?
16. Have you ever got any advices from health professionals about your epileptic situation? If no, why?
17. Have you ever used modern antiepileptic drug?
18. Do you think epilepsy is a contagious disease?
19. Which are your major sources of income?
20. Do you have Idir/Equb? If no, why?
21. Are you participating in any form of social gathering like mourning and wedding with the non-epileptic people around you? If no, why?
22. Could you marry with non-epileptic person? If no, why?
23. Do you think you are capable to be hired and work like non-epileptic people?
24. What are the physical health impacts of epilepsy during seizure?
25. Do you think epilepsy could be treated by modern antiepileptic drugs? If no, why?

### **Epilepsy related stigma**

1. Would you easily disclose your epileptic status to your friends? If not, why?
2. Do you think you have somebody to help you during seizure?
3. Do you think you can marry with non-epileptic person? If no, why?
4. Do you think you can participate in any social gathering in your community? If no, why?
5. Do you believe that you can be hired and work in any institution like non-epileptic people? If no, why?
6. Do you think you are worth living for your family and community? If no, why?
7. Do you think epileptic children can learn at same school together with non-epileptic children?
8. In case, if you need a help during active seizure, do you think you can easily find someone to help you? If no, why?

### **Access to basic services**

1. Educational opportunity and school environment
2. Access to balanced food, shelter and clothes
3. Medical services
4. Availability of burial sites for the dyed epileptics

5. Availability of sources of medical information
6. Ability to afford for modern antiepileptic drugs
7. Availability of toilet
8. Job opportunity (opportunity to get job and be hired)
9. Access to clean water
10. Access to burial site

### **Physical safety and wellbeing**

1. Living environment (hot, cold, rain)
2. Physical hurt
3. Getting banished forcibly
4. Injuries and wound during seizure

### **Gender based violence**

1. Rape
2. Fighting and physical violence
3. Sexual violence

