

Jimma University  
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Department of Sociology  
MA program in Sociology (Social policy concentration)

COMMUNITY'S BELIEFS TOWARDS EPILEPSY AND THE SOCIO  
CULTURAL CHALLENGES OF THE EPILEPTICS: THE CASE OF  
ME'INT GOLDIYA WOREDA, BENCH MAJI ZONE SNNPR, ETHIOPIA.

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A thesis submitted to Jimma University, department of Sociology, in partial  
fulfillment of the requirements for the degree of Master of Arts in Sociology  
(Specialization in Social policy)

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**Declaration**

I, Asaye Tirfu Wolde, hereby declare that the thesis entitled: “*Community’s beliefs towards epilepsy and the socio cultural challenges of the epileptics: A study in Me’int Goldiya Woreda of Bench Maji zone, SNNP’ Region*”, submitted by me to award of the Degree of Master of Arts in Sociology at Jimma 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.

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**Certification**

This is to certify that this thesis entitled: “*Community’s beliefs towards epilepsy and the socio cultural challenges of the epileptics: A study in Me’int Goldiya Woreda of Bench Maji zone, SNNP’ Region*”, prepared by Asaye Tirfu Wolde 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**

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## Abstract

*Epilepsy is the most common chronic neurological disorder affecting peoples across the globe. The disease remains one of the public health problems, with its devastating social, cultural, psychological and economic burdens on substantial number of people affected by epilepsy. Thus, the study was conducted with the aim of examining communities' beliefs towards epilepsy and the socio- cultural challenges of PWE in Me'int Goldiya Woreda of Benchi Maji Zone, SNNP's region, Ethiopia.*

*The study based on the constructivist paradigm, employed a phenomenological strategy to understand community's beliefs towards epilepsy and PWE experiences of the phenomena. Data was collected via focus groups, interviews, and observations. Field notes were also collected during each interview. Data collected from each interview together with the researcher's field notes were compared to identify themes.*

*As the study findings indicate, Meint community attributed various reasons for etiological causes of epilepsy. Epilepsy as contagious, trans-generational, curse from God or evil spirit, asset transference (inheritance), magic and low obedience to traditional beliefs culturally known as Qolle defined as an indigenous traditional belief of the community whereby the followers worship their traditional 'God' maintaining different practices and making scarifies was considered as etiological factors for epilepsy. Moreover, inheritability/transferability of the property of passed away epileptic patient to other family members is prohibited by community since it is considered as passing the curse of the dead to other family members. Consequently, assets/ properties/ produced by passed away epileptic patients is immediately burnt according to their social norm. Further, non-epileptic community's views towards people with epilepsy tended to be more negative in the study area. PWE were seen as physically weaker and less competent persons because of their tendency to seizures. In similar manner, non-epileptic community occasionally discriminate epileptic victims for their poor sanitations and feeding habit. Even though, there is an inadequate health facility in the study area, the trend of communities in seeking modern medical care is poor. Rather than modern medicine, epileptic patients prefer traditional medicine for their sickness. Thus, firing matches and spiritual healing was the most preferred method of treatment for epilepsy since they believe that the disorder was a result of affliction by evil spirits*

*In conclusion, as a result of wrong belief and miss information on etiological causes as well as community's negative view towards epileptic victims, the patients suffered from limitations in social interaction as well as faced social discrimination that made the lives more difficult.*

*Based on study findings, the belief of the community towards epilepsy as well as the problems related with the people living with epilepsy in the target area have multifaceted, so that the researcher recommends the need of concerted efforts of concerned body is crucial to combat the problem.*

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## **Abbreviations and Acronyms**

**ADA** - Americans with Disabilities Act

**BMDA**-Bench Maji Development Association

**CSA**- Central Statistics Authority

**FGD**- Focus Group Discussion

**NGO**- Non Governmental Organization

**PWE**- People with Epilepsy

**SNNPR**- South Nations Nationalities Peoples Region

**TOT**– Training of trainees

**WHO**- World Health Organization

**HBM**- Health Belief Model

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## Chapter One: Introduction

### Back ground of the Study

Epilepsy is a neurological disorder that affects large numbers of peoples around the world (Ngugi et al., 2010). Approximately 50 million people around the world have epilepsy which represents 0.5% of the global burden of disease, and 80% of that burden corresponds to developing countries (Herrmann et al., 2016). The disease has detrimental effects on social, cognitive, psychological, and physical components of life, and consequently on the quality of life of the patients (Gebre and Haylay, 2018).

Rates of incidence, prevalence, and mortality due to epilepsy are not uniform worldwide and depend on several factors (Burneo et al., 2005). Studies indicate that the annual incidence in developed countries is approximately 50 per 100,000 population, while in developing countries this figure is nearly double close to 100 per 100,000 (Heaney et al., 2008). Mortality rate is higher in people with epilepsy than in the general population (Dua et al., 2006). According to Bahia et al. (2013), in worldwide, estimated annual mortality rates range from 1 to 8 per 100,000 population.

Studies examining social attitudes towards epilepsy globally uncovered generalizations and describes peoples' beliefs towards epilepsy and argue that individual become epileptic as the patient did profane before and as a result of this, the epileptic patients have been punished by God for their sinning (Andermann, 2000). Moreover, as result of misinformation about the etiological causes, PWP becomes stigmatized and discriminated by non – epileptic members of the community. For instance, as Gagliardi et al. (2011) discussed, that people found to perceive epilepsy as more stigmatizing 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.

In African continent, epilepsy affects about ten million people of all ages but, especially affects children, adolescents and the ageing population (Shehata, 2016). When we see the trends in sub-Saharan African, active epilepsy was estimated to affect four million people and its prevalence is high among adults and children (Beghi et al., 2019). In spite of global

advances in diagnosis and treatment in recent years, about eight million people with epilepsy in Africa including countries located in sub-Saharan Africa, PWE are not treated with modern antiepileptic drugs due to inability to afford cash, lack of awareness about epilepsy to be a treatable disease, inaccessibility of modern health care centers, and so forth(Chita and Mwale, 2017)

Moreover, the issue of epilepsy becomes a contemporary debate in the world in relation to legislations of people's perceptions and wrong beliefs toward epilepsy. For instance, the legalization of epilepsy in America to ADA federal rehabilitation act becomes debatable issue among earlier Supreme Court ruler sand recent Supreme Court rulers. The federal rehabilitation act of America in 1973, recognized people with seizure disorders as disabled under the law on the basis of the stigma associated with seizure disorders and the varied nature of seizures. However, recent Supreme Court rulings suggest that a person with controlled seizures may not be considered disabled, even if epilepsy-associated stigma limits his or her employment opportunities (Morrell, 2002).

Beside this, there is debate between various epilepsy academicians concerning on the causes for epilepsy. Some epilepsy academicians explain the causal factor of the disease is unknown and other epilepsy academicians enlighten epilepsy causal factor in relation to an underlying genetic problem , brain damage caused by prenatal or prenatal injuries (for example, lack of oxygen or injury during childbirth), birth defects , cerebral malformations, head trauma, stroke and neural infections such as meningitis and encephalitis(Brady et al., 2015)

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 recently. However, studies conducted by Fanta et al. (2015) in Ethiopia, indicates 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. Likewise, public understanding towards epilepsy was so limited in Ethiopia and the victims were facing problems related to health, economic and other social services (Workineh, 2017).

Thus, this study was conducted with the aims of investigating the community beliefs towards epilepsy and the concomitant socio-cultural challenges of epilepsy victims in Me'int woreda of Bench Maji Zone, SNNPR.

### **Statement of the Problem**

Epilepsy is one of chronic disease and subsets of global burden of diseases, because it creates many problems such as physical hazards resulting from the unpredictability of seizures, social exclusion as a result of negative attitudes of others toward people with epilepsy and the stigma, as children with epilepsy may be banned from school, adults may be barred from marriage, and employment is often denied, even when seizures would not render the work unsuitable or unsafe (Beghi et al., 2019)

Globally, many researches have been conducted on the issue of epilepsy. However, majority of researches so far conducted were more inclined to health aspect. For instance, Duko et al. (2020), research work on the epidemiology of headaches among patients with epilepsy and Tomlinson et al. (2019), works on epilepsy surgery etc. can be mentioned as an example. However, research investigations conducted at global, regional and national level on social aspect were less in number compared to research undertaken on epilepsy vis-à-vis health aspect. Besides, most of these studies were confined to institutional settings. For instance, research conducted by Tiki et al. (2018), focuses on assessment of the prevalence factors associated to perceived stigma among epileptic patients who follow-up at hospitals, and Bifftu et al. (2015), perceived stigma and associated factors among people with epilepsy in public institution and Engebretson (2013), study concentrated on understanding of stigma in chronic health conditions in nursing school which was confined at institutional level.

The same is true in Ethiopia that, studies conducted on epilepsy to date prioritizes the medical and public health aspects and the settings of their study were institutional based. For instance: Abadiga et al. (2019), focuses on health related quality of life and associated factors among epileptic patients treated in hospital, Wubie et al. (2019), their study focuses on common mental disorders and its determinants among epileptic patients at an outpatient epileptic clinic, Gidey et al. (2019), their study emphasizes on treatment response and predictors in patients with newly diagnosed epilepsy in Ethiopia and Mamo et al. (2019), their study focuses on non-communicable disease in clinics of rural Ethiopia. More over the

studies conducted on epilepsy with regard to social dimension in Ethiopia were less in number compared to health aspect and their study is bounded at institutional level. For instance studies conducted on Knowledge, attitudes and practices with respect to epilepsy by Fekadu et al. (2019) and Gedefa et al. (2012), can be mentioned as an example from very recent studies conducted in Ethiopia.

Among research conducted on epilepsy vis-à-vis social aspect, we can mention the study of Workineh (2017), inquiry accompanied community based socio-economic and health situations of epileptics in Mizan- Teferi town of Bench Maji Zone, SNNPR. According to Workineh (2017), his study informants were those epileptic victims who migrated from Me'int Goldiya Woreda to Mizan- Teferi town of Bench Maji Zone. However, the current study attempts to address the research objective of the study on the original place i.e. Me'int Goldiya woreda where Me'int communities as well as epileptic victims reside.

In General, the current study attempted to address the gaps of the research mentioned above through utilizing community based research via phenomenological design to meet the objective of the inquiry in study area.

### **General and specific objectives of the study**

#### **General objective**

The overall objective of the study is to explore the belief of the community towards epilepsy and socio cultural challenges of peoples with epilepsy in Me'int Goldiya Woreda, Bench Maji Zone, Southern Nation and Nationalities Region of Ethiopia.

Therefore, the study was conducted to reveal and answer the following research questions.

1. What are the etiological beliefs of epileptically affected people and non affected community members towards epilepsy?
2. How do non- epileptically affected communities members feel towards epileptic patients in the study area?
3. What are the prevailing socio-cultural practices and challenges of people affected with epileptic in the study area?

4. What were the roles and interventions played by government and other like-minded organizations in relation to mitigate the impact of epilepsy in the study area so far?

### **Specific objectives**

The specific objectives of study are:

- To explore the etiological beliefs of epileptically affected people and non affected community members towards epilepsy in the study area.
- To explore the belief of epileptically non- affected community members towards epileptic patients in the study area.
- To explore the prevailing socio-cultural practices and challenges towards people affected with epilepsy in the study area.
- To assess the interventions done to mitigate the impact of epilepsy in the study area.

### **Significance of the study**

A study on community beliefs towards epilepsy and the socio cultural challenges of epileptics was important in terms of exposing the challenges as well as the psycho social vulnerabilities of people affected with epilepsy in Me'int Goldiya woreda for an appropriate intervention like creating awareness for the surrounding community about this disease and rehabilitating the victims. Further, the findings of this investigation can serve as a stepping stone for any further studies by interested researchers. Moreover, the findings of this study can attract a policy formulation to have adequate health policy which can solve the socio-cultural problems faced by epileptic people.

### **Scope of the study**

This study was confined and investigated the community beliefs towards epilepsy and the socio cultural challenges of epileptics in Me'int Goldiya Woreda. In this manner, the study was devoted to investigate and describe the objective of the research in hand with delimiting the scope of the study within two study sites. I.e. Me'int communities and epileptic patients reside in Chat Kebele and Bachuma.

### **Limitations of the study**

The researcher has encountered different challenges because of the emergence of COVID 19, pandemic at the global level that retards data collection process on time at study area. However, by using preventing mechanism of the pandemic the researcher completes the needed information from research participants. Besides, with regard to the limitations of this study, the study was only confined to only two Kebeles which may not fully represent the study area due to resource constraints.

### **Organizations of the paper**

Contents of this thesis are organized into five main chapters. The first chapter consists of the introduction, statement of the problem, objective of the study, scope, and significance of the study, limitation of the study and operational definition. The second chapters dealt with the review of related literature. The third chapter deals with the research methods that discuss the research design, the sampling technique, and the data collection and analysis as well as ethical considerations and chapter four deals with results of the findings and discussions. Finally, the last chapter presents conclusions and recommendations

## **Chapter Two: Review of Literature**

### **2.1. Introduction**

This chapter deals with review of literature related to meaning of epilepsy with its cause, trends of epilepsy in different countries, health and economic impacts of epilepsy on victims and other related issues was reviewed and assessed from different empirical studies so far conducted on the issue at hand. In addition to this, theoretical frameworks consistent with current study was employed and included in this chapter.

### **2.2. Historical and recent description of epilepsy**

#### **2.2.1. Historical description of epilepsy**

The earliest detailed account of epilepsy is mostly verified by ancient Babylonian text on medicine, which was written over 3000 years ago, i.e. before 1000 BC. The Babylonians had no concept of pathology. However, they associate each seizure type with invasion of the body by a particular named evil spirit. Thus treatment was not medical but spiritual (Reynolds, 2005). This supernatural view has dominated thinking about epilepsy until quite recently and even now remains a deeply rooted negative social influence in some parts of the world. Moreover, 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 ” .on the other hand in ancient and post ancient world of Christianity religion followers epilepsy was explained based on the Gospel of Mark (9:14-29) as “epileptics demoniacs and cause by unclean and deaf sprit”.

It was, however, in 5th-century BC, the School of Hippocrates challenged the dominant view of thinking on epilepsy as supernatural. He suggested for the first time in history that the brain was the seat of this disorder, as it was the mediator of the intellect, behavior and the emotions. So he clearly associates the causes of epilepsy with brain disorder. In a famous text Hippocrates stated: “I do not believe that the sacred disease is any more divine than any other disease but, on the contrary, has specific characteristics and a definite cause.



Interestingly, Hippocrates also had some notion that epilepsy could become chronic and intractable if not treated early and effectively, although it is not clear exactly what treatments he had in mind: Unfortunately the Hippocratic concept of a treatable brain disorder had little influence on the prevailing supernatural view, as is well described in the scholarly history of epilepsy from the Greeks to the late 19th century by (Temkin, 1994)

In this manner, despite scientific advances in the 19th century, 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).

### **2.2.2. Recent description and causes of epilepsy**

The reference definition for epilepsy was based on the International League Against Epilepsy (ILAE) Guidelines for Epidemiologic Studies on Epilepsy Thurman et al. (2011), defined an epilepsy case as someone with an active, recurrent condition of epileptic seizures (two or more) unprovoked by an immediate cause and who has had at least one epileptic seizure in the past 5 years regardless of antiepileptic drug treatment.

Epilepsy is a chronic disease of the CNS that affects individuals of all ages and the cause of the disease is still unknown in about 50% of global cases (Fiest et al., 2017). However, In some cases, there is an underlying genetic cause, but other frequent causes of epilepsy include brain damage caused by prenatal or perinatal injuries (for example, lack of oxygen or injury during childbirth), birth defects or cerebral malformations, head trauma, stroke, neural infections such as meningitis, encephalitis, and brain tumors (Brady et al., 2015). Moreover, the diagnosis of epileptic seizures and epilepsy and ascertainment of the cause are difficult tasks, especially in low-income countries where socioeconomic and cultural constraints are obstacles to the recognition and acceptance of the disease (Newton and Garcia, 2012).

### **2.3. Global trend of epilepsy**

Epilepsy is a very common neurological disorder that exists in a place where human population is found and it affects people of all ages, nations and races all over the world (Reynolds, 2000). Here below, the trend of epilepsy in selected countries such as countries like United States of America, Europe, Asia, Africa and in Ethiopia.

### **2.3.1. Epilepsy in America**

United States of America is one of the Nations that affected by Epilepsy and the disease is found to be the nation's fourth most common neurological disorder, after migraine, stroke, and Alzheimer's disease (Rolston et al., 2016). Approximately 1 in 26 people will develop epilepsy at some point in their lives and an estimated 2.2 million people in the United States are living with epilepsy which is just more than a seizures (England et al., 2012). Yet living with epilepsy is about much more than just seizures. For PWE, the disorder is often defined in practical terms, such as challenges in school, uncertainties about social situations , employment, limitations on driving and questions about independent living(England et al., 2012).

### **2.3.2. Epilepsy in Europe**

According to Bruno et al. (2012), in Europe, at least 6 million people have epilepsy. Nevertheless, in some countries of Europe, epilepsy is not recognized as a brain disorder, and up to 40% of people with this condition may become untreated(Forsgren et al., 2005).The prevalence of epilepsy in Europe is 8.2 per 1000 people, thus around 6,000,000 people in Europe currently have epilepsy whilst 15,000,000 people will have had epilepsy at some time in their lives (Picot et al., 2008). A typical family physician in Europe will have 10-20 persons with epilepsy among his or her patients and will therefore not consider epilepsy a priority problem of health and doesn't keep track of the latest developments in the field of epileptology (Reynolds, 2000). This shows that, quite a lot people are suffering from epilepsy in Europe as people of different countries are experiencing the same problem being affected by the disease.

### **2.3.3. Epilepsy among Asian countries**

According to Lim and Tan (2014), in Asian countries, at least 10 million people have epilepsy and the prevalence of epilepsy in Asian countries is 9.2 per 1000 people. In these regions there is wide negative public attitude towards epilepsy by peoples and the peoples with epilepsy that suffers stigma and discrimination. As a witness, the study conducted by Lim and Tan (2014) on stigma and public attitudes towards epilepsy, shows around (56-57) % of public respondents in epilepsy survey objected their children to play with people who

sometimes had seizures, 86% thought that epilepsy patients cannot work as other people, and (71-86)% objected to their children marry a person who sometimes has seizures.

Moreover, when we look at experiences of various Asian countries we can see similarities in the people's perception about epilepsy Lim and Tan (2014), for example, in Malaysia, 20% of the children with epilepsy were not receiving any form of formal education although primary education is free. In India, 25% of women with epilepsy had problems getting married as compared with 1% in controls, and 70% concealed their epilepsy from husbands. The divorce rate among people with epilepsy in Korea is higher, 9% versus 0.7% in general population.

#### **2.3.4. Epilepsy in Africa**

Although Africa is a diverse continent and represents people of different cultural background, a widely held notion is that epilepsy may be caused by evil spirits. Other beliefs include witchcraft and contagious fears from bodily secretions (saliva, stool, or urine) that could potentially transmit seizures to bystanders (Keikelame, 2016). In the continent of Africa, peoples attach a huge social stigma to epilepsy. Prejudice against the disease is common and persons with epilepsy are usually stigmatized and even pronunciation of the word 'epilepsy' is a taboo (Chita and Mwale, 2017). Moreover, the traditional indigenous beliefs and traditional treatment of epilepsy in Africa contribute to the under-utilization of the medical health services, to discrimination and social isolation (Diop et al., 2003).

#### **2.3.5. Epilepsy in Ethiopia**

Like any other African countries, epilepsy is the most common cause of neurological disability in Ethiopia. It affects an estimated 5.2 per 1000 of the population, but only 2–13% of people with epilepsy living in rural areas receive medical treatment(Fanta et al., 2015). Moreover, based on the study of Worku (2013), the highest age specific prevalence of epilepsy was found for ages of 10-19 years.

Many of the epileptic persons especially those who live in rural areas do not get treatments. Causes of this 'treatment gap' include inaccessibility of medical services, unavailability of antiepileptic drugs, lack of awareness of medical treatment and cultural factors (Fanta et al., 2015).

Even though, World Health Organization attempts to advocates the use of primary health care in less developed countries to improve access to treatment of chronic diseases, such as epilepsy in Ethiopia, but still approximately estimated that around 360 to 400 thousand epileptic Ethiopians are living with poor medication (Worku, 2013). Generalized tonic-clinic seizures were the most common seizure type and occurred in 69 - 81%, Worku (2013) and during seizures; many patients sustain burn injury and trauma. A history of head trauma was ascertained in 5.7% and was the most common possible etiologic factor identified followed by meningitis. Mental retardation was the most common associated disorder, found in 7.9 - 21% of the persons with epilepsy and EEG was recorded in 50 - 73% of patients in the capital city, Addis Ababa (Worku, 2013). Traditional treatment with local herbs, holy water and amulets was the most common. Only 1.6% had been treated with recognized antiepileptic drugs in rural part of the country and as few as 13% were treated with antiepileptic drugs in cities like Addis Ababa (Ejigu et al., 2019).

#### **2.4. Public beliefs and attitudes towards epilepsy**

The extent of the negative attitudes and beliefs of the community towards epilepsy 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). These 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 of incorrect information and gap of knowledge by the community towards epilepsy, epileptic patients suffer from stigma and discrimination that challenges their wellbeing. Thus, incorrect information about the causes and miss understanding by peoples towards epilepsy as inheritable that increase the stigma and make the lives of PWE more difficult (Aydemir, 2011).

Many communities in Africa believe that epilepsy results from insanity, witchcraft or possession by evil spirit. As a result of this, 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 et al., 2003).

Thus, discrimination against epileptic patients could also be due to lack of knowledge and understanding about epilepsy (Shehata, 2016).

## **2.5. Impacts of epilepsy**

Epilepsy has many non-medical effects on the people with epilepsy, their family and community (Devinsky, 2001). Most of the time, people with epilepsy exposed to fears as a result of embarrassment by a seizure, causing hesitancy to engage in social interaction, with concomitantly low self-esteem and academic under-achievement. These can result in a shrunken support network, fewer friends, a lower likelihood of marriage and greater likelihood of anti-social behavior (Buchanan, 2002). However, to control fully the disease, it requires a specialist neurologist or pediatrician with up-to-date detailed knowledge to diagnose and prescribe treatment, a general practitioner to supervise day-to-day medical management and an epilepsy specialist community worker to provide psychosocial support, information and education to help maintain quality of life (McCagh et al., 2009). In nutshell, the diseases have a broad social, psychological, health and economic impacts on the epileptic victims. Some of the impacts of epilepsy are explained below

### **2.5.1. Social impact**

It became clearer that people with epilepsy are socially discriminated against on the ground of wide-spread lack of knowledge, negative public attitudes, and misconceptions about the disease. The study findings of (Ojinnaka, 2002) support this argument by examining Teachers' perception of epilepsy in Nigeria: a community-based study. He indicates that the attitude and knowledge of teachers on adulthood epilepsy is likely influence the educational performance of students with the disease and he concluded that The social problems met by students with epilepsy is very enormous as a result of negative attitudes and beliefs (Ojinnaka, 2002) . Moreover, People with epilepsy (PWE) devalued and stigmatized as a result of false historical background, uncorrected knowledge and attitude about epilepsy by community.

### **2.5.1.1. Impact on social relationships**

As studies indication, social isolation and poor social adaptation can result from perceived stigma or over-dependency caused by parental overprotection. The people with epilepsy also often fears embarrassment by a seizure, causing reluctance to engage in social interaction, with concomitantly low self-esteem and academic under-achievement. These can result in a shrunken support network, fewer friends, a lower likelihood of marriage and greater likelihood of anti-social behavior(Buchanan, 2002).

### **2.5.1.2. Impact on marriage**

Lower marriage rates for men and women with epilepsy are partially attributable to stigma of having epilepsy (Ellis et al., 2000). Also as Zahn report 51% of men with epilepsy were married, in contrast to 63% of men without epilepsy. Likewise, only 48% of women with epilepsy were married, compared with 59% of women without epilepsy. Further, limited social opportunities contribute to lower birth rates among men and women with epilepsy (Alderson, 1998). In addition, patients refused to marry their offspring from PWE(Ngugi et al., 2010).

### **2.5.1.3. Stigma and misconception**

Cross culturally the impact of stigma on PWE has caused them to be excluded from important social roles, under achieve in school, to find it more difficult to gain employment, have disordered intimate relationships to maintain family relations(Kaddumukasa et al., 2018). Misconception, myths and stereotypes are still prevalent in media portrayals of epilepsy despite advances in education. These misconceptions contribute to the psychosocial limitations and stigma experienced by PWE. Negative attitudes in society have created fear and stigma. The stigma of epilepsy can often be more debilitating for PWE than presenting symptoms. Subsequently, individuals with epilepsy conceal their condition are isolated within their family in an attempt to lessen the social stigma associated with the disorder and to increase marital prospects(Spatt et al., 2005).

On a similar fashion ,as depicted on the works of England et al. (2014),People living with epilepsy are stigmatized and socially excluded in many situations and as a result of this

stigmatization leads to discrimination, and furthermore, PWE experience prejudicial and discriminatory behavior in many spheres of life and across many cultures. Thus, both historically and cross-culturally, with only rare exceptions, epilepsy has been represented as a stigma and, for many people with epilepsy worldwide and it is the continuing social reality(England et al., 2012).

#### **2.5.1.4. Impact on the family**

Diagnosis of epilepsy in their child leads to stress in parents, resulting in a higher divorce rate. As illustrated by(Devinsky, 2001) focus by parents on the child with epilepsy can result in poor relationships between the child with epilepsy and siblings and psychological difficulties among siblings and such focus can also affect family cohesion and relations between the family and their community.

#### **2.5.2. Psychological impacts**

Psychological impacts of epilepsy are among the most common problems epileptic persons that they face in all over the world(de Boer, 2010) and accordingly, psychological effect of PWE suffers include fears , emotional disturbances, anxiety and depression, self-esteem and sense of mastery are among the many problems. As a result of this, most epileptic persons feel helpless and hope less and feel psychologically inferior to their fellow age mates. As explained byStretton et al. (2013), to be epileptic is to be stressed and stress can influence the incidence of fits. Under stress many people develop anxiety symptoms which may be seen as a fight or flight reaction, some become depressed, and others show obsessive ritualistic behavior. Beside the significance of the stress to the epileptic person, the reaction of individual depends on several factors. Firstly, the support which a person has from family and friends affects his ability to cope. Secondly, the genetic constitution of the individual and the responsiveness of his autonomic nervous system to stress may play an important part. Thirdly, stress responses are influenced by educational and cultural background. Finally, many patients are afraid of dying during an epileptic attack, or seriously hurting themselves. These are feelings that are difficult to cope with both for the patient and the relatives. Also the experience of losing control is difficult to handle, rendering feelings of helplessness and being “reigned over” by the epilepsy(Helmstaedter and Witt, 2012).

Public ignorance and fear of the unknown is another important source for the epileptic patients' to be in a position of fear of everything. This is because there are quite many incidences that the fear of having attacks, being at a disadvantage position in terms of work and personal relationships, which would expose the person for being open to prejudice. Thus, fear of social exposure of fits and feelings of disgrace often further lead to social isolation(Abimbola, 2010)

As stated by Nickels et al. (2016),having epilepsy may mean coping with additional hidden deficits such as language and memory problems, or with a dual diagnosis and learning disability being the most frequent co-morbidity. In relation to diagnosis and prognosis aside, individuals have to cope with ongoing seizures. For some, these may be rare, short-lived episodes, but for others, epileptic attacks may involve bizarre behaviors', distorted awareness and perception, and embarrassing aspects such as incontinence. The unpredictability of the majority of seizures is sufficient to erode self confidence and self-esteem, even when events are infrequent. Public misunderstandings and stigma cause additional stress. Individuals also have to adjust to long-term drug treatment and accompanying side effects which may include weight gain, acne, unwanted facial hair, irritability and cognitive disturbances. These aspects may become more stressful at certain times of development, with adolescence being a vulnerable period. Many with poorly controlled seizures have to endure successive treatment failures and the accompanying emotional highs and lows as hopes are raised with the introduction of a new drug only to be dashed when seizures return(Nubukpo et al., 2003).

Both anxiety and depression are common co morbid features in PWE yet psychopathology is undertreated and under diagnosed. According to Hansen and Amiri (2015),40-60 % of PWE display symptoms of depression and more than 40% present with anxiety . Depression is 4 to 5 times more likely in PWE than in the general population and anxiety is the most common form of psychopathology reported. Moreover, Increased feelings of anxiety and depression can be further compounded by reduced social opportunities, lack of social support, poor self-esteem, a reduced sense of Self-esteem and sense of mastery that have been inversely related to higher scores on measures of depression and anxiety in PWE(McCagh et al., 2009).



Unpredictability is central problem to individuals living with epilepsy, since individuals may not know when a seizure will occur and often have difficulty accepting of their living with an epilepsy (Chew et al., 2018). This can cause PWE to feel that they lack control over their life, lower mood and heighten feelings of anxiety. This has been reflected in research where PWE demonstrate a lower sense of mastery in relation to healthy controls. Seizure severity and frequency have been shown to be the most influential factors in determining self-esteem and sense of mastery in PWE(Shih et al., 2017). Besides, knowledge has been found to mediate the impact on self-esteem. As explained by Shih et al. (2017), adolescents with more awareness of their condition report higher levels of self-esteem and thus, educational interventions aimed at increasing knowledge have been successful at enhancing self-esteem in PWE .

As described above, epilepsy has an effect on the victims life to get employment and lead their self-supporting life because of the perception of the people around them , that resulted the patients to live in a sever poverty situation(Ak et al., 2015). Existing evidences suggest that people with epilepsy are experiencing high levels of unemployment and underemployment(Baker, 2014). Employment problems are not simply due to seizures; rather they may be results of personal and social factors, including discrimination, stigma, passive coping styles and low self-efficacy interacting with one another in a complex manner(Ak et al., 2015).

To substantiate this with examples, experiences of few countries are presented here; the employment rate in Norway was 21 per cent below the general population. Unemployment is higher among people with epilepsy, and up to 50% of unemployment occurred in developed countries. Unemployment is happening in developing countries particularly if seizures are not fully controlled and thus unemployment rate will be go up to 100%. This can be caused by employer prejudice resulting from stigma and lack of information, a belief that machinery should be avoided by the people with epilepsy, inability to drive, or poorer academic achievement. Disclosure to an employer is therefore a difficult decision. Unemployment commonly results in a lower self-esteem, lessened well-being and a lower quality of life(Jacoby et al., 2005a).

Similar to the above description of people living with epilepsy and their linkage with work, it has many functions aside from the financial rewards. According to Schachter (2009), employed people with epilepsy experience fewer psychosocial problems than unemployed people with epilepsy. In general people with disabilities are vulnerable to employment difficulties and leading their independent life particularly at times of economic recession. In most cases people living with epilepsy are not getting employment opportunities at different places and companies. This is the major problem associated with their employability and earning income to support their lively hood. Various reasons are given by employers not to have them as an employee in their companies or organizations. Among the reasons which explained by Schachter (2009), are given in the following manner, these are: concerns about their safety if they got seizure at work, worry about the company's liability, belief that they have psychological problems or trouble thinking, fear that a seizure will scare off customers, having epilepsy is expensive, antiepileptic can be expensive, injuries can be costly to treat.

Furthermore, there are also other reasons associated with the social factors that affect the lives of epileptic people. In general, epileptic people are not much more concerned about their health condition but give higher attention for the people's perception about the disease and the patient.

### **2.5.2.1 Impact on quality of life**

Quality of life is “the degree to which a person’s cognitive, emotional, social and spiritual experience of life is positive”. Quality of life for a people with epilepsy can be reduced by higher physical morbidity rates, seizure-related accidents, antiepileptic drug side effects, more social withdrawal, increased social isolation, poorer sexual relationships, and lower marriage rates. Quality of life for the people with epilepsy may also be reduced by higher psychological morbidity rates, anxiety and depression, lower self-esteem, increased helplessness, defensive aggressiveness, poorer educational achievement and higher unemployment or under-employment (Andermann, 2000). Sachem et al. (2008) have also determined the education as an important factor for behavioral coping strategies which explains its impact on the QOL.

### **2.5.3. Economic impact**

#### **2.5.3.1. Impact on employment**

The unemployment is more frequent in people with refractory epilepsy (RE) compared to the general epileptic population. It varies from 35% in Sweden to 68% in Spain according to different literature sources(Sillanpää et al., 2004). Moreover, unemployment is higher among people with epilepsy, by up to 50% in developed countries if seizures are not fully controlled and up to 100% in developing countries. This can be caused by employer prejudice resulting from stigma and a lack of information, a belief that machinery should be avoided by the people with epilepsy, inability to drive, or poorer academic achievement. Disclosure to an employer is therefore a difficult decision. Unemployment commonly results in a lower SES, lower self-esteem, lessened well-being and a lower quality of life.(Baker and Jacoby, 2000)

#### **2.5.3.2. Impact on education**

A higher prevalence is found in people with epilepsy of learning disabilities and memory problems, often caused by co-morbidities such as brain damage(Devinsky, 2001). According to him, attention deficits occur during seizures, especially during absence seizures in school-children and Antiepileptic drug side-effects of drowsiness and short attention span can affect educational achievement, and are commonly exacerbated by poly therapy(Devinsky, 2001).

### **2.5.4. Health impact of epilepsy**

#### **2.5.4.1. Impact on sexual relationships**

Satisfactory relations with the other sex require self-esteem. Low self-esteem in a people with epilepsy can result in failure to establish good sexual relationships. Brain damage and/or antiepileptic drugs may also result in anhedonia. Head injury may result in reduced libido and erectile dysfunction. Inadequate sexual functioning may result in depression, marital distress or self-aversion(Cole and Cole, 1993).

#### **2.5.4.2. Effect of antiepileptic drugs**

Antiepileptic drugs (AEDs) have both negative and positive effects on cognition and behavior (Meador et al., 2005). AEDs are able to improve cognition and behavior, which has been attributed to reduction of seizure activity, and modulating effect on neurotransmitters and their psychotropic effect. AEDs reduce neuronal irritability and increase postsynaptic inhibition or alter synchronization of neural networks to decrease excessive neuronal excitability associated with seizure development and secondary spread of epileptic activity to the surrounding normal brain. However, excessive reduction of neuronal excitability may result in slowed motor and psychomotor speeds, and poor attention and memory processing, which are common side effects of sodium channel blockade and increasing inhibitory activity (Bradford, 1995). It is not surprising that patients with epilepsy are more susceptible to the adverse behavioral effects of AEDs than other populations, possibly due to the disease associated structural or functional changes that increase their risk of psychiatric disorders and that lead to more stigma.

#### **2.5.4.3. Impact on women**

Epilepsy causes unique problems for women. Seizure frequency and severity can be exacerbated by menstrual hormonal changes. Women with epilepsy often experience anxieties concerning children. Doubts about seizures being triggered by labor, their ability to care for their child, the possibility of inheritance of epilepsy and birth defects are compounded by fears about antiepileptic drug side effects and the mother's ability to be a good role model during child-rearing (Gummit, 1997).

#### **2.6. Association of epilepsy with religion**

Epileptic seizures have a historical association with religion and spirit possession (Ellis et al., 2000). Moreover, Religious and supernatural beliefs act as facilitators of epilepsy-related stigma in some contexts, with some believing that epilepsy is a curse or caused by witchcraft (Stangl et al., 2019). As a result of this, PWE devalued and stigmatized because of false historical background, religion aspect, uncorrected knowledge and attitude about epilepsy (Shehata, 2016). PWE have themselves used terminology such as their epilepsy

being an unclean spirit, evil, a craziness or mental illness(Dua et al., 2006).Some adolescents believing that epilepsy can be ‘caught’ by bystanders, causes mental handicap and can lead to death Abimbola (2010),not altogether unfounded beliefs.

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

Epilepsy is highly associated with so many social problems (Sharon, 2011).The disease is not only a medical condition, but also includes social, economic and cultural dimensions(De Boer et al., 2013).One of the most significant impacts of epilepsy on adult patients is employment opportunities(Biffu et al., 2015).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 (Thomas and Nair, 2011).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, feels embarrassed and as a result guilt would be very strong(Hills, 2007). Hence, PWE most of the time feels 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(Hills, 2007). 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

Shehata (2016) told that recent judicial rulings suggest that persons with epilepsy have little protection against unreasonable employment practices.

## **2.8. Theoretical frame work**

As it is known , scientific theories powerfully influence how evidence is collected, analyzed, understood and used to reveal or obscure new insights (Alderson, 1998).As such, it is useful to have an explicit theoretical framework that can both guide research and intervention development on individual socio- cultural and health conditions that allow for comparisons and responses across various dimensions.

Thus , having sharing the idea of Alderson, this research paper will utilize, health Stigma and discrimination framework, which is a global, crosscutting framework based on theory, research, and practice, that applied to a range of health conditions, including epilepsy and other chronic diseases(Stangl et al., 2019). Moreover, the paper will also employ works of Erving Goff man stigma and discrimination theory because it helps to understood about how stigma operates and induces harm in the context of different diseases and identities.

### **2.8.1. The Health Stigma and Discrimination Framework**

Health Stigma and Discrimination Framework comprises six domains that used for assessing health related stigma and discrimination. The domains are termed as drivers, facilitators, intersecting stigmas, manifestations out comes and Impacts. In general, health stigma and discrimination frame work domains were used to understand health related stigma and discrimination by assessing attitudes of people towards a particular disease , to understand the main facilitators and drivers that escalate stigma and discrimination, to understand the impact of the diseases on the patient for instance in terms factors that contribute for social stigma and discrimination, employment discrimination , social rejection and distancing and stereotypes about PWE and impact of the disease on quality of life(Stangl et al., 2019). The domains mentioned in health stigma and discrimination frame work are direct linked to current thesis objectives.

Moreover the study derived some insights from Goffman, since sociologist Erving Goffman published his seminal and research work on stigma, across the disciplines of sociology, psychology, social science, medicine, and public health have expanded, and the current

study applied that enabled the researcher to understand about how stigma operates and induces harm in the context of different diseases and identities. Stigma, as Goffman notes, enables varieties of discrimination that ultimately deny the individual/group full social acceptance, reduce the individuals' opportunities Goffman (2009), and fuel social inequalities. Stigma influences population health outcomes by worsening, undermining, or impeding a number of processes, including social relationships, resource availability and stress. Moreover, stigma influences psychological and behavioral responses, that exacerbate poor health(Hatzenbuehler et al., 2013).

In conclusion, the study employed the domains of health stigma and discrimination framework together with Erving Goffman theory on stigma and discrimination since they were linked and pertinent with objectives of current study.

## Chapter Three: Research Methods

### 3.1. Description of the study area

Meinit Goldiya is one of the woredas in the Southern Nations, Nationalities, and Peoples' Region of Ethiopia. Part of the Bench Maji Zone, MeinitGoldiya is bordered on the south by Meinit Shasha, on the west by Debub Bench, on the northwest by She Bench, and on the North and East by the Keffa Zone.

Based on the 2007 census conducted by the CSA, this woreda has a total population of 88,863, of whom 43,594 are men and 45,269 women; 2,547 or 2.87% of its population are urban dwellers. The woreda has 31 Kebeles .The majority of the inhabitants were Protestants, with 65.08% of the population reporting that belief, 27.41% practiced traditional beliefs, and 6.37% practiced Ethiopian Orthodox Christianity.

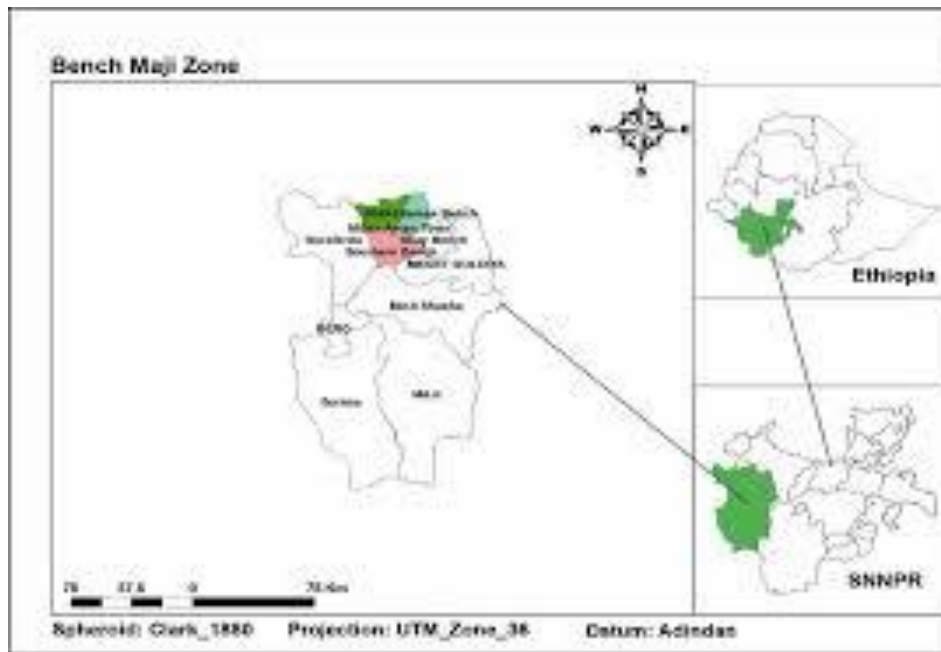


Figure 1: - Map of the study area/shaded region indicate Me'intGoldiyaWoreda/.

The four largest ethnic groups reported in Me'int were the Me'en (87.97%), the Bench (3.77%), the Amhara (3.14%), and the Dizi (3.08%); all other ethnic groups made up 2.04% of the population. Me'en was spoken as a first language by 87.82% of the inhabitants, 5.21% spoke Amharic, 3.51% spoke Bench, and 2.91% spoke Dizin; the remaining 0.55% spoke all other primary languages reported. Concerning education, 6.18% of the population were



considered literate; 4.33% of children aged 7-12 were in primary school; 2.14% of the children aged 13-14 were in junior secondary school, and 0.69% of the inhabitants aged 15-18 were in senior secondary school. Concerning sanitary conditions, about 48% of the urban and 5% of the total had toilet facilities.

### **3.2. Study design**

As Dowling (2007), the basic purpose of phenomenology is to understand the lived experience of peoples . In cognizant to this, the paper utilized phenomenological design through collecting data from persons who have experienced a phenomenon and develops a composite description of the essence of that experience for everyone who lived it, to understand how one or more individuals experience the phenomena, situations and experience in relation to the objective of this study via cross sectional study(Groenewald, 2004). Besides, as Smith and Shinebourne (2012), evidences phenomenological design is special for raising awareness and increasing insight about certain issue. Hence, phenomenological design is carefully selected by investigator in order to raise awareness and increases insight on the community beliefs towards epilepsy and the socio- cultural challenges of epileptic since the researcher have long time work exposure in study area.

### **3.3. Sampling design**

Sampling in qualitative research plays a vital role, as the essence of most qualitative researches is to study a phenomenon in its natural setting and as it has been suggested byMarshall and Rossman (2014), that sampling in qualitative research helps the researcher to identify persons or localities rich in information and can be studied in much depth. Thus in cognizant to this the current study employed purposive sampling strategy to collect rich information that helps for in- depth rationalization of the phenomena in the study area(Lincoln et al., 2011). Informants of epileptic victims were identified with collaboration of community gate keepers. Besides, in the study area, substantial amount of epileptic victims resided and settled in isolated place from the living area of non- epileptic community members. However, the epileptic victims move from place to place to search their daily needs, so this is the reason that why the researcher employed purposive sampling strategy rather than survey. The residing place for victims was facilitated with local government administration.

Moreover, non-epileptic community informants was selected purposively depending on their work engagement, lived in study area for more than two years, experience. Besides governmental and NGOs had been purposively selected based on their knowledge, exposure and work experience vis-à-vis to epileptic issue. Hence the sampling technique utilized for this research was purposive, i.e. for PWE and the non-epileptic community. Totally 25 informants was purposively selected from the community. Number of interviewed informants was fourteen from non epileptic and eleven from epileptic peoples from the community since saturation is emerged at mentioned figures during interview process. The interviewed informant from both groups was purposively selected because of their deep experience and knowhow on the study topic at hand.

### **3.4. Methods and instruments of data collection**

To collect an abundant amount of information, the study employed different methodological techniques such as key informant's interviews, in-depth interview, focus groups and observation study to collect plentiful information which would help to lessen bias, and enhance data credibility in the research and for yield well-balanced empirical results Marshall and Rossman (2014), in the study.

#### **3.4.1. In-depth interview**

An in-depth interview was carried out with available epileptic peoples in investigation sites of Me'int Goldiya Woreda in order to extract their experiences and to collect information about the socio- cultural challenges they suffer from. The researcher used one-to-one interviews with purposively available epileptic informants due to the study type while questioning deep experience on the challenges currently they suffer from. The researcher had managed to contact them by visiting them at their home as well as assessing the place in which they live, such as in streets, around church compounds etc. in Bachuma Town with the help of community gate keepers. Using interview guides, a detail interview was conducted toward achieving the specific objective of describing the socio- cultural challenges of epileptic. The inclusion criteria for PWE, was epileptic patients from both sex who have age of greater than 18 years old. Age of respondents greater than 18 years old were selected by researcher because to collect meaningful and explanative in-depth experiences needs matured informants who can justify the encountering situations clearly.

As Creswell (1998), for phenomenological studies he recommended 5–25 interview informants but the required number of participants should depend on when saturation is reached. Besides, Guest et al. (2006) proposed that saturation often occurs around 12 participants in homogenous groups. If different types of participants interviewed in phenomenological study it should be needed to interview around 12 to 15 informants of each type in order to reach saturation(Latham, 2013).

Cognizant to this the current study, interviewed informants of both epileptic and non epileptic community members. During interview process, saturation is occurred after interview of 14 informants from non epileptic community and 11 from epileptic victims. At this point no any new or relevant data is obtained during interview process (Guest et al., 2006). Hence totally, 25 informants were interviewed during study.

#### **3.4.2. Interview with non epileptic communities**

Here interview was conducted among with non epileptic community members and government as well as non-governmental office representatives. The interview process that had been undertaken with community members was open ended interview with prepared interview tools ,for understanding peoples experience and their way in which they beliefs or perceive of the issue at hand since the unique source of absolute existence is based on what the person thinks, feels, and perceives (Moustakas, 1994). Thus under community interview, purposively selected informants was from non-epileptic communities from both sexes who engage in different livelihood activities such as merchants, farmers, youths, priests, government worker etc., was participated in order to understand their beliefs towards epileptic victims and their etiological views on epilepsy in general. The inclusion criteria for such informants was non-epileptic patient, lives in the study for at least two years, age of informants should be more than eighteen years old and free from cognitive impairment.

The second interview was conducted among government as well as with non-governmental organizations in the study area. They were purposively selected by researcher since they have work experience on the issue of epilepsy and meaningful experience concerning the phenomenon under the investigation. Thus, informants from government office representatives will be from Me'int Goldiya Woreda administration offices, labor and social affairs office of Me'int Goldiya woreda, women, children and youth office office of Me'int

Goldiya woreda and health office representative of Meint Goldiya woreda. Besides, informants from non-governmental organizations that will be participated in interview process had been included. Thus, the study that was conducted with mentioned stake holders is aimed towards for assessing their contribution and support for epileptic victims in study area and further to understand the depth and width of the problem epileptics in study area. Mentioned stakeholders selected since they have great deal of information, knowledge, and intervention in study area about the issue of epilepsy and related problems in the study area.

### **3.4.3. Focus group discussions**

As Casey, (2000), argument focus group discussion as carefully planned series of discussions designed to obtain perceptions and beliefs of the communities on a defined area of interest in a permissive, non-threaten environment. Thus the current paper employed FGD with communities having almost the same social back ground to dig the collective views about the issue identified in the study. Due to the emergence of corona virus pandemic, the researcher employed and utilizes health professional's advices for prevention of the pandemic for those informants that participated in FGD sessions.

This type of data collection is selected by researcher to cover large number of people in the same group Wall, (2001) and to use it in conjunction that was used as a form of validity of research findings (Threlfall, 1999). Besides it used for researcher as was a way of learning from every body's faces and speech.

FGD was held at field setting which free from any barriers; voice and disturbance. Four FGDs each in average consisted of eight participants were participated. The first FGD was conducted with religious leaders from four denominations, i.e. Muslim, Orthodox, Catholic and protestant religious leaders to extract information on religious view towards epilepsy and their beliefs towards epileptic victims. The second FGD was conducted with traditional religious leaders in study setting in order to collect information on, traditional religion views on epilepsy, their beliefs towards epileptic patients and to understand their cultural practices for healing of epileptic patients. These traditional religion leaders were selected from locally worshiped god by a community which differed from Muslim, orthodox, Catholics and Protestants denominations in terms of religious practices and faith. The third FGD was

conducted with a community who doesn't get opportunity in first phase of interviewing and the objective for conducting discussion is to collect their beliefs towards epileptic, their views on etiological cause of epilepsy and their way of social interaction with epileptic communities. The fourth discussion was conducted with epileptic patients to get information on their socio- cultural challenges they suffer from, psycho social problems and related issues.

The inclusion criteria of religious leaders participated in FGD was those who have stayed in the study area for at least two years, had positions of Imam/sheik in mosque, Orthodox priest, Catholic priest and pastors. The inclusion criteria for second FGD that was conducted with traditional religious leaders of informants was those popular traditional religious leaders and known by the community from both sexes and stayed in the study area for more than two years. The inclusion criterion for third FGD session conducted with communities, was non-epileptic patients, had age greater than eighteen years old, stayed in study area for more than two years and it invited both sexes for discussion. The inclusion criteria for fourth FGD that was conducted with epileptic patients was epileptic patients from both sexes had age of greater than eighteen years old and communities of the study area.

In general, FGD is selected by researcher in order to collect the opinions of several people at the same time. It also provided as a measure of validation for the information that allows others to challenge extreme or false views in the group. Data was collected using a semi-structured guide. The researcher played the role of a facilitator and interviewer. FGD was start at the beginning of the research, in order to explore an unknown area and to generate discussion and consensus around a topic of inquiry. It enabled to gather information about shared understandings of community's belief and attitude toward epilepsy, socio cultural situations of peoples having epilepsy in the study area.

#### **3.4.4. Observation**

The observation for study included observing environment of community (social interactions, support of communities during epileptic seizure occurrence by patient, observing the home and personal sanitation keeping ways of epileptic patients, etc. The observation schedule was indicated below.

<b>Observation schedule protocol</b>	<b>Parameters/indicators</b>
<b>Belief of the community towards epilepsy</b>	
Social interaction of communities with PWE	Observed in social gatherings such as in Idir, religious ritual
Business men way of serving PWE	Observed in restaurants, in coffee and tea shopping,
Extent of first aid support from bystanders , when patient suffers from sudden epileptic seizure	Critically observed the situations in where much populations engaged, might be in market days, probably may be in streets
<b>Socio cultural practices</b>	
Cultural practices undertaken by community to healed from epilepsy	<ul style="list-style-type: none"> <li>- Observed at churches, health center, visiting traditional medicines home.</li> <li>- Observing the utilized medicine by PWE, when they feel sick.</li> </ul>
<b>Challenges</b>	
The current living situations and challenges of the victims.	<ul style="list-style-type: none"> <li>- Living environment of the victims visited.</li> <li>- Extent of social interactions of victims with non- epileptic communities was inspected.</li> </ul>

*Table 1: Observation schedule*

### **3.5. Instruments of data collection**

To conduct this study, the researcher had been used interview and discussion guides to dig out pertinent data in relation to research objective. The interview guide for depth interview, FGD and observation was semi-structured due to its advantages. The semi-structured interview helps to fix the areas of information required and extract pertinent data as well as guides the process. The tool written in English will be translated into the language of participants by the researcher.

### **3.6 Sources of data**

Both primary and secondary data sources had been extracted to conduct this research. Primary data sources was collected using in-depth interview, key informant interview, focus group discussions. These methods helped to triangulate the finding with different data sources. Secondary data also was collected from different related documents and related

study findings conducted at global, national and local level that were pertinent to current study.

### **3.7 Methods of data analysis**

The thematic analysis was employed to analyze the data and thus themes had been developed based on the research objectives and emerging issues (Gasson, 2004). The data collected by using the tools listed above was organized and transcribed accordingly. Then this transcription broken into manageable units and coded based on the information they reveal. Finally, the patterns had been searched and the main themes were identified, and the categories brought together and rearranged under the themes.

### **3.8. Validity and reliability of the study**

In order to assure quality and thrust worthiness, qualitative research embraces multiple standards of quality, known variously as validity, credibility, rigor, or trustworthiness. Cognizant to this the current study applied various measures to keep quality and trust worthiness(Morrow, 2005).

According Lincoln et al. (2011), credibility (vs. internal validity) refers to the idea of internal consistency, where the core issue is “how we ensure rigor in the research process and how we communicate to others that we have done so”(Gasson, 2004). Thus the current meets the issue of credibility with achieving continuous engagement with participants, persistent observation in the field; researcher reflexivity; and participant checks(Geertz, 1973).

As (Gasson, 2004) transferability (vs. external validity or generalizability) addresses the core issue of “how far a researcher may make claims for a general application of their study. Hence to achieve transferability, the study conducted provided sufficient information about the self (the researcher as instrument) and the research context, processes, participants, and researcher– participant relationships to enable the reader to decide how the findings may transfer.

As Gasson (2004),enlighten dependability (vs. reliability) emphasized on the way in which a study is conducted should be consistent across time, researchers, and analysis techniques(

Thus, the process through which findings are derived should be explicit and repeatable as much as possible. Hence the study addressed the question of dependability through carefully tracking the emerging research design, through consulting with study advisors and other colleagues in the field.

According to Gasson (2004) confirm ability (vs. objectivity) is based on the acknowledgment that research is never objective. Therefore, study conducted addressed confirm ability through working as far as is (humanly) possible in order to achieve representative findings without the biases of the researcher(Gasson, 2004). Hence to accomplish the goal of dependability the researcher had been managed him more or less from subjectivity.

### **3.9. Ethical Consideration**

Researchers have a clear responsibility to ensure and protect the rights and general well-being of their participants and the setting. Ethical issue had been followed through the whole process of the research. To keep the research ethical and academic, the researcher took every possible precaution to refrain from doing any unethical works.

Informed consent of research participants in the interview and focus group discussion was employed. An extended discussion had been held with potential informants after introducing about the purpose and importance of the research. After the interviewers briefly introduce themselves to potential informants, they was present them with a participant information sheet in order to learn about the nature and purpose of the research, enabling them to make an informed decision to volunteer or to decline participation including withdrawal at any time. After their agreement, they were asked to sign the consent form and then the interview processed.



## Chapter four: Findings and Discussion

### Introduction

In this chapter, the major findings of the study based on the data obtained through, in-depth interview, focus group discussions and observations are presented and analyzed. The data analysis was done based on the identified thematic areas which were all set in reference with the objectives of the study and basic research questions. Besides, the researcher looked critically on patterns and relationships in the data within and between cases for searching of emerging themes for analysis. As a well, direct quote by informants was translated into English from the recorded and transcribed discussion which was written in italics to illustrate the theme from the direct perspective of research informants.

### 4.1. Community beliefs towards epilepsy

Scientifically, epilepsy is a neurological disease which affects all social groups without selecting sex, race, ethnic back ground (Sander, 2003). Besides, scientific definition of epilepsy, different community members in Me'int community have wide-ranging awareness and concepts on epilepsy in which some arguments contradicts with scientific explanations of epilepsy and only few of them agrees with scientific premises since as there are best healthy beliefs towards epilepsy, there are also unhealthy beliefs by diverse community members. Contently, six categories regarding on the belief of Me'int community towards the disease are developed. These are contagious beliefs, trans-generational, curse from God, magic, low obedience to traditionally worshiped God and asset transference/inheritance/.

#### 4.1.1. Contagious beliefs

Participants spoke out that the disease transmits from one individual to another. Eating, drinking together and contact to saliva of epileptic patient are the most discussed means of transmission. The participants were highly familiar with such types of beliefs. They mentioned that their beliefs were a long time ago. They are giving shadow of tree to sit there and bring edible food outside and never want to spend time with them. Never sit next to them and not share common materials.

One of community member from non epileptic who has 33 years old told the trend in the following way:

*‘Well, I don’t let epileptic patient to get at my home. The disease is very contagious and transmits to someone who approaches with epileptic patient’.*

Thus, from the above testimony it is possible to understand that non epileptic community members do not approach with epileptic victims even they didn’t invite epileptic patients to their home for the reason of the thoughts that the disease is contagious.

#### **4.1.2. Trans-generational beliefs**

In Me’nt community, non epileptic peoples never marry epileptic victims because marriage arrangement with epileptic patients was considered as transmitting the disease to other group of people. Many community informants also believed that it can be transmit to their children since the disease was considered as a trans-generational disease. One of the female informants aged 36 years old from epileptic community explains the social challenges she faced as follows.

*‘ Just I have two daughters from first husband and they never got married; all of my community knew when my partner evicted me out of my home due to this disease. All considering that they will give birth to infected babies’.*

#### **4.1.3. Curse from God or evil acts**

As any traditional community, Me’nit peoples are also living in a context of traditional beliefs which guides the way of their life in their localities. They associate etiological causes of epilepsy with different causes. Curse from God or evil acts was another etiological cause for epilepsy as mentioned by interviewed participants. One of the male informants aged 39 years old from non– epileptic community explains his idea as follows:

*‘Wow, the symptoms that the patient showed were very shocking. The disease by itself is unique from other illness. So one cannot become deliberately insane, but it is the curse from God, we know and believe it is from God’.*

Hence, through observing the symptoms of the disease, like shaking, foaming of mouth, rolling of eye, etc... communities believed and attributed the etiology of epilepsy with a curse from God since seizure characteristics of this disease quite different and strange than signs and symptoms of other diseases.

#### **4.1.4. Magic**

In Me'int community, magic is believed to be one of the etiological causes for epilepsy. As a result of this epileptic patients became whipped and put into isolation because his/ her seizures were thought to result from magic. This was very severe in epileptic patients in surviving their life. One of the epileptic informant from Me;int ethnic clan, who have age of 39 years old explains how he becomes epileptic patient as follows. .

*Still I am Shocking when I remember what happened in my life after I caught with epilepsy. The scenario of becoming caught by epilepsy is like this. During that time I was 34 years old. I was married and live with four children. Even though I am poor and my livelihood depends on hand to mouth, I and my family used to lead happier and healthier life. But the challenge in my life comes when I quarreled with my neighbor for piece of plot of land. We share similar farming field boarder with him. He blamed me for fencing of my farming land. He accused me by assuming that the fenced farming land illegally stretched up to his legal faming land that I did not. He went to Keble administration and Woreda justice and peace Keeping office for accusations. But the concerning peace keeping institutions negotiated us and find no fault is committed by me. But my opponent did not give up. He plans and got to popular wizard who lives in Mei;nt Shasha Woreda around 35 Kms from my living area. Once up on a time, I wake up early for my farming activity. During my journey to my farming field, unknowingly I crossed the dead animal that leashed with blood around 20 meters away from my home. At that time I feel disappointed and frighten when I observe the thing that I crossed is magic. When I try to go back home suddenly I failed on the ground. Starting from that day, I feel sick and I experienced seizure after one year since these bad scenarios happened to me.*

#### **4.1.5. Low obedience to traditional worships**

In Me'int communities there are traditional religious practices. During harvesting time, the communities must sacrifices products they gained in kind or cash for locally worshiped God. The amounts of the products they earn may be small or large in amount. But it depends and

hence, any Meint clan should obey and respect the rules of worshipped Qollo. In Me'int culture, Qolle is an indigenous traditional belief of the community whereby the followers worship their traditional 'god' maintaining different practices and making scarifies.

Thus, owner of the product should give gift for the worshiped Qollo as a return. Failure of the communities for gifting of the products they earn would be punished by locally worshipped Qollo. In this case communities believe epilepsy emanates as a result of low obedience of peoples towards their indigenous traditional belief. The participants were highly familiar with such types of beliefs. They mentioned that their beliefs have been practiced for a long time. The above arguments was supported by the view of community elder, who have age of 47, during FGD discussions.

*“Personally I worshiped Qolle. The believers should give gift from earned products to Qolle. If someone refused and missed this gift, he will be punished by traditional God and consequently suffered with epilepsy. Not only suffering he may lost all properties owned by him and even he may lost his life”.*

#### **4.1.6. Asset transference**

In Me;int community when epileptic victim is passed away, inheriting the assets of passed away epileptic patients to other family is sanctioned. Violating this norm is considered as sin and taboo according to their traditional norms. It is immediately burnt by community. According to their beliefs and arguments inheriting the passed away epileptic patient property to other family's considered as passing the curse of the dead to other family members.

Discussions was conducted at FGD sessions for the reason of prohibitions by Me;int community for inheriting passed away epileptic patient of Me;int community to his family . One of the traditional religious leader aged 47 years old explained his ideas during FGD session in the following way.

*“Ooh, well! , inheriting or transferring property of epileptic patients to other families and closed relatives is strongly prohibited and considered as taboo in our*

*tradition as it is believed that this action means transferring the curse of passed person to other family.”*

Further, discussion was made during FGD with traditional religious leaders regarding on inheritance of property and to elicit information on to which groups i.e. epileptic patients or non-epileptic communities does inheritance of dead persons property banned in their community. A 55 years old traditional religious leaders and non-epileptic Meint clan elaborates the issues like this.

*“Oho, it is very serious. In our culture, inheritance of the passed away epileptic patient of any property to his family’s and cloth friends is prohibited. When, I say this it is prohibited only the transference of the property of epileptic patients”.*

From the above statement, we can understand that the inheritability/transferability of property is prohibited for only Meint clans who have epilepsy. Moreover, when one epileptic house hold patient passed away, his all assets that he have developed and accumulated throughout the entire life should be burnt immediately. The assets may include home, animals, the crops and plants in his garden, clothes of the patients etc. One of the community elders from Me;int clan have age of 65 years old, explains this trend during FGD discussions as follows.

*“In our community, inheriting the assets and properties of the passed away person due to epilepsy is considered as a taboo. Hence, we completely burn out the overall properties that the person produced throughout his entire life and the assets accumulated by an individual died of Epilepsy”.*

As indicated, the assets of the passed away person are not allowed for inheritance for families of the passed away individual, even to his wife and child.

#### **4.1.7. Beliefs of epileptic victims towards epilepsy**

In similar to non – epileptically affected communities, epileptic victims also believe and attribute the etiological causes of epilepsy with curse from God, magic, low obedience to

traditional worship towards Qolle and asset inheritance. One of male epileptic participant who has age of 36 elaborates the etiological causes of epilepsy at FGD session as follows:

*‘Well, epilepsy is caused as a result of curse from God. I told this by terracing from my own experience. I have caught with epilepsy since epilepsy was existed in my parents’ life history.’*

From the above interview, it is possible to understand that epileptic victims associated the etiological causes of the disease with curse from God. They accepted the disease can be transmitted from parents who have epilepsy to his/her child. They also believe that the sin committed by families will be punished by God to all child of epileptic parent.

Further, deep interview was conducted with epileptic patient for eliciting their beliefs towards epilepsy. One of male epileptic patient from Meint community, who has age of 29, explains his views on epilepsy as follows.

*I was first child for my family and I have one sister. She is 27 years old. My mother died during delivery complications. My sister marries two years ago after my mother passed. I married one year later since my sister’s marriage. Before one year ago, my father was suffered with epilepsy. Unfortunately at the age of 52, our father passed away. Our father assets and properties were burnt out according to Meint community’s traditions and cultural norms. Nothing is else. Completely all properties including crop products and domestic animals owned by my father was completely destroyed. I and my sister do not inherit anything from my family’s property, since we accept inheriting the property of passed away individual’s asset as sin.*

Thus, based on mentioned fact, inheritance of the property/assets/ of the passed away epileptic patients by his family considered as the other etiological factors for epilepsy according to Me’int cultural norms.

#### **4.2. Non epileptic community views towards epileptic victims**

View of non epileptic communities towards people with epilepsy tended to be more negative in the study area. Peoples with epilepsy were seen as physically weaker and less competent persons because of their tendency to seizures. Moreover, as a result of community’s misconception, epileptic patients was suffered stigma and discrimination in their leaves. One

of male informant aged 31 and business men from non-epileptic explains his view on employment of epileptic patient for his business during interview as explained below.

*I didn't let to employ epileptic patient for running my business. You don't know the time when he shows seizure. Who will take the risk, if your business failed as a result of employing unfit person? You know, this is a business. I do it for profit. In my side, I don't do it'.*

From the above point of view, non-epileptic community members believe that PWE were unsuited to the demands of paid employment. Besides, it is common perspective among the community that PWE can't able to do heavy physical or 'brainwork'.

### **4.3. Socio cultural practices and challenges of people affected with epilepsy**

In the study area peoples with epilepsy internalize and undertake some socio cultural practices in order control the sudden seizure which occurred as a result of the disease. Further, peoples with epilepsy suffered multifaceted social problems as a result of deep rooted and long standing culture of the community. Physical hazards/ injury/ as a result of traditional way of cooking with fire and social abuses from some community members are the main challenges that PWE suffered from.

#### **4.3.1. Socio cultural practices**

In the study area, epileptic patients utilize various cultural and traditional medicines for the disease. Firing matches and holy water are the two main healing mechanisms for epilepsy in Me'int community when seizure episode occurred.

##### **4.3.1.1. Traditional medicine**

In study area, most of the time epileptic patients utilize traditional medicine for treatment. They prefer and gave priority for traditional medicines rather than modern medicine. As a result firing matches and holy water are the two main healing mechanisms for epilepsy in Me'int community. The FGD participants explained the practice of the community during

seizure episodes and one of the non- epileptic female FGD participants who has age of 23 noted:

*‘We help patients through firing matches. After firing matches the patient will become conscious. But sometimes some patients would not recover immediately from seizure even doing such practices. If it is beyond to our potential we call health workers for support’.*

Another FGD participant from the male epileptic group who have 39 years old said:

*‘Some people give aid by washing a patient with holy water if he/her is Christian religion follower. They will get well if they utilize holy water regularly simultaneously with continuous praying’.*

Thus spiritual healing was the most preferred method of treatment for epilepsy in Me’int community and they choose this method of treatment since they believe that the disorder was a result of affliction by evil spirits

#### **4.3. 1. 2. View of epileptically affected patients towards modern medicine**

As it was reported, many epileptic patients in Africa go untreated(Dua et al., 2006). The treatment gap in developing countries is mainly emanated for the reason of inadequate health delivery systems, lack of trained personnel, and lack of essential drugs(Tran et al., 2007). However, in Me’int Community, inadequate health delivery systems, lack of trained personnel, and lack of essential drugs are not only the reasons for the epileptic patients to seek medical care. The long lasting traditional beliefs and practices often do not consider epilepsy as a treatable condition. One of the female epileptic patients who have 31 years old explains her views as follows:

*‘I believe epilepsy is not medically treated. I try to visit medical centers here in my woreda. But, nothing of them not able to cure me and calm my sickness I visit traditional herbalists. I feel well when use this cultural medicine for at least for few months. But, to honest speaking, I am not relived completely from my sickness’.*



Thus, epileptic patients most of the time do not consider epilepsy as a treatable condition. However, there is evidence that anti-epileptic drugs are effective for the treatment and control of seizures (Jacoby and Austin, 2007). Hence as a result of this, treatment gap greatly increases in the study area which in turn mounted the burden of epilepsy and disability.

#### **4.3.1.3. Birth delivery trend of PWE**

In Meint community culture most of the time pregnant epileptic women deliver birth outside of the home. In support to this, different study findings indicate that, epilepsy has been associated with multiple causes poor antenatal care and intracranial infections was thought to be the main causes (Ngugi et al., 2013). To validate this, the researcher examined the delivery trend of epileptic women. One of female informants from epileptic family who has age of 29 years old explains her birth delivering experience like this;

*In our culture mothers usually used to give birth at home and they consider institutional delivery as a taboo. We have got health education about the benefits of health care delivery as well as the risks of home delivery. But individually, I believe that it will not be easy to comply with this idea since our culture greatly limits us due to some underlining factors such as refusal of the women to expose their naked bodies to other party.*

Besides, the pregnant women in Meint community deliver birth with the help of traditional birth attendants. Their trend of visiting health care center for medical health diagnosis is very low.

#### **4.3.2. Challenges of PWE**

In the study area peoples with epilepsy suffered multifaceted social problems as a result of deep rooted and long standing culture of the community. Physical hazards/ injury/ as a result of traditional way of cooking with fire and social abuses from some community members, stigma and discrimination are the main challenges that PWE suffered from.

#### **4.3.2.1. Physical hazards**

As different literatures indication, physical hazards are one part of the global burden of epilepsy that results from the unpredictability of seizures (Abimbola, 2010). In similar manner, in Meint communities, many people with epilepsy experience problems with physical abuses and injury, which truly lead to poor quality of life and even for deaths. An injury was from disease condition or from outsiders.

Most of the times Me'int women are using open fire for cooking purposes. This highly exposes people with diseases to extreme heat. Research based fact mentioning that extreme heat induces frequent seizures. Besides, Meint people never approach to seizing individuals since they perceive it as a contagious. This makes no saves from disease based injury especially from burns since you never feel when fire burns. One of female epileptic patient who have 34 years old married woman explains her view during in depth interview as follows:

*'Just my hands burnt out when I was cooking lunch for my family and no one had saved me from fire; that is why I lost my hands out of work.'*

Further, another epileptic patient who has 26 years old boy mentioned his view during in depth interview as follows:

*'Always I am in suffering; you can observe it! Look this; my leg is useless and also my one left eye with my face due to the fire burns'*

#### **4.3.2.2. Physical injuries from outsiders**

Besides, people with epilepsy have been facing physical injuries from outsiders even from their family due to the diseases. In Me'anit culture, keeping and approaching epileptic patients is unbelievable. The family of non epileptic community member will be isolated by neighbors if they keep epileptic victims at their home. Thus, community must stop any social interactions with epileptic victims like marriage, attending funerals, Ikub etc. with that family unless they take serious measurement up to killing. For this purpose, family of the epileptic victim may kill and send epileptic victim by river for sake of avoiding social

burden that arose from other community members. Informant from female epileptic patient who have 35 years old explains her physical abuse like this:

*“ I injured my right leg when my family attempted to kill me. But thanks to God, I am alive even though I lose my leg “.*

Moreover, sending epileptic patients by river and forcedly falling into halls in hidden way is also one of serious undiagnosed injury. Hence, substantial number of children was killed in this way by their families. During FGD discussion with community elders, one of the male informants from non epileptic community who has age of 47 elaborates the issue in the following way.

*Oh! They throw you to the river if they never wanted you; they make you drunk and then push you into big hole!”*

Of course, unlike other ethnic groups in Ethiopia and rare outside, murder of epileptic client is culturally prohibited act among the Me'inet people. But, sometimes there is a hidden practice by rare individuals at the nomadic areas. Even, to make the matter worse, in these areas nobody is willing to bury the dead body of epileptic patients as per discussants. One of male non epileptic informant aged 35 years old and a higher official of the Kebele district in the study area explains the situations of epileptic sufferers as follows:

*There is one Kebele administrator who is affected with this disease; we invited him to town to work here and to follow up drugs; however, he refused to stay here and return back to his home origin in where community's harshly hate PWE , then all Kebele officials and militias have stopped working due to his refuse for medical adherence through staying with them . Unfortunately, he was killed by unknown body immediately due to this case.*

Hence, in study area there is a hidden practice of murdering of epileptic victims by other community groups due to for their negative beliefs towards PWE and miss conception on the disease as contagious and curse from the God or evil. Further, one of the community

informant and merchant aged 32 years old from non epileptic community explains his views as follows:

*“ Oh! Really this was the worst scenario! I heard a sure thing in this weekend that a tenth grade student from kurta village is wanted by their community to be killed. Since he lives with them and attending school.”*

#### **4.3.2.2.3. Challenges in health care accessibility**

Many discussants spoke out; they were neglected in different health care services like treatment, malnutrition and family planning services. Furthermore, people with epilepsy not got anti-epileptic drugs as discussants mentioned. One of female epileptic victim from the community who has age of 25 explains limited access of drug distribution during depth interview in the following way:

*“There was no drugs distribution timely. Once they came and disappear for more than three months. No access to it regularly”*

Government officials were also believed the mentioned case. One informant from Health office who has age of 28 explained the emerging issue in the following way:

*“We have observed that problem, in last week we put the direction; not only drugs of epilepsy, for family planning as well; Drugs are there but not distributing timely for patients, that is a problem.”*

From the above statement, it is possible to understand that governmental officials more particularly health professionals who worked at the community level have low motivation and commitment to deliver medical help for epileptic victims. They also believe there current problem as well based on the above mentioned fact.

#### **4.3.2.3.1. Health facility distance**

In the study area, health facility was located at far distance. One of female married epileptic patient informant who has 35 years old explains the challenge in the following way:

*' It takes more than two hours on foot to find health facility, it really mountains to reach it. Due to this case, we were not going to there even disease worsens'*

People with epilepsy discussed and agreed that they did not get health services and health workers didn't visit to their home even for campaign activity. One of FGD participant from epileptic group aged 27 years old single man told the issue as follows:

*“Just we have heard that there were a lots child's food and selling in every shop. Even it was expiring in every health facility. I think health extension worker were distributing it in other community. However, no one remembered our children”*

#### **4.3.2.4. Stigma and discrimination**

According to the study findings of Workineh (2017) ,majority of epileptic victims lives in absolute poverty. They have no income to afford their basic daily needs. Moreover, based on researcher observation, some of epileptic patients eat and consume slaughtered animals by finding where it is available besides begging in streets in market days, in church and mosque compounds. Furthermore, based on observation result, substantial amount of epileptic victims does not keep their personal as well as their living home sanitation in proper ways. As a result of this, significant number of non epileptic communities discriminate epileptic victims for their poor sanitations and feeding habits which was presented as follows.

##### **4.3.2.4. 1. Poor sanitations**

Further, non-epileptic Me'int communities view epileptic patients as nauseating bad body odor. They argue that most of the epileptic patients do not keep their sanitation properly. As a result of this peoples with epilepsy, discriminated on interpersonal relationships and overall quality of life in general. One of the male non epileptic community informants of restaurant owner who has age of 38 years old told his views at interview in the following way:

*Well, to honest speaking sometimes I didn't let epileptic victims to be entered and served in my restaurant. I tell and ordered this for my waitresses to follow up. Because most of the time epileptic patients do not keeps their personal sanitation*

*properly since inviting them to my restaurant means taking risk for rushing or loosing of other customers who served at my restaurant for next time.*

Thus in Meint communities, non-epileptic peoples discriminate epileptic victims for their usual poor sanitation keeping mechanism. In support to this the researcher observed the physical as well as living shelter of epileptic patients through visiting their home. It seems like true in the eyes of the researcher that some epileptic patients didn't keep their personal as well as living environment sanitation and hygiene in proper way even if hating discrimination of the victims by community. Based on researcher observation, poor sanitation occurred as a result of the nature of the disease since during seizure epileptic patients experience unconscious urination, foaming and bleeding that in turn affects their personal safety and health. Furthermore, the embedded poverty and socio economic status of the patients fuels this challenge and this may need further research. Hence, poor sanitation by peoples with epilepsy is one of the consequences for the epileptic victims to be discriminated by non epileptic community groups.

#### **4.3.2.4.2. Feeding Habit**

As study indicates, majority of epileptic Meint community's lives in absolute poverty and their livelihood highly depends on begging in streets in market days, in church and mosque compounds(Workineh, 2017). They have no income to afford their basic daily needs. As result of this they eat and consume un-slaughtered animals by finding where it is available besides begging in streets in market days, in church and mosque compounds. Due to this, community discriminate epileptic sufferers for their feeding habit of un-slaughtered animals in view of the fact that eating dead animal flesh is taboo and sin which disappoints God. One of the male informants from non epileptic community who has age of 26 explains the situations during interview as follows:

*'Some epileptic victims eat un-slaughtered animal flesh. I can give witness for this. I didn't approaches with such like peoples. Because they break the rule of the god since the action were sin the eyes of God.'*

Epilepsy also leads to multiple interacting medical, psychological, and social repercussions, all of which need to be considered. Fear, misunderstanding, and the resulting social stigma and discrimination surrounding epilepsy were the main challenges in which PWE suffer. The social effects may vary from country to country and culture to culture, but it is clear that worldwide the social consequences of epilepsy are often more difficult to overcome than the seizures themselves. Therefore, communities discriminate PWE by banning eating, sharing common resources like water sources, firewood and marriage with epileptic victims.

In Me'int communities , a single undiagnosed seizure like falling is considered as epilepsy. This was mentioned by study discussants. Then after, immediately all family and community members are never approach the potential individual. Besides, epileptic victims isolated and banned by the community and they kept in the small huts to avoid its transmission. One of male non epileptic community leader aged 39 years old explained his during interview as follows:

*'' Then, we looked her; it was seems the epilepsy and then, decided not to approach her. Since she is very old at this time, we prefer her to stay at very small village alone since she may transmit her disease to us and to our children. That is why we made her house far away from our village. In near distance, we are following her and keeping our community.'*

In Me'int communities sharing common resources with epileptic patients were banned. For instance, it is not permitted by non-epileptic Me'int community using water materials they used and even fetching from different water resources. Isolating people from using common house hold materials. One of the male community informants from non epileptic group who have age of 44 explains his idea during depth interview as follows:

*''If you feed her mouth remnants and when you share drinking materials with her, it could be contaminated in different ways; that is why we left her and lived alone; there is someone who was infected with this disease after living in the house with client; No one wants to visits that house or place where lived/sat in.''*

Participants talked about the extension of segregation. Families never allow victims home return after disease appearance. One of the male FGD participants who have age of 32 years old explains the scenarios as follows:

*“ We think it was before 15 years; we did not seen when it falls currently. Now, she is living alone and nobody wants to approach her and even when fetching water, she fetches from different source.”*

#### **4.3.2.4. 3. Challenges in martial relationships**

People with Epilepsy had difficulty in marrying when they developed epilepsy (or their epilepsy was disclosed to the community).If epilepsy is developed after marriage; divorce is one means of solution as invitees spoken. One of the married epileptic informants aged 29 years old explains his view as follows:

*”One of our friends got married and in a meantime, she experienced this disease and then neighbors neglected them and now they were not living together and she went Mizan.”*

If people with epilepsy develop seizures, asking for prices expensed for marriage is very common and uncertain but leading to family conflict.

*“ Just I have fallen and then I never got injured; however, my partner denied and banned me out of my home with my two kids. And he aggressively asked my family to return all expenses that we used for marriage.’*

Thus, social stigma has great consequences on daily life of people with epilepsy which results in loss of trust on others. This may leads to further complication like it leads to anxiety, depression, suicidal thoughts; sign of bad omen. PWE experience low perception from other non-epileptic Meint communities and as a result of this, they lose hope. One of epileptic female informant who has age of 29 years old explained encountered challenges during FGD discussion as follows:

*When we go to market or town, children on road always ridiculed and teased us; Oh! I feel great! Really I feel great! Do you know why? I never got it from my*



*mom's womb; People live for long-life in mean time they become epileptic; Like that, just I cannot bring by myself; It is not man-made.''*

In general, epilepsy-related stigma is largely driven by fear of infection by non epileptic community. Despite epilepsy not being contagious, some believe that epilepsy is contagious through saliva and such fears of contagion and related prospects of community towards epilepsy created a problem when the patient experience sudden fall due to the disease. In some contexts, some community's believed that epilepsy is a curse or caused by witchcraft. Hence, members of the general community endorse beliefs that people with epilepsy cannot contribute meaningfully to society and are poor prospects for marriage and employment. As a result of this people with epilepsy experience a several challenges from community. The current study identified various manifestation factors such as social discrimination and exclusion in a range of contexts, including familial, marriage arrangement and job opportunity which is almost similar and consistent with the issues listed under manifestation model of health stigma and discrimination frame work. Further, through looking the health stigma and discrimination theoretical frame work, problem in familial interaction, marriage restrictions and denied job opportunity was intersecting stigmas according to study results. More over epileptic victims suffered stigmas that intern negatively influence and impacts their daily lives. Thus, based on current study the impacts of stigma on the lives of affected people included lower self- esteem lower medication adherence etc... which greatly undermined the quality of life of people living with epilepsy.

#### **4.4. Roles of various actors to mitigate the challenge**

##### **4.4.1 Role of religious leader towards mitigating the challenges of epilepsy**

Different religious denominations in study area, such as Muslim, Orthodox, Catholic and Protestants have their own healing mechanisms and religious teachings based on their religious scripture towards epilepsy. In general ,the perceptions and beliefs associated with epilepsy are similar in various religious denominations despite of variation in healing mechanisms (Bolhari et al., 2002). The same is true in the study area. According to FGD results , religious leaders from Muslim, orthodox Christian, Catholics and protestants argue that their religious scripture accepts every disease including epilepsy considered as much

as God calls for tolerance and respect for the patient since the disease may occur for the will of the God and not necessarily a punishment for something bad that epileptic patients done. Rather, religion followers should deal with patients in all matters of life of the victims. One of the FGD male participant and religious leaders from Islam who has age of 55 years old explains his idea in the following way:

*‘‘Well, Islamic religious scriptures contains some interesting elements on its teachings about persons suffering from different types of disorders. Whatever happens to a person may be the will of God and not necessarily a punishment for something bad they have done’’.*

This suggests that persons suffering from disorders should be treated in a dignified manner with love and respect. Besides, the Muslim religious leader extends his idea as the following on the holy Quran sayings in all aspects of life and medical concepts in general.

*‘‘There are some chapters in the Quran that deal with health and sickness, rules of hygiene, and medical concepts in general. Further, Muslims refer to the holy Quran in all aspects of their life’’.*

Similarly, Christianity in its Holy scriptures and different teachings of the Church stresses that every mankind have a responsibility to provide care and support with special attention to these categories of discriminated or isolated persons in need. Religious fathers of the three major Christian denominations in the area (Protestant, Orthodox and Catholic) hinted to the researcher that this phenomena is clearly indicated on the Bible John 4:4 where Jesus demonstrated the needs to help the sick and the dying destitute with his love, affection and belongingness to persons suffering from Albinism and ‘Evil Sprit’ respectively.

But in some parts of the area, based on our FGD session and observation result, communities especially children and youth comply with this actions negatively as it is witnessed by the case story of the poor girl who lives under the shade of a tree on the way to one of the school who became a blind with a stone thrown by the school children while they throw it to hit her.

#### 4.4.2 Role of governmental office stake holders towards mitigating epilepsy

Based on the research findings, epileptic people's faces challenges in their daily lives. The researcher tried to assess the role of governmental office stake holders in relation to mitigating the problem of epilepsy in the study area. The researcher interviewed, health office professional who currently worked at study setting through putting the study findings in mind that since pregnant women in Me;int community deliver birth with the help of traditional birth attendants and the trend of visiting health care center for medical health diagnosis is very low. Thus, one of female health professional aged 24 years old worked on Bachuma Woreda health office explains her idea as during interview as follows:

*“ Delivering child at home by women accounts long time ago and I and my colleagues try to change the attitudes of the communities as far as our potential. Before I mentioned Me;int women deliverance takes place in the barn & at home. During this, the baby would face falling to the ground. Besides, instead of coming to health post for delivery, some Me'int women invite traditional birth attendants. Imagine delivering mechanism by this traditional birth attendant is not safe and didn't use gloves to take deliveries”.*

Moreover, another question is raised for her on how to minimize unsafe way of birth delivery outside health post.

*“ We tried a lot to break this way of doing by creating awareness. Still I never forgive up! We give awareness creations and trainings in health center as well as on spot in which the clients available. In so doing, the trainings result a remarkable drop in the number of children delivered at home plus it is possible to minimize number of children that will develop epilepsy”.*

Hence from the above point, it is possible to understand that government office stake holders tried to minimize the problem related with epilepsy through delivering awareness creation for the communities even though the results achieved was not sufficient and satisfactory.

#### 4.5. Discussions

This chapter presents discussion of the results regarding on community's beliefs towards epilepsy, etiological views of the community towards epilepsy, and socio cultural challenges of epilepsy with incorporating various studied thoughts that directly or indirectly touched the current study.

In study area, communities were not well informed about the cause of epilepsy. The research finding deduced that the beliefs of the community toward epilepsy worrisome. Communities attributed various etiological causes for epilepsy. Magic, low obedience to locally worshiped Qolle, epilepsy as contagious, trans-generational and inheritance were considered as perceived cause of epilepsy by Me'int community. This finding was mainly consistent with the study of Workineh on socio economic and health situations of epileptics in Bench Maji Zone, south western Ethiopia. His study reported that, epilepsy is caused as result of curse from God and considered as mental disease by community (Workineh, 2017). But the current study finds out further thoughts and beliefs by community regarding on etiological causes of epilepsy.

Moreover, in the study conducted on prevalence and factors associated with perceived stigma among patients with epilepsy in Ethiopia indicates, 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 and the rest 31.5% of the respondents didn't know the cause of epilepsy (Fanta et al., 2015). In similar fashion, study conducted on perceived stigma and associated factors among peoples with epilepsy at Gondar university hospital in 2015, indicates 46% of the study respondents consider epilepsy caused as a result of God punishment for the commitment of sin by individual (Bifftu et al., 2015). However, the recent study finds out that substantial number of study informants consider etiological causes of epilepsy with magic and inheritance of properties from passed away epileptic patients by families mentioned as etiological causes.

As per many studies, a person with epilepsy faces various problems, stigma and discrimination due to disease condition and wrong perception about the condition(Birbeck et

al., 2007) . In cognizant to this, in the current findings, several numbers of epileptic victims in the study area face social banishment, stigma and discrimination from the community. Moreover as a result of enacted stigma, PWE most of the time not ever uses drugs for their diseases and also has not getting basic health services. This finding was similar with the study conducted in Zambia that Stigma impacts a person's ability to access and adhere to medical treatment, erodes their quality of life, and may threaten their basic survival (Birbeck et al., 2007).

Moreover, quantitative studies of PWE in this region have shown that PWE are less likely to use basic health services, have poorer food security, and are more likely to experience sexual assault than their peers unaffected by a health-related stigma (Birbeck et al., 2007). . But current study is more consistent with this the current study findings on that, PWE in the study area have poorer food security and faces health stigma. However, it showed difference in findings that majority of epileptic victims in the study area not use basic health services and faces social discrimination by non epileptic community rather than suffering sexual assault from other peers unaffected by epilepsy.

Further, the current findings showed that medical adherence of epileptic patients to modern treatment is low. As option the patients prefer traditional medicine for their sickness. However, evidence has shown that these negative societal portrayals of epilepsy may affect the initiation of prompt medical treatment and management of the disorder (Jacoby et al., 2005b) . This has made people with the disorder to have poor self-image, low self-esteem that compromised their mental health status, such as anxiety, depression, shame and the feeling of guilt. This finding is similar to current study that the imbedded negative social portrayals of community towards epilepsy crucially affect the initiation of victims to adhere medical treatment on time.

Moreover, as studies indication, Epilepsy is associated with increased levels of psychological and psychiatric morbidity, including anxiety and depression, low self-esteem and a reduced sense of mastery (Devinsky, 2001). In similar fashion, the current study findings is consistent with this study findings on that PWE faces with high level of

psychological and psychiatric morbidity, including anxiety and depression, low self-esteem and a reduced sense of mastery. The current study is consistent with these study findings but finds out also the factors that magnifies psychological morbidity of PWE. Despite the above mentioned causes for physiological and psychiatric morbidity for PWE, the current study additionally found lack of social support and stigma as factors that fuel the psychological problems of epileptic victims.

## Chapter Five: Conclusion and Recommendations

### Conclusion

As any traditional community, Me'ent peoples are also living in a context of traditional beliefs which guides the way of their life in their localities. Based on the study findings, the communities attributed various reasons for etiological causes of epilepsy. These are epilepsy as contagious, trans-generational, curse from God or evil things, asset transference (inheritance), magic and low obedience to traditional beliefs. As a result of this, non epileptic communities did not approach with epileptic victims, for their belief that epilepsy as contagion and transmittable disease which in turn fuels social discrimination. Beside, the communities did not allow marriage and other social interaction with peoples with epilepsy. This is due to the deep rooted traditional culture of the community's and their belief that the disease can transmitted through blood contamination as well as the pregnant epileptic women will transfer the disease to the new born baby. Further, through observing the symptoms of the diseases in which epileptic victims experience likes shaking, foaming of mouth, rolling of eye etc , the non epileptic communities associates the etiological causes of epilepsy with curse from Gods since the characteristics of this disease quit different than signs and symptoms of other diseases as well as strange in the community. Magic and low obedience by Me;int communities to traditionally worshiped God, which is traditionally termed as Qolle is the other etiological causes of epilepsy. In Me'int culture, Qolle is an indigenous traditional belief of the community whereby the followers worship their traditional 'god' maintaining different practices and making scarifies. Thus, according to Meint community cultural belief, epilepsy is caused as a result of sin from Qolle, when the individual Meint clan failed to sacrifices intended gift for the worshipped Qolle. Moreover, inheritability/transferability the property of passed away epileptic patient to other family members is considered as the reason for one to develop epilepsy. Hence, the inheritability/transferability of property is prohibited according to their community norms and this norm is complied with only the families of the passed away epileptic victims. Violating this norm is considered as sin and taboo according to their traditional norms. The overall assets produced by the passed away epileptic patient are immediately burnt by community. According to their beliefs and arguments inheriting the passed away epileptic

patient property to other family's considered as passing the curse of the dead to other family members.

Therefore, unreasonable beliefs of the Me'int community towards epilepsy and their miss information on etiological causes of epilepsy create serious negative social and psychological consequences for people with epilepsy create limitations in social interactions as well as increase the stigma and make the lives of people with epilepsy more difficult.

Attitudes towards people with epilepsy tended to be more negative in the study area. In Me'int communities PWE were seen as physically weaker and less competent persons because of their tendency to seizures. Moreover, as a result of community's misconception, epileptic patients were suffered stigma and discrimination in their Jobs as well as in their daily leaves.

In similar manner, in study area, many people with epilepsy experience problems with physical abuses and injury, which truly lead to poor quality of life and even for deaths. An injury was from disease condition or from outsiders. Moreover, people of Menit never approach to seizing individuals since they perceive it as a contagious. This makes no saves from disease based injury especially from burns. As a result of this, the patients lose their physical bodies.

Besides, People with epilepsy have been facing physical injuries from outsiders due to the diseases. For this purpose, family may kill and send by river for sake of avoiding social burden. Unlike other ethnic groups in Ethiopia and rare outside, murder of epileptic client is culturally prohibited act among the Me'net people. But, sometimes there is a hidden practice by rare individuals at the nomadic areas. Even, to make the matter worse, in these areas nobody is willing to bury the dead body of epileptic patients as per discussants.

According to the study findings of (Workineh, 2017) , majority of epileptic victims lives in absolute poverty. They have no income to afford their basic daily needs. Beyond, poor living conditions of epileptic victims, non epileptic communities occasionally discriminate epileptic victims for their sanitation keeping standard and their feeding habit which was observed by researcher at the study area.



In Me'int community, inadequate health delivery systems, lack of trained personnel, and lack of essential drugs are not only the reasons for the epileptic patients to seek medical care. The long lasting traditional beliefs and practices often do not consider epilepsy as a treatable condition. Hence as a result of this, treatment gap greatly increases the burden of epilepsy and disability. Besides in Meint community culture most of the time pregnant epileptic women deliver birth outside of the home and also consider institutional delivery as a taboo but they have got health education about the benefits of health care delivery as well as the risks of home delivery. Hence, the pregnant women in Me;int community deliver birth with the help of traditional birth attendants. In support to this, different study findings indicate that, epilepsy has been associated with multiple causes' poor antenatal care and an intracranial infection was thought to be the main causes. As study finding indication, epileptic patients were neglected in different health care services like treatment, malnutrition and family planning services.

As result of misinformation on treatment gap of epilepsy most of the patients prefer traditional medicine for their sickness. Thus firing matches and spiritual healing was the most preferred method of treatment for epilepsy in Me'int community and hence, they opted this method of treatment since they believe that the disorder was a result of affliction by evil spirits

In conclusion, as a result of wrong belief and miss information of non epileptic communities on etiological causes of epilepsy, peoples with epilepsy suffers limitations in social interaction as well as faced social discrimination and stigma that make the lives of peoples with epilepsy more difficult. Persons with epilepsy suffered from enacted stigma in the form of isolation and bystanders' unwillingness to intervene in providing needed social support. Besides, the long lasting traditional beliefs and practices often do not consider epilepsy as a treatable condition, there is, inadequate health delivery systems, lack of trained personnel, and lack of essential drugs in the community which in turn greatly increases the burden of epilepsy.

## **Recommendations**

Based on study findings, the belief of the community towards epilepsy as well as the problems related with the people living with epilepsy in the target area have multifaceted forms and requires long term plan and concerted efforts of concerned body. The investigator has drawn possible recommendations below that was direct linkage with the major findings of the study and by tracing on reflected views and opinions of the people participated in the study.

- Coordinated and strong effort should be exerted towards improving the knowledge or awareness of the community about epilepsy especially the local beliefs or longstanding perceptions on the cause and transmission of epilepsy. With this regard, the community leaders (clan leaders, youth leaders, village representatives, influential women) should get better awareness as a TOT on the issue so that they intern may transmit the knowledge they acquired to their fellow community members.
  
- Leaders and followers of the indigenous traditional beliefs in the area should get a continuous formation as a community conversation about human dignity in order that they may understand they are adding more harms to the victims of this chronic disorder and abstain from doing such harmful inhuman actions.
  
- The governmental health extension workers in the area should get more practical trainings on provision of special care and support to the victims of Epilepsy like First Aid support to the patient during Epileptic seizures. This should include antenatal care, institutional delivery service, and postnatal care.
  
- In most distant and rural areas where there is no access road, it is better to train traditional birth attendants in order to reduce the prevalence of Epilepsy in the area as they will work to tackle the strongly suggested predisposing factor to the cause of Epilepsy in the area which is head or skull injury which happen when mothers give birth in standing positions.

- The Ministry of Health through its local health facilities in the area should avail necessary Epileptic Medicines and important medical equipment in favor of the patients.
- The major religions in the area with their golden teachings about provision of care or support to the sick and the destitute should exert more practical efforts to relieve the pain and alleviate the sufferings of the victims. In addition; the local governmental organizations, community based associations and regional development associations should strengthen their efforts to improve the awareness of the community towards the victims and also to build self esteem of the patients. This should include medical care support, nutritional support, psychosocial support, support to improve the sanitation and hygiene practices, rehabilitative supports to the physically disabled and special economic support to sustain livelihood.
- Legal aid and Shelter/Housing support are also the major areas that the local community, developmental partners and the concerned governmental departments should give more attention to ensure the survival of the Victims as it will help them lead a dignified life.
- Major Research centers and higher educational institutions like Mizan-Teppi University and Aman Hospital should undertake further study on the magnitude and severity of the problem since the researcher believes that there are many problems to be studied or investigated so as to put measures to tackle the disorder and its associated consequences.

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## Appendix

### Appendix I: Action plan/ Research Plan

No.	Activities	Time frame in terms of months October 2019- June 2020												
		No v	Dec	Jan	Feb	Ma	Apr	May	June	July	Aug	Sep	Oct	Nov
1	Topic approval	*												
2	Preparation of thesis proposal		*											
3	Submission of the first draft thesis proposal		*											
4	Submission of the final thesis proposal			*										
5	Approval of proposal (Final)			*										
6	Data collection					*	*	*	*					
7	Data analysis and report writing					*	*	*	*	*				
8	Submission of the first draft thesis										*			
9	Submission of the final thesis											*		*
10	Presentation and defense of the thesis													*

## Appendix II: Budget Plan

No.	Description	Unit of Quantity	Unit price	Total price
	Stationary			
	Computer paper	5	10	50
	Flash memory	2	150	300
	CD-RW	2	125	250
	pen	10	5	50
	Stapler	2	40	80
	Staples	30	25	750
	Clip board	3	35	105
	Photo copy	400	2	800
	Printing	400	2	800
	Binding	2	300	600
	<b>Subtotal</b>			<b>3785</b>
	<b>Other expenses</b>			
	Digital camera	1	4000	4000
	Secretary cost	2	400	800
	FGD participants costs	35	20	700
	Key informants refreshment	25	30	750
	<b>Sub total</b>			<b>6250</b>
	<b>Personal expense</b>			
	Transportation cost	300	17	5100
	Daily expenses	150	60	9000
	Internet expenses	20	30	600
	Telephone expense	25	60	1500
	<b>Sub total</b>			<b>16200</b>
	<b>Grand total</b>			<b>26,235</b>

### **Appendix III: Letter of Introduction and Informed Consent**

Study Title: community beliefs towards epilepsy and the socio-cultural challenge of epileptics. In the case of Bench Maji Zone, Me'int Goldiya Woreda, SNNPR.

My Name is Asaye Tirfu. I am graduate student at Jimma University in the department of Sociology concentration in (Social Policy). The purpose of my study is to investigate community beliefs towards epilepsy and the socio-cultural challenge of epileptics in Me'int Goldiya Woreda. The interview will last an hour to two hours and will be conducted in your suitable place. In order to not miss, any information, the interview will be audio taped and its identity number given for each. All the information you provide will be kept confidential and the raw data filled in the safe place where only the researcher can access, and finally the record voice will be formatted. Your names and any other identifying details never are revealed in any publication of the results of this study. The results of the research will be published in the form of a research paper. The knowledge obtained from this study will be of great value in contributing its part for the effort of overcoming the socio cultural problems aroused as result of being epileptic.

**Appendix IV: Consent Form**

**Email: asayetirfu@gmail.com**

**Tel. +251917100831**

**Consent Form**

I, \_\_\_\_\_ the above informant, freely agree to participate in this study. I understand that I am free to refuse to answer any question and to withdraw from the study at any time. I understand that my responses will be kept anonymous. Participants Signature: \_\_\_\_\_

Date: \_\_\_\_\_

If you would be willing to be contacted again in the future for a possible follow-up interview, please provide contact information below:

Mailing address: \_\_\_\_\_

Email address: \_\_\_\_\_

Tel: \_\_\_\_\_

If you are willing to participate, shall I proceed to the questions? Thank you!

## **Appendix V: Instruments of data collection**

### **Interview guidelines for communities**

This in-depth interview Guide is prepared for the purpose of eliciting information on the beliefs of the community towards epileptics in Me'intGoldiyaWoreda. Hence, under this section, questions are designed to assess the belief of the surrounding community towards PWE based on several aspects of social life.

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 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. Religion \_\_\_\_\_
4. Ethnic background \_\_\_\_\_
5. Marital status \_\_\_\_\_
6. Occupation \_\_\_\_\_
7. Do you know the problem of epilepsy? How do you know?
8. How much the problem of epilepsy is serious in your community?
9. Do you think that people can contract the problem of epilepsy?
10. Do you think everyone in the community is convinced to avoid an epileptic person from his/her village?
11. Does an epileptic patient from your village participate in any form of social gathering like Idir, Equb, mourning and wedding? If no, why?
12. How do you explain the sanitation issue in peoples with epilepsy?
13. In case, if someone with epilepsy experience active seizure and falling in somewhere, in this moment what do you do?
14. Would you hire an epileptic person to your own business, provided that she/he has the skill?
15. What do you think that epileptic people should do to recover from their illness?

## **Appendix II: In-depth interview guidelines for PWE.**

This interview Guide is prepared for the purpose of eliciting information on the socio-cultural challenges in which peoples with epilepsy suffer. 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 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. Religion \_\_\_\_\_
4. Ethnic background: \_\_\_\_\_
5. Marital status \_\_\_\_\_
6. Occupation \_\_\_\_\_
7. Do you know the problem of epilepsy? How do you know?
8. For how long since you become epileptic?
9. How do you check your sickness as epilepsy?
10. How you disclose your epileptic situation for the first time you face seizure?
11. How you feel in that moment when you realize you become epileptic patient?
12. What type of medicine you receive to calm your disease? Is it from government or from traditional medicine?
13. Are you participating in any form of social gathering like mourning and wedding with the non-epileptic people in your surrounding community? If yes/no, why?
14. How do you rate your interaction with non-epileptic patients?
15. How do communities react, when you experience seizure suddenly?
16. In case, if you need a help during active seizure, do you think you can easily find someone to help you? If no, why?
17. How much the problem of being epileptic is serious in your community?
18. Do you experience body damage as result of the disease?
19. What type of body injury damage you experience?

20. How this physical injury occurred?
21. Have you ever got any advices from health professionals about your epileptic situation?  
If yes/no, why?
22. How do you rate government as well as non-governmental contribution and support in relation to solving problem of your disease?
23. At the end if you have any suggestion and comments regarding on related issue, you most welcome.

### **Appendix III: Interview guide prepared for government and non-governmental stakeholders**

The objectives of conducting interview with government as well as non- governmental organizations are to gather information on their work experience and contribution towards epileptic victims in relation to solving their social problem so far.

1. Sex: \_\_\_\_\_
2. Educational background: \_\_\_\_\_
3. Occupation: \_\_\_\_\_
4. Name of organization: \_\_\_\_\_
5. Religious background: \_\_\_\_\_
6. How do you rate the living standard and social interaction of epileptic patients with other non-epileptic patients?
7. What is your organizational role in a way to address the social problems of epileptic patients?
8. How do you see the level of confidence and emotional stability of PWE in their day to day activity as compared to other people?"
9. How do you level your organization intervention on improving the living conditions of epileptics?
10. What do you recommend to improve the living conditions of epileptics?



# FGD

## Appendix 4: FGD Interview guide prepared for Religious leaders

Focus group discussion had been conducted with religious leaders from four religious denominations, such as Muslim, Orthodox, Catholic and protestant religious leaders having objective of digging out the collective religious views and opinions about the issue of epileptic community in the study area. Besides FGD was selected by the researcher in order to cover enormous number of informants and to use the identified data gathering tool in conjunction that will be used as a form of triangulation. Further it used for researcher as was a way of learning from every body's faces and speech.

1. Sex: \_\_\_\_\_
3. Religious type: \_\_\_\_\_
4. Educational background: \_\_\_\_\_
5. Role/position in the church/ mosque: \_\_\_\_\_
7. How do epilepsy explained in terms of religious point of view?
8. How much the problem of epilepsy is serious in religious aspect?
9. How do you rate the participation of epileptic patients in religious institutions?
10. How do you rate the interaction level of epileptic patients with non-epileptic?
11. What do you think is the role of your church/mosque, to improve the socio cultural and health situations of PWE?
12. At the end if you have any further comments, suggestions and ideas regarding on the issue of PWE and non- epileptic communities, you most welcome.

## **FGD with traditional religious leaders**

### **Objective**

The objective of conducting FGD with traditional religious leaders in study setting was collecting information on traditional religion views on epilepsy, their beliefs towards epileptic patients and to understand their cultural practices and experience for healing of epileptic patients.

1. How does epilepsy understood and interpreted based on traditional religion aspect?
2. How much the problem of epilepsy is serious in your community?
3. Do have epileptic patient in the community who follows traditional religion institution in the community?
4. What about non- epileptic communities?
5. How do you rate the interaction of epileptic victims with non- epileptic community during traditional religious worship?
6. According to traditional religion faith, how do epileptic patient can be relieved from their sickness?
7. What do you think is the role of traditional religious institutions, to improve the socio cultural and health situations of PWE?
8. At the end if you have any ideas, suggestions and comments cognizant with the issue at hand, you most well-come.

## **FGD with community elders**

### **Objective**

Focus group discussion had been conducted with community elders in study setting with objective of eliciting their social interaction experience with epileptic victims, their beliefs towards epileptic and their views on etiological cause of epilepsy. Besides, discussion had been conducted with community elders aimed to get information on their socio- cultural challenges in which epileptic patients suffer from

1. Do you know the problem of epilepsy? How do you know?
2. How much the problem of epilepsy is serious in your community?
3. Do you think people can contract the problem of epilepsy?
4. Do have epileptic patients participated with non-epileptic patients in the same Idir. If not, why?
5. If they participate with the same Idir with non- epileptic patients, how do you rate their social interaction?
6. What do you think is the major psycho social and health challenges of PWE in the community?
7. What do you think is the role of community elders to improve the socio cultural and health situations of PWE?
8. At the end if you have any ideas, suggestions and comments on cognizant with the issue at hand, you most well-come.

## **FGD with epileptic victims**

### **Objective**

Focus group discussion had been conducted with epileptic victims to collect information on the psycho social challenges of epileptic victims due to the disease. Besides, it was conducted with objective of eliciting information on psychosocial challenges and opinions of several epileptic victims with covering more informants at the same time that provided as a measure of validation for the information that allow others to challenge extreme or false views in the group.

1. How much is the problem of epilepsy is serious in your community?
2. How do you rate social interaction of PWE with non-epileptic communities?
3. What are the major psycho social and health challenges faced by epileptic's community
4. How do you rate the commitment of government, NGOs and other stakeholders in relation to support they delivered for mitigating the problem of PWE?

## Appendix six -Observation Check list

### Observations

Observation schedule protocol	Parameters/indicators
<b>Belief of the community towards epilepsy</b>	
Social interaction of communities with PWE	Observed in social gatherings such as in Idir, religious ritual
Business men way of serving PWE	Observed in restaurants, in coffee and tea shopping,
Extent of first aid support from bystanders , when patient suffers from sudden epileptic seizure	Critically observed the situations in where much populations engaged, might be in market days, probably may be in streets
<b>Socio cultural practices</b>	
Cultural practices undertaken by community to healed from epilepsy	<ul style="list-style-type: none"> <li>- Observed at churches, health center, visiting traditional medicines home.</li> <li>- Observing the utilized medicine by PWE, when they feel sick.</li> </ul>
<b>Challenges</b>	
The current living situations and challenges of the victims.	<ul style="list-style-type: none"> <li>- Living environment of the victims visited.</li> <li>- Extent of social interactions of victims with non- epileptic communities was inspected.</li> </ul>