A Study on the Socio-Economic Problems of Epileptic People Among Me'enit Tribe

The Case of Me'enit Goldia Wereda SNNPR Ethiopia

A Desertaion Prepared in Partial Fulfillment for Master of Arts Degree in Rural Development

Prepared by: Sileshi Getahun Melisie [**IDNo.089132473]**

Advisor's Name: Milkesa Wakjira **(PhD)**

Submitted to: **Indira Gandhi National Open University**

School of Continuing Education

May 2015

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ABSTRACT

This study sought to explore the socio economic problems of people living with epilepsy in Me'enit Goldia wereda at Bench Maji zone administration from the point of view of rural development .The study used qualitative research method to collect and analyze primary data from the target people and other community members.

Accordingly, structured interview questions were presented for the PWE and open ended questions for focus group discussion participants. Few of the PWE in the target area were pulled to gether and settled by Ethiopian Red cross Society and Mizan Aman town administration to the village called "BALA". Many of them still are living in different towns in a vanguard manner. For this reason, the investigator chose to focus on those who were pulled to gether from towns and settled at the village though they are small in number. In spite of the small sample size, the investigator concluded that the people living in the village could possibly represent the whole population group affected by the disease. This was justified through the data collected using the various data collection instruments. Therefore, investigator has came in to conclusion that the main reasons for the problems related with these groups of people remains to the traditional and cultural beliefs of entrenched through the history of the people and requires concerted efforts of various group of people and institutions to work to gether in a sustainable manner.

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Photo of epileptic persons at different places in towns and Bala village

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ABBREVIATIONS AND ACRONYMS

AIDS-Acquired Immuno Deficiency Syndrome

BMZFEDD-Bench Maji Zone Finance and Economic Department

CSA- Central Statistics Authority

EU- European Union

FDRE-Federal Democratic Republic of Ethiopia

FGD- Focus Group Discussion

GTP-Growth and Transformation Plan

HIV- Human Immuno Virus

IGNOU-Indira Gandhi National Open University

NGO- Non Governmental Organization

PWE- People with Epilepsy

SNNPR- South Nations Nationalities Peoples Region

USDH- United States Department of Health

WHO- World Health Organization

1. INTRODUCTION

1.1 Background of the Study

Epilepsy is a neurological disorder that affects large group of people around the world. Anders Hildeman (2010) stated as the World Health Organization (WHO) estimates the point prevalence of active epilepsy is generally 4 to 10 per 1,000 people. The trend in developing countries ranges from 6 to 10 per 1,000 people. This illustrates, the estimated number goes to 50 million people in 108 countries in the world. The mean number of people with epilepsy per 1000 people is therefore 8.93. However, the incidence of epilepsy in developing countries is about twice that in developed countries, and about 80% of the world's epilepsy patients are living in developing countries.[1]

Depending on the above description on the incidence of epilepsy worldwide the estimation on the incidence of epilepsy cases in Ethiopia and the study area would be done respectively. Accordingly the populations of Ethiopia were 87,952,000 in the year 2014[2] and the incidences of epilepsy based on the ratio presented above were about 87,952 in the same year. Furthermore, this can also be taken to the

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[1] Anders Hildeman(2010),Early Predictors Of Seizure Outcome In Newly Diagnosed Epilepsy, Sydney :Chalmers University of Technology.

[2] Annual Statistical Abstract ,Central Statistics Authority (2014) ,Ethiopia

study area where the populations were found to be 133,556 in the year 2014 according to the data obtained from BMZFEDD[3]. Based on this proportion (10 per 1000 people) ratio since Ethiopia is one of the least developed country, and the possible estimation should be in the range between 133--140. However, according to the data related to epileptic incidences collected from the study area, the number exceeds the projected figure and found to be nearly 440 which is more than double of the normal estimation.

Furthermore, epilepsy is one of the world's most common neurological disorders, public understanding was so limited and the victims were facing problems related to health, other social services and economic deprivations. Parallel to other forms of marginalization practiced in many parts of rural Ethiopia, epileptic persons who live in Bench Maji Zone ,Me'enit Shasha and Goldia weredas were suffering from the worst kind of discrimination that was expressed in the form of evicting a ictim from his/her village. Moreover, the wider communities in the study area were not accepting epilepsy as any other medically treatable disease and have considered it as a catching disease. This implied , epilepsy in this society would be taken as a hereditary and contagious disease and the person

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[3] Bench Maji Zone Finance and Economic Department,2014.

affected by the disease was regarded as evil caller on the respective family .

Though it was not supported by research and empirical findings, the investigator has observed that there were high incidence of epilepsy in Me’enit tribe people that was largely associated with the cultural practice of child delivery which normally be carried out in unsafe and unprotected manner outside home with no support from any other skilled person or family member.

The FDRE government is taking various measures to improve peoples' health, productivity and skills. Among other benefits, these measures will increase the potential for government's policies, strategies and programs to realize their objectives. As indicated in the GTP (2010),the main initiatives that were expected to be realized in the strategic pillars are improving access to good quality higher and adult education ,very wide access to good quality primary health care services ,better access to safe water and sanitation facilities ,halting the spread of HIV/AIDS and other key infectious diseases ,improving food security and nutrition, and improved housing conditions [4]

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[4] FDRE, Ministry of Finance and Economic Development , Growth and Transformation Plan ,2010/11-2014/15, (2010),Addis Ababa

However, like any other socially marginalized people epileptic people who were denied of these rights and set aside suffering from extreme social and economic marginalization’s in their respective localities. These people have not been enjoying equal opportunities for social services like education, health and housing.

1.2 Statement of the Problem

Me'enit Shasha and Me'enit Goldia weredas are found in Bench Maji Zone/SNNPR; the people living in these weredas are known as Me’enit tribe people who have their own identity as a tribe and speak their own language and exercise their own culture.

As a matter of fact, if any member of Me’enit people regardless of age and sex found epileptic , the families, relatives and the whole community in the respective area would refuse to share any kind of social interaction with that person. For instance, if any one in a family found epileptic in these communities and the parents of the affected person tries to hide the fact and tolerate to live with them, the whole community put sanctions in their social life and it would largely affect their confidence and livelihood. For these cultural reasons, the families of the victims would evict them from their village mostly to towns.

After ones being expelled from their village, one can easily identifies them by their reckless personality and demonstration of un common behavior like shouting at people, crying and sleeping on streets in towns. Churches, mosques and market areas are the most common places in the towns for the victims to get shelter, food and clothes. Furthermore, this situation is more sever when it happens on woman, girls and children in general. Furthemore,the victims were facing various social problems like having no access for education, no access for health care services that would include family planning services and other medical facilities and housing to survive. Moreover, in relation to the income they may have, almost all of them are living in beggary in the places where they were evicted.

The problems of these people are not limited to starvation. Moreover, it requires much attention and care to protect them from further injury at the time of seizure. In actual fact, nobody would take initiative to support them when they found in seizure. Due to this reason, they frequently got injury in different parts their body. Physical damages were very common incidents happening in their day to day life, especially when they fall down around a fire, the flame burns any part of their body exposed to the flame. Based on the personal observation of the investigator, many of the victims who were living in Bala village were seen fatally injured. They didn't get any medical service even first aid support from other community members whether they fall in a fire, in a gorge or in a roads etc.

In spite of these fact, some efforts were being done by Mizan Aman town administration and Ethiopian Red cross society Mizan Aman branch, they brought them together and to got them settled in a small village called "Bala". This action has helped few of the target people (twenty six households) at least to have small land and struggling for survival. However, pulling them to gether in one place has also been criticized by some people for the reason of further isolation from other community members.

Therefore, if the problems continue affecting the target people and no any support provided ,the issue will be aggravated much and will affect the development initiative of the nation in general and the study area in particular . Having sought deeply in the impact of the problem the investigator believed to undertake the study so as to reveal the social and economic problems of the target people and give recommendations to contribute for the improvement of their living situation and help them lead better life and take part in the social and economic activities of their locality. For this reason the investigator took the initiative to conduct the study considering that the study is timely and crucial so as to help improve their lively hood and enjoy better life.

1.3 Definition of Operational Terms

Antiepileptic drug (AED): a seizure-preventing drug carried to the brain through the bloodstream.

Cognition: the process by which knowledge is acquired; awareness, thinking, learning and memory.

Convulsion: involuntary muscle contractions common in generalized tonic-clonic seizures.

eCommunities: A place for all people affected by epilepsy to share their stories

Epileptologist – a neurologist who specializes in epilepsy treatment. This is usually only recommended if standard treatment isn’t working or if diagnosis remains unclear

Epilepsy :is a medical condition that produces seizures that can affect mental and physical functions. It is also called a seizure disorder

Neurologist – a doctor who specializes in treating brain disorders, including epilepsy. A pediatric neurologist specializes in children’s brain disorders.

Incidence: the frequency in which something occurs over a specified time period

Seizure: abnormal electrical discharge in the brain. Seizures can be related to injury, high fever, substance abuse,metabolic disorders and other health conditions such as diabetes, and are not always a sign of epilepsy.

Social Life – This is the time of life when having friends and fitting in may seem to be all a child is thinking about. Being “different” in any way, such as having epilepsy, is not easy.

Substance Abuse – Alcohol and drugs are dangerous for all children, but even more so for children who are prone to seizures and may be taking medication for epilepsy.

1.4 OBJECTIVES

1.4.1General Objective:

The general objective of this study is to explore the socio economic problems of epileptic persons among Me'enit tribe so as to seek for means of improving the livelihood of the target people.

1.4.2 Specific Objectives

- To point out the social problems epileptic persons are facing in the study area and promote social inclusion;
- To explore the economic problems of the target people and propose measures to be taken to improve their living standard;
- To contribute to the efforts being done by various actors in the study area so that the living condition of the target people will be improved;

1.5 Basic Research Questions

- What are the Psycho social problems faced by epileptic persons among Me'enit ethnic groups?
- What are the economic problems faced by epileptic persons among Me'enit tribe?

- What are the underlining reasons for epileptic persons to be isolated and evicted from their families and relatives at the study area?
- What should be done by Government, NGOs and community groups to help improve the living situation of the target people?

1.6 Scope of the Study

The problems related to marginalization and social exclusion of epileptic persons is understood as high in the two weredas of Bench Maji Zone administration as in other weredas of the administrative zone during the discussion carried out with various Government offices, Community based organizations and people living in the target wereda during problem identification. The problems of epileptic persons are mainly associated with socio cultural factors and deep rooted beliefs that, epilepsy is hereditary and contagious disease.

Though the problem is a common concern in the two weredas of Me'enit tribe people, the investigator has decided to delimit the scope of the study to one of the two weredas. This is actually done in order to make manageable the study interms of geographic area, time and availability of resources. Based on this fact, the scope of the study is delimited to one of the two weredas namely Me'enit Goldia wereda and the epileptic people who live in shay Kebele ,Bala village where those epileptic persons pulled to gether from Mizan Aman town and surrounding areas have settled.

1.7 Limitations of the study

There were a number of limitations in this study but the key ones are described in the following manner : the broadness of the topic for it was not specific to one type of decision and the depth of the problems faced by the target of people, the distance the target people are living from the area where investigator is living ,the data collection setting almost all respondents were not only less conversant with Amharic language but also apprehensive about it this has forced the investigator to work with a translator who can understand both the local language and Amharic . The other limitation was the expectation manifested by the target people for some kind of material or financial resource after the interview and discussion sessions.

1.8 Chapter Plan

This part of the study presents the major components of the study which were classified in to seven chapters. The first chapter shall be an introductory part to the study and comprises of eight sub topics. These are: Back Ground of the Study, Statements of the Problem ,Definition of Operational Terms, Objectives of the Study ,Basic Research Questions ,Scope of the Study, Limitations of the Study and finally the Chapter Plan .

The second chapter has dealt with the Literatures' reviewed in the course of the study. The review has covered Theoretical review and Empirical reviews done by different authors. Furthermore, people's perception about epilepsy in different countries have also been reviewed to enhance the knowledge and understanding of the investigator so as to give shape and focus for the study.

The third chapter has dealt with the Research Design under which Description of the Study Area, Population; Sampling Procedures, Types of and Data Collection Tools, Data Collection Process and Organization and finally the Data Analysis Methods were presented in the given order.

The fourth chapter has also dealt with the data Analysis and Interpretations. The datas were analyzed and interpreted in such a way that the responses collected from various groups of respondents were classified in to four Thematic areas which were :Psycho-Social Effects of , Perceptions and Beliefs, Economic Implications and finally the Roles to be Played by Various Actors have been presented in their order of importance.

The fifth chapter comprises the major findings of the study and the conclusions where as the last chapter comprises the summary and recommendations of the study.
Finally the report included the reference section under which bibliography and appendices put to gether as complementary part of the study.

2. REVIEW OF RELATED LITERATURES

The literature review includes concepts and definitions related to the problem under study and helps the investigator to have better understanding on the socio economic problems of epileptic persons in various cultures and countries. Accordingly, literatures that constitute some facts about epilepsy and its impact in the life of the victim and related documents reviewed by the investigator while undertaking the study and are presented in the following manner.

2.1 Theoretical Review

2.1.1Definition

Epilepsy is defined by different authors in a more similar way , as defined by Folarin Oluseye Abimbola (2010),it is “an umbrella term used for neurological disorders characterized by seizures. Since the seizures might originate in different locations of the brain, the symptoms can differ greatly between patients all diagnosed with epilepsy" Seizure in Epilepsy can be viewed in different forms and the usual symptoms of seizures are classified as uncontrolled motoric movements or spasms, convulsions, emotional or psychological sensations, loss of consciousness and more. These are usually caused by signal feedback oscillations between neurons.[5]

Similarly, as defined by National Center for Project Access(2013)

Epilepsy is a medical condition that produces seizures that can affect mental and physical functions. It is also called a seizure disorder. Many illnesses or severe injuries can affect the brain enough to produce a single seizure. When seizures continue to occur for unknown reasons or because of a problem that cannot be corrected, the condition is known as epilepsy.

2.1.2 What Causes Epilepsy?

Causes for epilepsy to happen in a person can be seen differently in different contexts. According to National Center for project center (2010) for instance in about seven out of ten people with epilepsy, no cause can be found. This is called idiopathic epilepsy. Idiopathic is a Latin word meaning "of unknown cause". Among the rest of the people with epilepsy, the cause may be any one of a number of things that can make a difference in the way the brain works. For example, head injuries or lack of oxygen during birth may damage the delicate electrical system in the

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[5] Folarin Oluseye Abimbola (**2010)**Classification of epileptic seizures using accelerometers, Chalmers university of technology

brain. Other causes include brain tumors, lead poisoning, problems in development of the brain before birth and infections like meningitis or encephalitis. Epilepsy can run in families but it is not contagious you cannot catch epilepsy from someone else and nobody can catch it from you.

2.1.3 What is Seizure?

Seizures occur due to brief disturbances in the normal electrical functions of the brain. Millions of tiny electrical charges pass between nerve cells in the brain and connect to all parts of the body. When someone has epilepsy, this normal pattern may occasionally be interrupted by short bursts of electrical energy that are much stronger than usual. This can cause muscle spasms or uncontrollable body movements, loss of consciousness or confusion. These physical changes are called epileptic seizures. Normal brain function cannot return until the electrical bursts stop. Seizures can occur in just one area of the brain (partial seizures) or may affect nerve cells throughout the brain (generalized seizures). Most last a few seconds or minutes.[6]

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[6] Folarin Oluseye Abimbola (**2010)**Classification of epileptic seizures using accelerometers, Chalmers university of technology

2.1.4 Types of Seizures

There are different types of seizures manifested by epilepsy patients, as defined by Abimbola (2010**),** seizures are classified in to two general forms; these are seizures by origin and seizures by motoric symptoms. According to the same author , classification of epilepsy symptoms are further done into two major classes depending on the initiation of the case. They are called partial-onset and generalized-onset seizures. Partial-onset seizures start in a specific area of the brain. The symptoms depend on the function of that specific area. If the seizure does not alter consciousness it is known as a simple partial seizure. Partial seizures that cloud consciousness and cause abnormal repetitious movements are known as complex partial seizures. Partial seizures are usually associated with some kind of damage to a part of the brain. Not only these, Generalized seizures are those seizures where the whole or large parts of the brain experience abnormal electrical activity. This kind of seizure is usually much more dramatic given that many of the brain functions are affected at the same time. In many of these types of seizures, the subject will not have any recollection of the seizure afterwards. On the other hand, Seizures by motoric symptoms are classified by its symptoms that affects motoric functions. For instance, tonic episode of a seizure is the phase of constant muscle contraction that comes due to the disease. If a tonic seizure affects the heart, it will stop beating due to the contraction of the heart muscle. Contractions are caused by oscillations of neuro-electrical signals with frequencies so high that the muscle fibers will not have time to relax in between each pulse. This causes the muscles to experience a constant contraction [7]

2.1.5 Superstitions, Religious Beliefs, and Concepts of Epilepsy

Religious beliefs are a very important aspect of the life of societies. It is a relatively recent development, and with many restrictions, that they are considered a private matter. In early history, when much still needed to be explained about life, the realm of religious beliefs was large and included matters of health and illness. Hippocrates' polemic against the belief that epilepsy in its variable appearances was sent by gods and should be treated by purifications and incantations (Hippocrates, around 400 BC) is recognizable in what was documented in a Babylonian cuneiform medical diagnostic series from the middle of the first millennium BC (Kinnier Wilson and Reynolds 1990). The Greeks referred to epilepsy as the Sacred Disease, and over the millennia, the disorder has been associated with prophets, mystics, diviners, and the like (Temkin, 1971). Hippocrates began his discourse on the "sacred disease" by refuting the connection between epilepsy and the divine; he argued

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[7] Anders Hildeman(2010),Early Predictors of Seizure Outcome In Newly Diagnosed Epilepsy, Sydney :Chalmers University of Technology

against the widespread beliefs of prophetic and mystical powers attributed persons with epilepsy and the disorder's divine causation. However, Hippocrates attempt to dissociate epilepsy and religion was unsuccessful. Subsequent religious figures were asked to heal people with epilepsy. The New Testament gospels of Matthew (17: 14-20), Mark (9: 14-29), and Luke (9:37-43), who was a physician; recount how Jesus cast out the evil spirit from a boy with epilepsy who just had a seizure, there by curing him. According to De Toledo & Lowe (2003) throughout the Middle-Ages and the Renaissance, religious and magical treatments of epilepsy predominated and in the nineteenth century the religiosity of persons with epilepsy was stressed by physicians. [8]

2.2 Empirical Review

2.2.1 How common is Epilepsy? The Trend in Selected Countries

Epilepsy is a very common neurological disorder that exists in a place where human population is found. It affects people of all ages, Nations and races all over the world. According to National Center for Project Access,(2010),there are records of it since biblical times. Many literatures put peoples' perception in a negative way which is common to all countries whether in developed or developing. However ,in this study the

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[8] Wolf P (2006) Descriptions of clinical semiology of seizures in literature. Epileptic Disord pp.35-37

investigator has made review on the matter focusing on the situation of the epilepsy and its perception in Nations/countries like United states of America, Europe, Asia, Africa and finally in Ethiopia.

2.2.1.1 Epilepsy in America

United States of America is one of the Nations that affected by Epilepsy and epilepsy is found the nation’s fourth most common neurological disorder, after migraine, stroke, and Alzheimer’s disease. As reported in The Institute of Medicine's report (2012) 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.[9]

Furthermore, an estimated 2.2 million Americans have epilepsy, with approximately 150,000 new cases diagnosed in the United States each year. This shows that approximately 1 in 26 people will develop epilepsy at some point in their lives, and the onset of epilepsy is highest in children and older adults. Yet living with epilepsy is about much more than just seizures. For people with epilepsy, the disorder is often defined in practical terms, such as challenges in school, uncertainties about

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[9] The Institute of Medicine's report (2012) , Epilepsy across the spectrum: promoting health and understanding

social situations and employment, limitations on driving, and questions about independent living. [10]

2.2.1.2 Epilepsy in Europe

The European Region of the World Health Organization comprises 53 countries, covering the usual 'European' countries west of the Ural but also the former Soviet Union Republics including the 5 Central Asian Republics. The European Union (EU) is a grouping of twenty seven independent states and founded to enhance political, economic and social co-operation and integration. According to WHO Global Campaign Against Epilepsy (2007)In Europe, at least 6 million people have epilepsy, and 15 million Europeans will have one seizure at some time in their lives. Nevertheless, in some countries of Europe, epilepsy is not recognized as a brain disorder, and up to 40% of people with this condition may be untreated. This regional report for Europe provides a panoramic view of the present epilepsy situation in the Region, outlines the initiatives taken by the Global Campaign partners to address the problems, define the current challenges and offers appropriate recommendations. It is an advocacy tool and an instrument for dialogue

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[10] Institution of Medicine(2012)Epilepsy Across the Spectrum: Promoting Health and understanding :Washington DC,National Academy of Sciences pp.2-3

with governments, consumer associations, nongovernmental organizations, academic institutions and development partners.

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 . Studies of the prevalence of epilepsy show that 1 out of every 20 or 30 persons in parts of the world with poor health conditions has epilepsy; in other parts, such as Europe, the prevalence is about 1 out of every 100 to 150. Thus 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 and may not keep track of the latest developments in the field of epileptology.[11]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.

2.2.1.3 Epilepsy Among Asian

A cross-cultural comparison in Europe showed that there were significant differences in perceive stigma among people with epilepsy

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[11] Global Campaign against Epilepsy. Out of the Shadows: an introduction to the Global Campaign and its demonstration projects. Heemstede: Global Campaign against Epilepsy, 2001.pp.5-9 Also accessible at http://www.who.int.

from various European countries. It is expected to have a greater cross-cultural difference in stigma between the Western and the Asian countries. According to Kheng-Seang Lim, Chong-Tin Tan (2014), In the Various studies on social stigma or public attitude towards epilepsy, there were as high as (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.

When we look at experiences of various Asian countries we can see similarities in the people's perception about epilepsy, 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.

In a systematic review of public attitudes toward epilepsy, Asia and Africa were shown to be the two continents with the worst attitudes against employment in epilepsy where 50.0% and 80.0% of the published papers respectively reported more than 40% of participants with negative attitudes, as compared to none in North and South America, and Australia [12]

2.2.1.4 Epilepsy in Africa

The reaction to epilepsy in Africa is shaped by traditional indigenous beliefs which are surprisingly similar, in some way or other, throughout most of the African continent and result in severe psychological hardship. The African epilepsy sufferers have a hard time to achieve positive feelings about themselves and frequently suffer deprivations without protest. In 1970 Osuntokun & Odeku, reviewed 522 Nigerian epilepsy sufferers and observed that the patients suffered psychosocial handicaps including suicidal tendency because they themselves considered epilepsy a social disgrace. Moreover, modern treatment for epilepsy is often unavailable in Africa. The reason might be different in diverse situation but lack of treatment facilities take the major one, because the general belief that epilepsy is of supernatural causation and

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[12] Kheng-Seang Lim, Chong-Tin Tan(2014) **Epilepsy stigma in Asia: the meaning and impact of stigma** *Division of Neurology, Faculty of Medicine, University of Malaya, Malaysia*

therefore not treatable by Western medicine (Osuntokun & Odeku, 1970). [13]

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 (Carod-Artal &Vazquez-Cabrera, 2007). A person affected with epilepsy often demonstrate behavior of sudden impulsive onset and discharge of bursting seizures make the victim become visible as if in the hold of an eccentric power. This provokes powerful panic in those present and has most likely done much to be responsible for the belief that epilepsy is caused by evil spirits or other supernatural forces.[14]

An added cause cited by Mauritania Moorish populations is the diet; the term "iguindi" refers to all clinical manifestations including seizures attributed to excessive eating. In Nigeria, Africa's most populous country, epilepsy is thought to be contagious, and that belief is even popular

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[13] Osuntokun, B.O. & Odeku, E.L. (1970). Epilepsy in Ibadan, Africa *Journal of Medical Nigerian Science, 1*: p 185

[14] Carod-Artal FJ, Vazquez-Cabrera CB. (2007). An anthropological study about epilepsy in native tribes from Central and South America. *Epilepsia* 48(5):p.886.

among medical school students. A belief of the Bini of Nigeria is that epilepsy is a disease where the heart gets blocked by foam, restricting circulation and resulting in a seizure.

In Uganda epilepsy is thought to be a result of a lizard spinning around in circles in the head disturbing the brain causing dizziness, usually followed by a seizure. In Malawi epilepsy is thought to be due to an insect moving inside the stomach. In Swaziland epilepsy is thought to be caused by sorcery, which sends evil animals or spirits into the body, causing convulsion (Andermann, 2011). A connection between the phases of the moon and convulsive attacks has been made since ancient times. It was, and still, is believed that either the new or the full moon is directly influencing and provoking seizure activity). Sub-Saharan Africa- and the continent of Africa as a whole- attach a huge social stigma to epilepsy). Prejudice against the disease is common, persons with epilepsy are usually stigmatized and even pronunciation of the word ‘epilepsy’ is a taboo (Jilek et al., 1999).[15]

The traditional indigenous beliefs and traditional treatment of epilepsy in Africa contribute to the under-utilization of the medical health services,

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[15] Jilek-Aall L. Morbus sacer in Africa: some religious aspects of epilepsy in traditional cultures. *Epilepsia,* 1999;40:382–6.

to discrimination and social isolation. In 1997 the Global Campaign against epilepsy was launched to bring epilepsy 'out of shadows' to reduce treatment gap and social and physical burden, educate health personnel, dispel stigma, and support prevention (Diop et al., 2003). Cultural aspects should be studied with regard to patients' perceptions, attitudes and practices in relation to epilepsy, as well as their socio-familial relations. Information and education of the public in general is important in order to enable and empower people to make informed choices.(WHO, 2004).[16]

2.2.1.5 Epilepsy in Ethiopia

Ethiopia is one of the least developed countries in the world and the incidence of epilepsy in less developed countries tends to be higher than in industrialized countries. 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,2 but only 2–13% of people with epilepsy living in rural areas receive medical treatment. Berhanu S, Alemu S, Asmera J, and Prevett M (2008) .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

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[16] WORLD HEALTH ORGANIZATION 2004 Regional office for Africa: Regional Strategy for Mental Health, 2004.

treatment and cultural factors. The World Health Organization advocates the use of primary health care in less developed countries to improve access to treatment of chronic diseases, such as epilepsy .In Ethiopia, rural health centres, run by nurses and health officers are the focus of primary health care services to be given to the residing community. In line with health centre policy, patients who are unable to afford the cost of drugs and have the appropriate papers were given treatment without charge even for those patients having to pay for their treatment the cost of Phenobarbital is low.[17]According to the study conducted by Dawit Worku (2013)

It was estimated that 360 to 400 thousand epileptic Ethiopians are living with poor medication. The prevalence of epilepsy was 5.2/1000 inhabitants at risk, 5.8 for males, and 4.6 for females. The highest age-specific prevalence was found for ages 10-19 years. The annual incidence of epilepsy was 64 in 100,000 inhabitants at risk, 72 for males, and 57 for females. Generalized tonic-clonic seizures were the most common seizure type and occurred in 69 - 81%. 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

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[17] Berhanu S, Alemu S, Asmera J, Prevett M. Primary care treatment of epilepsy in rural Ethiopia. Ethiopian Journal of Health Development 2008;16: P.235

common associated disorder, found in 7.9 - 21% of the persons with epilepsy. EEG was recorded in 50 - 73% of patients in the capital city, Addis Ababa. 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.[18]

2.2.2 Public Perceptions in Some Selected Countries

Epilepsy as a natural disease is understood in many forms that in general reflect negative attitude towards the person affected by the disease. Some examples of these reflections are presented in the following manner as adopted from US Department of Health (2012) misunderstandings about epilepsy from around the world is presented in the following manner:[19]

- **In Cameroon** it is believed that people with epilepsy are inhabited by the devil. This does not mean that they are seen as evil, but that evil invades them and causes them to convulse from time to time.
- **In China**, epilepsy diminishes the prospect of marriage, especially for women. A survey of public awareness in 1992 revealed that

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[18] Dawit Worku (2013) **Resources, Quality Measures, and Epidemiology** Review Article: Epilepsy in Ethiopia Addis Ababa University, School of Medicine, Department of Neurology.

[19] US Department of Health; The World Health Organization(2012)

72% of parents objected to their children marrying someone with epilepsy.

- In some **rural areas of India**, attempts are made to exorcise evil spirits from people with epilepsy by tying them to trees, beating them, cutting a portion of hair from their head, squeezing lemon and other juices onto their head and starving them.
- **In Indonesia**, epilepsy is often considered as a punishment from unknown dark forces.
- **In Liberia**, as in other African countries, the cause of epilepsy is perceived as related to witchcraft or evil spirits.
- **In Nepal**, epilepsy is associated with weakness, possession by an evil spirit or the reflection of a red color. Bystanders who witness a seizure will often spray water on the forehead of the person experiencing the seizure of make him or her smell a leather shoe.
- **In the Netherlands** in 1996, a person was whipped and put into isolation because her seizures were thought to result from magic.
- **In Swaziland**, many traditional healers mention sorcery as the cause of epilepsy.
- **In Uganda**, as in many other countries, epilepsy is thought to be contagious and so people with epilepsy are not allowed to join the communal food pot for fear of others contracting epilepsy through that person's saliva.

2.2.1 Social Factors

2.2.1.1 Stigma and Misconception

Historical and media misrepresentations of epilepsy have been over whelmingly negative and consequently the condition has been clouded by misunderstanding, superstition and discrimination present over many centuries and across different cultures. This in turn increases the experience of stigma in PWE. 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 intimate relationships or maintain family relations. Consequently negative attitudes and lack of family support render the individual as being more vulnerable to psychosocial difficulties . 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 or are isolated within their family in an attempt to lessen the social stigma associated with the disorder and to increase marital prospects[20].

On a similar fashion ,as depicted on the works of Mary Jane (2012),People living with Epilepsy are stigmatized and socially excluded in many situations .Stigmatization leads to discrimination, and people with epilepsy experience prejudicial and discriminatory behavior in many spheres of life and across many cultures . A significant challenge for people with epilepsy, as well as for the epilepsy field, has been the multitude of ways that epilepsy is perceived and, in many cases, misperceived. As a consequence, people with epilepsy and their families may be faced with a lack of social support from extended family members; feelings of parental guilt; social isolation, embarrassment, and fear; and discrimination. Although efforts are being made to correct these misconceptions and to better inform people about the epilepsies, doing so remains a challenge. Both historically and cross-culturally, and with only rare exceptions, epilepsy has been represented as a stigma and, for many people with epilepsy worldwide; it is the continuing social reality.[21]

2.2.1.2 Effects on Marriage and Family Life

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[20] Quality of Life Issues in Epilepsy http://dx.doi.org/10.5772/58689 229

[21] Mary Jane(2012),Epilepsy and Behavior Boston University, 715 Albany Street, T5W, Boston, MA 02118, USA

Like any other person, people living with epilepsy have a desire to establish a family life. This actually is not a simple task for many of them to accomplish it within their own community, the potential impact of epilepsy on the family is difficult to gauge and is likely to be variable which would most affect the victim to feel loneliness. In addition to feelings of loneliness, as a consequence of Social isolation, emotional problems are the most common hindrances to marriage .Many of them have lacked close friends and unable to establish families in most cases (Temkin, 1971). Parents may be overprotective through fear of injury or death and they may harbor misconceptions about epilepsy and thus become socially isolated for fear of adverse public reactions.

The attitudes and understanding of families should therefore form a prominent part of any treatment programme.[22].

Little attention has been given to the possible impact on the family of a parent with seizures. Parents and potential parents with epilepsy often express doubts about their suitability for such a role and mothers may have the greatest concerns. Fears expressed include the potential inheritability of epilepsy and the possibility that antiepileptic drugs may lead to birth defects. As children grow older, parental vigilance may

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[22] Temkin O (1971) The falling sickness. A history of epilepsy from the Greeks to the beginning of modern neurology, 2nd edn, rev. Johns Hopkins University Press, Baltimore, MD

intensify as a watch is kept for any behavior or physical sign that might herald the onset of epilepsy in their child.[23]

2.2.1.3 Educational Aspects

Children with epilepsy have shown under achievement at school in comparison to their peers and are more prone to educational difficulties. These difficulties may arise as a consequence of a number of factors. Drug therapy and postictal confusion may slow cognitive functioning and impact on children's capacity to learn. Children who experience absence seizures in class can often be mistaken for daydreaming, consequently they may not take in all the material taught to them or their attentiveness and behavior in class may be misinterpreted by the teacher and result in adverse consequences. Children with more severe seizure types may miss time off school and may also be more prone to stigma if they have a seizure in class. Seizures can impair storage learned information and consequently frequent seizures are more likely to interfere with educational progress. [24]

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[23] Quality of Life Issues in Epilepsy http://dx.doi.org/10.5772/58689 229

[24] McCagh J., Fisk J.E., Baker G.A. Epilepsy, psychosocial and cognitive functioning. Epilepsy Research, 2009; p. 230.

2.2.1.4 Health Care Problems

Improving the lives of people with epilepsy and their families, to a large extent, begins with access to high-quality, patient-centered health care that facilitates accurate diagnosis and effective treatments and management. The many challenges that people with epilepsy and their families face are so diverse, even from a medical point of view, that although treatment must continue to be held to high standards, it nevertheless should be tailored to individual patient needs and characteristics, and no single health professional discipline can provide all of the elements required for high-quality epilepsy care. Historically, persuading health professionals to work across professional boundaries has been difficult. One of the challenges for government and institutional policy makers will be to devise organizational structures and incentive systems that make it easy—even attractive—for people from multiple professions to work together Even in an ideal system of care, the epilepsies will remain complex to diagnose and treat. While significant progress has been made in developing seizure medications with fewer adverse effects, as well as in refining medical devices and surgical techniques for select types of epilepsy, much remains to be done to reduce the sometimes lengthy delays in diagnosis and referral to more advanced levels of care, to improve care for those with refractory epilepsy, and to provide a better response to co morbidities, including mental health conditions.[25]

2.2.4 Psychological Factors

Psychological factors of epilepsy are among the most common problems epileptic persons are facing in all over the world; accordingly, psychological effect of epilepsy, fears ,emotional disturbances ,anxiety and depression, Self-esteem and sense of mastery are among the many problems reviewed from various literatures and presented in the following manner.

2.2 .4.1 Psychological Effects

Epilepsy has negative effect on the life of a person affected by the disease. Most epileptic persons feel that they are helpless and hope less and psychologically inferior to their fellow age mates.

As explained by Thompson PJ (2010) , 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

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[25] M.J. England et al. / Epilepsy & Behavior 25 (2012) P.266

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. [26]

2.2.4.2 Fears

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. For many people it is frightening to see a person having an epileptic attack, losing control of himself. The simplest way to prevent

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[26] THOMPSON PJ (2010) The neuropsychology of epilepsy and its treatment. In: *Oxford Handbook of Clinical Neuropsychology* (Eds J Gurd et al), pp 637-661. Oxford University Press, Oxford.

such fear is to avoid the person with epilepsy which could commonly happen in many parts of the world. Fear of social exposure of fits and feelings of disgrace often lead to social isolation many epileptic patients develop an extreme dependence upon their relatives as Abimbola (2010).

2.2.4.3 Emotional Problems

Living with epilepsy means coping with an uncertain prognosis regarding seizure control. Epilepsy carries increased risks of mortality and morbidity. As stated by **Hermann B, Jacoby A** (2009) Having epilepsy may mean coping with additional hidden deficits such as language and memory problems, or with a dual diagnosis, a learning disability being the most frequent co-morbidity. 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. Potentially more damaging psychologically is the failure of surgical treatment (which can arise in approximately one-third of cases), particularly when this follows several years of freedom from seizures.

2.2.4.4. Anxiety and depression

Both anxiety and depression are common co morbid features in PWE yet psychopathology is undertreated and under diagnosed. According to Jane McCagh (2009),(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. Suicide is also far more common in PWE than in the general population. There is a reciprocal relationship between anxiety, depression and epilepsy such that those with anxiety and depression are more likely to experience epilepsy and those with epilepsy are more likely to experience anxiety and depression. The exact mechanism that underpins this relationship as yet is not fully understood. Consequently social isolation is very common in PWE. 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 have been inversely related to higher scores on measures of depression and anxiety in PWE.[27]

2.2.4.5 Self-esteem and Sense of Mastery

Unpredictability is central to living with epilepsy. Individuals may not know when a seizure will occur and often have difficulty accepting living with a chronic condition that may or epilepsy topics may not improve. This can cause PWE to feel that they lack control over their life, can 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. Knowledge has been found to mediate the impact on self-esteem.

As explained by Jane McCagh(2009) ,adolescents with more awareness of their condition report higher levels of self-esteem and educational interventions aimed at increasing knowledge have been successful at enhancing self-esteem in PWE . Low self-esteem is commonly reported in PWE and is often mediated by employability, with those being

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[27] McCagh J., Fisk J.E., Baker G.A. Epilepsy, psychosocial and cognitive functioning. Epilepsy Research, 2009; pp. 1-14.

unemployed reporting poorer self-esteem. Over protective parental styles can work to reduce a sense of mastery and consequently make PWE less independent in adulthood .

2.2.5 Economic Factors

House hold income, individual income, employment and work opportunities for people living with Epilepsy are among the major economic problems they are facing. Literatures reviewed under this topic have shown much more similar contexts in various countries of people living with the disease. Majority of the people who are victims of the disease live under Sevier poverty. The following section describes about the living situation of the target people which is common for all that live in different countries.

2.2.5.1 Employment

Under this topic it is tried to review literatures by the investigator about availability of employment opportunities for people living with Epilepsy and those who have a history of epilepsy are prohibited by law from a variety of occupations. As described by McCagh J., Fisk J.E., Baker G.A. (2009) practices that discriminate against people with epilepsy are another major contributing factor to unemployment. In most cases it is common phenomena that PWE are unemployed and underemployed in relation to the general population all over the world. Seizure related variables contribute to this, PWE who experience frequent seizures have less chance of employment and so do those who experience tonic clonic seizures. Adequate seizure control, early age of onset, stigma, poor self-efficacy, poor social skills, education level, social isolation, cognitive deficits, negative attitudes of family members, employers and teachers have all been linked to unemployment and underemployment.

Work in general is not an easy task for these people because of various reasons . A major barrier is stigma which in turn may lower self-worth and discourage PWE from seeking employment, conversely being part of the workforce is also likely to increase self-worth. As well as individual feelings of stigma, professional stigma may affect employability in the work place. Perceptions of stigma in the workplace and experience of stigma have been found to be of a similar magnitude. Discrimination is apparent in relation to the availability of employment and employers[28].

However, internal work beliefs have been highlighted as an important factor in the successful inclusion of people with epilepsy into the

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[28] McCagh J., Fisk J.E., Baker G.A. Epilepsy, psychosocial and cognitive functioning. Epilepsy Research, 2009; p.234

workplace. According to McCagh J., Fisk J.E., Baker G.A. (2009), Self-worth, worry about safety at work, perceptions of the likelihood of injury in relation to self and others at work and attitudes of family members were primary factors in work status.[29]

2.2.5.2 Feelings of Dependency

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 would resulted the patients to live in a sever poverty situation. Existing evidences suggest that people with epilepsy are experiencing high levels of unemployment and underemployment. 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.

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, by up to 50% in developed countries. The same is happening in

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[29] McCagh J., Fisk J.E., Baker G.A., LoC.Cit

developing countries and if seizures are not fully controlled, the un employment rate could 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 (Bishop & Hermann, 2000; Gumnit, 1997).

Similar to the above description of people living with epilepsy and their linkage with work, it has many functions aside from the financial rewards. It provides a way of structuring time and, more importantly, contributes to a person's identity and feelings of self-worth. According to Gumnit, 1977 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. If paid employment seems increasingly unobtainable, then alternatives should be sought to enable people to make a meaningful contribution to society.

2.2.5.3 Employers Attitude towards Epilepsy

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 Dr Steven stachtcher (2008) are given in the following manner, [30] 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.

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[30] Dr. Steven Schachter, MD, Harvard Medical School, Beth Israel Deaconess Medical Center, Adapted from Epilepsy.com. Dr. Steven Schachter, M.D

2.2.3 Treatments of epilepsy

Epilepsy is most often treated with medication. According to National Center for Project Access,(2010),there are many seizure-prevention drugs (also known as anti epileptics or anticonvulsant drugs) available and it can sometimes take awhile to find the one that works best for each child.

It is important to follow your doctor's instructions about when and how much medication to give your child. The medication won't work properly until it reaches a certain level in the body, and that level has to be maintained. The goal is to keep the blood level high enough to prevent seizures, but not so high that it causes excessive sleepiness or other unpleasant side effects. If medication doesn't work, other options include surgery, a medical device or a very specialized, high-fat diet.

3. RESEARCH DESIGN AND METHODOLOGY

This part of the study describes the research methodology employed by the investigator to collect, organize, analyze, interpret and present the findings in the research process so as to come up with valid conclusions and recommendations. In view of that, the section comprises, the research methodology, the study area and context, population and the sampling techniques, the data collection instruments, the data collection process, data organization and analysis to carry out the study.

3.1 Methodology of the Research

The research employs qualitative research approach and case study method by which the opinion of the target people and community representatives that include religious leaders, elders, youths, women and government representatives is explored to deepen understanding about the socio economic problems of the target people so as to enhance public awareness and find out means to reduce the intensity of the problem endure in the target people.

The participants in this study are called respondents. The term is used to emphasize the role the participants played in the data collection process. Those invited were presented with information about the purpose of the study and would be interested to respond to the questions in a cooperated manner. General information about measures taken to guarantee confidentiality and informed consent were also given.

3.1 Study Area and Context

Me'enit Goldia wereda is one of the 10 weredas in Bench Maji Zone administration. The administrative zone is one of the fourteen zonal administrations in SNNPR and is located to the south eastern part of the country 561 kms away from Addis Ababa and 836 kms away from the regional capital Hawassa. The administrative zone comprises 10-weredas and 1 town administration, the total population size in the year 2014 G.C was 788,988 people as projected from the-2007 G.C census where 49.58% constitutes Men and 50.4% constitute Women. The administrative zone covers an area of 19,965 square Km and constitutes seven ethnic groups, of these, Me'enit tribe people are the focus of the study and reside in the two weredas namely Me'enit Goldia and Me’enit Shasha Weredas. These people have their own language, culture and identity which can make them peculiar as other ethnic groups in the area.

Me’enit Goldia , the target wereda of this study is bordered on south with Me'enit Shasha wereda, on the west by Debub Bench wereda, on the northwest by She bench wereda , and on the north and east by Kaffa Zone. Bachuma, the capital of the wereda is located 85 k.m to the south west of MizanTeferi; it is a small town where epileptic persons are also living in the same manner as they live in other towns. The woreda has 31 Kebeles with a total population of around 133,556 people of which 76,833 are male and 56,723 are female as projected from the 2007 G.C census in the year 2014G.C.[31]

There are many people affected by epilepsy in the target wereda and the reason for high prevalence of the disease is not studied so far. By and large due to cultural belief in this particular area epileptic persons have been considered as evil callers on their families, wider communities and their tribe as a whole. Thus, they do not allowed to live in their birth place because of the deep rooted belief entrenched towards epilepsy in

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[31] Bench Maji Zone Finance and Economic Department,2013G.C

the society which disfavor the patient and make them subject to expulsion.

After being casted out from their birth place, they live in a speckled manner around churches, mosques, market areas without any protection and care in different towns of the administrative zone. If they are once identified as epileptic patient no one shows interest to give them employment opportunities even for menial works in the towns. The marginalization usually continues in a different form affecting their lively hood where ever they go.

3.2 Population of the Study

As indicated above, Me'enit tribe people are living in the two weredas of Bench Maji zone administration namely Me'enit shasha and Me'enit Goldia weredas. Some of the epileptic people who had been evicted from their village to the towns were gathered from Mizan Aman town and have settled in the village called 'Bala' which is found in shy Kebele at the study area. Even though some of the target people are pulled together to settle in this village, it is obvious that many more are left disorganized in various towns of the zone. Therefore, the populations of the study are defined as the people affected by epilepsy from the study area and living in and outside of the target wereda after being expelled by their respective families.

According to the data collected by Mizan Aman town administration Department of Labor and Social affairs, the total number of people affected by epilepsy that are living in different towns in the zone are found to be 444 along with their children. This number includes those people already settled in Bala village. The person living in the target area constitutes 26 households who have been identified as victims of epilepsy and lead their life in the village where there is no clean water, other social services like school, health post and etc. The total numbers of settlers in the village were 130 including their children. The total number of epileptic people therefore is 52 in this village and the children of these families have not acquired the disease but affected by the impact of the disease.

3.3 Sampling Procedures

As indicated above, the people living with epilepsy from the target wereda lead their life in a scattered manner after being evicted from their birth place in different towns of the administrative zone. Due to the nature of the subject and the study group, the investigator has decided to make the focus of the study on those people who already settled in the village called ‘Bala’ assuming that they can give depth information about the living condition of epileptic persons. These groups of people were important to undertake the study in a way they can best represent others who were living outside the village in a vagrant manner.

The sampling method employed to take on the study was a non probability sampling method and the selection of the key informants were done through purposive sampling technique which has given opportunities for the investigator to obtain the required data from the respondents in appropriate manner. Though, the population size in the study area found to be 130 the study focused to collect the data from 52 people who were epileptic in a fair representation of gender balance.

Alternatively, the investigator has also got the views and opinions of the different groups of people and Government representatives through focus group discussion in the target wereda. Accordingly 12 people are selected for the discussion and their composition looks like the following. 6 of them were representatives from traditional leaders, elders, and religious leaders and ‘6’ were representatives from various Government offices. When we look at the specific areas of their representation we can see that, representatives from wereda education office, wereda health office, wereda administration, wereda women, youth and children office, Finance and Economic and two representatives from religious institutions, two elder representatives at local level, two representatives from traditional leaders and a representative from Bench Maji Development Association has participated in the discussion.

3.4 Types of Data and Data Collection Instruments

The data collection tools chosen for this study were intended to include qualitative data collection instruments such as close ended questions through structured interview, focus group discussion and observation check list. Accordingly, the close ended questions were mainly used with the people affected by epilepsy in a face to face manner and the focus group discussion held with the representatives of government offices and various community groups selected from elders, religious leaders and traditional leaders in order to get their views and opinions on the matter. Furthermore, the investigator had collected information through a check list by direct observation in the study area.

3.5 Data Collection Process and Organization

As can be seen in the above paragraph the data collection instruments employed were close ended questions through structured interview for the people living with epilepsy, focus group discussion with various community groups and Government representatives, check list to see the status of the availability and utilization of social and economic services in the target area which might be in use by the target people.

Correspondingly, the interview questions were presented to the epileptic persons living at Bala village in a face to face manner with the help of the local language translator and the recording was done at the spot and followed with final editing by the investigator. Not only this, the investigator has arranged a discussion time for the participants of the focus group discussion and conducted the meeting and captured the most important points of the discussion in a minute that reflects the views and opinions of the participants in the issue under study .

In relation to the data organization, the responses related to Psycho - social problems were organized in one category and presented in three tables, the responses related to public perception and beliefs in another category and presented in two tables, economic implications of epilepsy at house hold level in another category and presented in two tables. Furthermore ,the roles of various actors to mitigate the challenge of epileptic people were organized in another category and presented in two tables. This shows that the data collected through various instruments were organized and presented in different categories of thematic areas of the study to be able to respond to the basic research questions and objectives of the study.

3.6 Data Analysis methods

The data analysis of the study has employed univariate data analysis technique in which the investigator used multiple of single variables for analysis in the whole process of the study. It has also used Frequency distribution tables to show the percentage of respondents for each unit of analysis. This step came next to data editing, coding and computing of the scores.

Once the qualitative data collection were completed and appropriately scored for recurring themes and codes, It has also addressed the coding categories that were constructed from the concepts and themes pertinent to the review of literatures and basic research questions.

4. DATA ANALYSIS AND INTERPRETATION

This part of the study refers to the data analysis process and the corresponding interpretations. The data collected through various instruments were analyzed and interpreted to be able to respond to the research basic questions and presented in the following manner:

4.1 Data Analysis and Interpretation

The data analysis was done based on the thematic areas identified which were all set in reference with the objectives of the study and basic research questions namely: The Psycho social problems faced by epileptic persons among Me'enit People, the economic problems faced by epileptic persons among Me'enit tribe, the underlining reasons for epileptic persons to be isolated and evicted from their families and relatives, and the roles to be played by Government, NGOs and community groups to help improve the living situation of the target people. Accordingly, the responses collected through the various data collection instruments were classified in to major and interrelated thematic areas. These are: Psycho Social effects of epilepsy, Perception and Beliefs about epilepsy, Economic implications of epilepsy at house hold level and the roles to be played by different actors like Governmental and Non-governmental organizations and different community groups. In order to make the analysis responsive enough to the objectives of the research, the investigator has also critically examined the processed data in the form of frequency distribution techniques and re-categorized them to arrange categories with the help of master charts to avoid overlapping and duplication of data. The following section illustrates the data analysis based on the thematic areas identified and the interpretation followed the analysis.

4.1.1 Demographic Characteristics

The demographic characteristics of the respondents is presented in the following Table and shows the general characteristics the people affected by epilepsy and participated in the study by responding to the questions during data collection. Furthermore the table shows some characteristics of focus group discussion participants' interms of gender and age group.

Table-4.1 Profiles of Respondents

Typeof Respondents	Respondents status at "Bala village"			Sample			Remarks
	Male	Female	Total	Male	Female	Total	
Epileptic persons	26	26	52	26	26	52	All responders were between 30-60 years of age
Religious representatives		-		2	-	2	
Elders				2	-	2	
Traditional leaders				2	-	2	
Wereda Education office				1			
Wereda health office					1	1	
Wereda W/C/Yoffice					1	1	
Wereda F/E/D/ office				1		1	
Wereda Administration				1		1	
Bench Maji Development Association				1		1	
Total				**36**	**28**	**64**	

Figure-1 Demographic Characteristics of the Population

As indicated in the above Table 4.1, there were different categories people have participated in responding to the questions. The first category represents epileptic people and they were twenty six men and twenty six women, the other category represented various community groups represented from traditional leader,elders,religious institutions representatives and Government offices and a representative from Bench Maji Development Association. The age category of the respondents were between 30-60 years old .

4.1. Data Analysis and Interpretations

The responses given by all the respondents were coded and presented in a frequency distribution technique to make the data analysis easy and understandable. The thoughts and opinions of community groups and government representatives have also been merged with the responses of epileptic persons under each thematic area. Accordingly the above categorization of the responses, the data analysis and interpretation were presented in the following manner.

4.1.1 Theme1: Psycho-Social Effects of Epilepsy

This section has described the data collected through all the tools used in the study from different groups of respondents. The focus or center of analysis under this section has given more emphasis on the Psycho-Social effects of epilepsy. The thoughts and opinions of the respondents are categorized in to three different tables, the first table concentrates on questions related to 'social marginalization and stigma' applied on epileptic patients and the second table shows questions related to 'Access to Social services' like education and health . Finally the third table constitutes questions related 'Psychological problems of epileptic people' in the study area.

Table-4.2 Social marginalization and stigma

S.N	**Items**	

		Yes		**No**		**I don't know**	
		F	**%**	**F**	**%**	**f**	**%**
1	Access for a marriage with a person free from epilepsy			52	100%		
2	Public support for epileptic people health condition	8	15.38%	40	76.92%	4	7.69%
3	Social exclusion	52	100%				
4	Participation in public, cultural, and religious events			48	85.2%	4	7.69%
5	Feelings about family membership	6	11.53%	36	69.23%	10	19.23%

As indicated above in Table-4.2, opinions of epileptic persons in relation to social marginalization and stigma were assessed and five questions were presented in the order designated. Accordingly, the first question refers to the possibility of having marriage with non epileptic person and 100% of the respondents replied “NO” to the question. This implies that an epileptic person in the target area would not think of having marriage with non epileptic person. In question number two respondents were asked to give their opinion with regard to Public support for epileptic people health condition , 76.92% of the respondents have answered as d “NO”, 15.38% have answered “YES” and 7.69% have responded as “I don’t know”. This shows that, majority of the epileptic persons in the study area feel that nobody is carrying about their health and well being. In question number three, opinions of respondents were assessed to know the level of social exclusion applied on them. For this question 100% of the respondents have felt that they were socially excluded and marginalized. In relation to taking part in public events as seen in question number four, 85.2% of the respondents have answered that they didn’t take part in public, religious and cultural events. Finally in question number five Feelings of epileptic persons about family membership were assessed. Accordingly *69.23%* of the respondents have replied “NO”, 19.23% said they don’t know and 11.53% of them feels they are member of their respective families. These show that majority of the respondents did not feel that they are member of their respective non epileptic family members.

On the other hand, in the focus group discussion held at the target area participants were asked to give their opinion for the question “what is your opinion to the level of stigma and social marginalization applied on epileptic people in your surrounding?” the responses were captured in a minute and reflected their views in such a way that all the representatives from various community groups and government offices have agreed in common that there is high level social marginalization and stigma on the people affected with epilepsy in the target area. Not only have these it has also been verified by the observation checked list that the people affected by the disease are living in isolation at Bala village and around churches and market places in the nearby towns.

As can be understood from the above explanation, it has been verified by various groups of respondents that majority of them have agreed in the matter and said, there is high level of social marginalization and stigma applied on them from the wider communities of the same ethnic group.

Table 4.3 Access for Social Services

S.N	**Items**	**Level of responses**					
		Yes		**No**		**I don't know**	
		F	**%**	**F**	**%**	**f**	**%**
1	Access for education			52	100%		
2	Importance of education	36	69.23%			16	30.76%
3	Health care services	12	23.07%	40	76.92%		
4	Believing on medication	12	23.07%	32	61.53%	8	15.38%
5	Access for family planning services			52	100%		
6	physical injury	44	84.6%	8	15.38%		

The above Table 4.3 has questions related to availability and use of social services by the people living with epilepsy in the study area and the responses indicated in the Table are described in the following manner. For question number 1,100% of the respondents have said, they have no access for education so far and for question number 2, 69.23% of the respondents have said "YES" and 30.76% of the respondents said "I don't know". This shows that majority of the respondents knew that education can improve their lively hood. For question number 3, it was assessed the use of health care services by the patients. Accordingly 76.92% of the respondent said "NO" and 23.07% of them said "YES". On the other hand for question number 4, 61.53% of the respondents said "NO",23.07% of them said "YES" and 15.38% of them have also said "I don't know" . From the responses given, we can see that majority of the respondents have no access for health care services and most of them don't believe epilepsy can be cured with proper medication. Furthermore 100% of the respondents don't use family planning services to manage their family size. Similarly, in question number 6 it has been tried to assess the level of injury they may have due to uncontrolled seizure and 84.6% of the respondents said "YES" and 15.38% said "NO". This implies that many of them have injuries at their different body parts.

On the other hand ,in response to the question stated above ,participants of the focus group discussion have had similar opinion that epileptic persons have no or limited access for social services like education and health care services. This has also been verified by the observation check list filled by the investigator in such a way that infrastructures for social services are not established in the target area to make use of the services in a coordinated manner.

Table 4.4 Psychological problems of being epileptic

S.N	**Items**	**Level of response**					
		Yes		**No**		**I don't know**	
		F	**%**	**F**	**%**	**f**	**%**
1	Feeling of strangeness	44	84.61%			8	15.38%
2	Assuming roles in community activities			52	100%		
3	living with other people who are free from epilepsy	6	11.53%	46	88.46%		
4	Feeling of Suicide			40	76.92%	12	23.07%
5	Feeling of depression	52	100%				

6	Having personal goal	6	11.53%	46	88.46%		

In most cases epileptic patients have been observed as they have psychological problems in the views of the public at large and it has been manifested in different forms in the day to day life of the victims. As can be seen in Table-4.4, in question number one respondents were asked to reply on the feelings of strangeness on public gatherings, 84.61% of them have responded “YES” and 15.38% have responded “NO”. This implies that majority of them have had feelings of strangeness in public gatherings and few of them didn’t even know what strange means. In question number two, they were asked to know whether they had taken roles in community activities so far or not. For this question 100% of the respondents have said they did not take any role in community activities so far. This implies that the mainstream community didn’t want to give them the chance of sharing social life and the epileptic people themselves did not try to challenge the trend in their localities. In question number three, it was asked to assess their confidence to live with people free from epilepsy , correspondingly,88.46% of the respondents have replied as “NO” to the question and 11.53% have said “YES”. This implies that, majority of the people with epilepsy have had no confidence to live with other people who are free from epilepsy. In Question number four, it was asked that whether they knew a person who has committed suicide being epileptic ,and the responses were summarized in a manner that 76.92%

of them said “YES” and 23.07% have said “NO”. This implies that feeling of committing suicide is common and many of them knew a person who committed suicide because of the psychological suffering that came out of being sufferer by the disease. The last question in this section was about assessing the views of the PWE with regard to having personal goal in life .Accordingly, very few of them 11.53% have replied as “Yes” and 88.46% of them have replied as “NO”. These show, majority of PWE have not had any personal goal in life.

On the other hand, during the FGD conducted with community groups and government representatives, views of the participants were assessed for the question presented as “How do you see the level of confidence and emotional stability of PWE in their day to day activity as compared to other people?” few of the participants said , “PWE are like any other normal person in accomplishing their day to day activities” and majority of the participants said “PWE are mentally abnormal persons and are emotionally disturbed and have no confidence in their life”

In general, the responses from the FGD and interview questions have shown that, PWE are considered as mentally ill and emotionally disturbed people who are exposed for various forms of psychological problems like fear, anxiety and depression. Furthermore, these happened as a consequence of social marginalization and stigma they are experiencing in their day today life.

4.1.2. Theme 2: Perceptions and beliefs

As any traditional community Me'enit people are also living in a context of traditional beliefs which guides the way of their life in their localities. Not only this, superstations and religious beliefs are also among the kind of beliefs that shape the society to continue as it now. Under this section of the study, the investigator has assessed the perception of local people about 'Epilepsy' in Me'enit communities with reference to the traditional beliefs and religious beliefs about the case. Accordingly, the first Table has contained issues related to traditional beliefs and the second Table has constituted issues related to religious beliefs. Furthermore, the same issues were discussed at the FGD session and the participants' views and opinions were discussed in order to triangulate the responses of the PWE with the FGD participants to come to conclusion.

Table-4.5 Traditional beliefs

S.N	**Items**	**Level of response**					
		Yes		**No**		**I don't know**	
		F	**%**	**F**	**%**	**F**	**%**
1	Evicting an epileptic person from his/her village	36	69.23%	16	30.76%		
2	Having chat with family members who have not acquired epilepsy	8	15.38%	44	84.61%		

3	Epilepsy is Medically treatable disease	4	7.69%%	40	76.92%	8	15.38%
4	Epilepsy is contagious disease	44	84.61%	4	7.69%	4	7.69%

There were four questions presented in Table 4.5 to the respondents, the first question referred, to assess the attitude of PWE about the practice of being evicted by their families from their village and the responses were bestowed as 69.23% of the respondents replied “YES” and 30.76% replied “NO”. This indicates that, still majority of the PWE have been convinced that the mainstream communities would continue the practice. However, there be some improvement on their perception towards the public attitude of avoiding the victim because significant number of respondents replied as “NO” the question. In question number two, they were asked to respond to the question aimed at assessing the confidence and the opportunity they have to share ideas with people who were free from epilepsy. Correspondingly, 84.61% of them replied as “NO” and 15.38% have replied as “YES”. This implies that, majority of them have not had any opportunities to deal with social issues with their relatives. In the third question they were asked to respond to the question that focused on the medical treatment of epilepsy. 84.61% of the respondents replied as “NO” and 15.38% have replied as “I don’t know”. This implies that majority of the PWE didn’t consider epilepsy as a medically treatable disease. In the same Table, respondents were asked about the disease in a way to assess their opinion whether it is contagious or not.

Accordingly, 57.69% of the respondents replied as “YES” and 42.30% have replied as “NO”. This implies, PWE have had different opinions on this regard. Though majority of them believed that it is contagious disease and significant number of the respondents believed that it is not contagious, they explained this in example and said ,we have children that have not acquired epilepsy.

Table-4.6 Religious beliefs

S.N	Items	Level of response					
		Yes		No		I don’t know	
		F	%	F	%	F	%
1	Being cursed person	44	84.61%	8	15.38%		
2	Treatment by purifications and incantations	44	84.61%	8	15.38%		
3	Epilepsy happens due to evil spirit	48	92.30%	4	7.69%		
4	Epilepsy is considered as a sacred or untouchable disease	44	84.61%	8	15.38%		

Similarly, Table 4.6 has contained four questions to assess the opinions of PWE and their perception about religious beliefs. Accordingly, it was stated in question number one that epileptic person is considered as a cursed person; accordingly, 84.61% of the respondents have replied “YES” and 15.38% have replied as “NO”. These shows, majority of the PWE were convinced that they had acquired epilepsy because they were cursed. The second question also refers to the treatment type in a spiritual sense and it was presented as treatment can only be through purifications and incantations. The same way as above, 84.61% of the respondents have replied “YES” and 15.37% have replied “NO”. This has also capitalized the above response in such a way that epilepsy can only be treated through purifications and incantations.

Furthermore, question number three states that epilepsy happens in a person due to evil spirit. Accordingly, 92.30% of the respondents have replied “YES” and 7.69% have replied “NO” for the question. This indicates, almost all people living with epilepsy thought that epilepsy would happen due to evil spirit and not for some other reason. The last question stated that, it was considered as untouchable disease. Similarly 84.61% of the respondents have replied “YES” and 15.38% have replied “NO” for the question. This shows, insignificant number of the respondents believed as a normal disease and quite large number of the respondents have taught as untouchable disease.

On the other hand, in a question presented as “How did the customary and religious beliefs practiced on people living with epilepsy?” The FGD participants shared their views from different angles and finally those who came representing different community groups and religious institutions reached in consensus among themselves that epilepsy is a disease caused by evil spirit and can only be treated with purifications and incantations. For this reason a person affected by the disease should be placed in untouchable situation far away from other community groups. However, participants of the FGD who came from the

Government offices argued that epilepsy should be considered as a natural disease and could be treated as any other disease through hospitalization and medication.

4.1.3Theme 3: Economic implications

Observably epilepsy would affect the income of the person affected by the disease in many ways. One way of affecting their income as observed by the investigator was the attitude of the employers towards epilepsy took the larger share. Moreover, the following two Tables constitutes issues related to economic implications of epilepsy at house hold level. Table one consists of questions related to employment and epilepsy and Table two consists of questions related to capacity to buy services.

Table 4.7 - Employment and epilepsy

S.N	**Items**	**Level of response**					
		Yes		**No**		**I don't know**	
		F	**%**	**F**	**%**	**f**	**%**
1	Having one's own business to run			52	100%		
2	Employment at public and private sectors			52	100%		
3	Feeling of dependency on the general public	36	69.23%	16	30.76%		
4	Do you think you can get employment at public and private sectors?			48	92.30%	4	7.69%

Employment opportunities were not an easy task for people living with epilepsy , in Table 4.7 issue number one it was assessed whether epileptic persons run their own business or not . Accordingly 100% or all respondents have replied “NO” for the issue raised and it implied that none of them run their own business. In the same way on issue number two, it was assessed to know their views whether they can get employment at public and private sectors or not . In a similar fashion 100% of the respondents replied “NO”. This shows employment has been a very difficult challenge for people living with epilepsy. Moreover, Issue number three states about the feelings of dependency on the general public. Accordingly, 80.76% of the respondents replied “NO” and 19.23% replied “YES”. This means majority of the people living with epilepsy in the target area felt as they were highly dependent on the public at the towns. The fourth issue indicated in the table assessed about the possibility of getting employment at public and private sectors and the corresponding responses were seen as 92.30% of the respondents said “NO” and 7.69% of them said “YES”. These imply that the target people in the study area would have not had the opportunity of getting employment at the public and private institutions.

Table 4.8 – Capacity to buy public services

S.N	Items	Level of response					
		Yes		No		I don’t know	
		f	%	f	%	f	%

1	Affording schooling expenses	12	23.07%	40	76.92%		
2	Affording medical services			52	100%		
3	Employers attitude	6	11.53%	46	88.46%		

In a similar manner Table 4.8 has contained three different but interrelated issues that were related to the capacity of the people living with epilepsy to buy public services. Hence issue number one assessed opinions of the PWE about affording schooling services for their children. In this regard 76.92% of the respondents said “NO” and 23.07% replied “YES”. These implied, majority of the target people didn’t cover schooling expenses for their children. Similarly, issue number stated about affording health services and the responses were summarized in such a way that 100% of the respondents were not able to afford the health care services at public and private institutions. The other issue raised in the Table was about employers attitude towards epilepsy and the responses were summarized in such a way that 88.46% have replied as “NO” and 11.54% have replied “YES”. These implied, PWE have taught, employers have no interest to give them employment opportunities for people living with epilepsy. On the other hand, questions that have similar content were asked to focus group discussion participants in the form of “What do you think the income source of people living with epilepsy to lead their lively hood?”

4.1.4 Theme 4: Roles of various actors to mitigate the challenge

As can be seen indifferent parts of the study, the psychosocial and economic problems of epileptic people is more of external to the patients and requires concerted efforts of all concerned parties such as Government, Non Governmental organizations ,Religious institutions and traditional institutions need to play constructive roles to alleviate their problems and help them live better life. Views and Opinions of these stake holders have been obtained during the focus group discussion and the summary of their views and opinions is presented in the following manner:

4.1.4.1 Government Role

As per the discussion held, government representatives have reflected their views in the following manner:

> They suggested that problems related to the target group should get attention as much as possible in all the local government plans and programs.
>
> They have also agreed to promote awareness raising on the rights of the target people .
>
> Propose resource mobilization strategies and stakeholders cooperation in order to avail social and economic services to make use of them by the target people.
>
> Agree to organize public awareness raising events to enhance the knowledge of the public in the problem underlined by the target people.

Suggested means to strengthen the works of bringing together those who live in different towns of the zone in a vanguard manner to a place where they can get public services and improve their livelihood.

Agree to work with Traditional institutions and Religious institutions to enhance public perceptions to fight the tendency of mistreatment of epileptic persons and reduce stigma.

4.1.4.2 Religious Institutions Role

During the FGD held at the study area, the views and opinions of religious institutions' one from the Orthodox Christian church and the other one from Mekaneyesus church suggested that,the issue under discussion was not an issue that can simply taken to their respective followers to take for a positive actions on changing the trend towards people living with epilepsy . However, on gradual basis, they agreed to recognize and promote the problems of PWE to be understood by their respective followers and institutions under the curtain.

4.1.4.3 Traditional leaders Role

Two representatives of traditional leaders who have been culturally recognized and respected by the wider communities and two other participants who were elders and recognized by the local communities had taken part on the FGD session conducted in the study area. Accordingly, they have thoroughly discussed on the roles that can be played by them to contribute for the mitigation of the challenges faced by the target people. Finally, they came in to consensus that, the deep rooted belief of avoiding an epileptic person from their respective villages could not be changed in a short period of time; however, they have shown commitments to take personal responsibilities to contribute for others to understand the problems of the target people rather than considering them as an evil caller person to their families.

5. MAJOR FINDINGS AND CONCLUSIONS

The major findings of the study were drawn from the data analysis and interpretation process completed in the previous chapter. The proceeding chapters had precisely and objectively verified the issues raised in the research basic questions. Accordingly, the main findings of the study are presented in a logical order, these are:

5.1 Major Findings

- An epileptic person in the target area did not consider the possibility of having marriage with non epileptic person;
- The PWE has believed that there is high level of social marginalization and stigma applied on them from the wider communities in the study area;
- There was good understanding on the PWE about the importance of education to improve their livelihood;
- Majority of the target people have injuries at their different body parts.
- Infrastructures for social services were not established in the target area to make use of the services ;
- Majority of them have had feelings of strangeness in public gatherings ;
- The mainstream communities didn't show interest to give them the chance of sharing social life with PWE.
- Majority of PWE have not had any personal goal in life.
- PWE were considered as mentally abnormal and emotionally disturbed persons who did not have confidence in their life;
- Majority of the PWE didn't consider epilepsy as a medically treatable disease.
- Majority of the PWE believes that epilepsy is contagious disease however.

- Majority of the PWE were convinced that they had acquired epilepsy because they were cursed and can only be treated through purifications and incantations.
- Almost all people living with epilepsy in the target area were convinced that epilepsy would happen due to evil spirit;.
- Employment has been a very challenging task for people living with epilepsy and majority of them were living on beggary so that they feel that they were highly dependent on the public in the towns.
- Majority of the target people couldn't cover schooling expenses for their children;
- 100% of the respondents were not able to afford the health care services at public and private institutions
- PWE have taught, employers have no interest to give them employment opportunities in towns.

5.2 Conclusions

This study was initiated by the investigator after personal observation on the target area and discussion conducted with various people, government representatives, Bench Maji Development Associations staff members and some epileptic persons who live at the study area in relation to the people affected with epilepsy and living on Mizan Aman town streets.

Like any other people living with epilepsy in different places of developing nations, the people living with epilepsy in the study area were facing extreme form of discrimination by their respective families and the wider communities that made the victims highly vulnerable for severe poverty and illness. Although the problems related with these people have multifaceted forms, however, the investigator has focused on the social, psychological and economic problems of the target people that would greatly affect their livelihood.

As indicated in the research findings ,there have been various issues to be addressed related to the people affected by epilepsy in the target area and the intensity of the problem requires further study and intervention by various actors who have interest and willingness to support them . Furthermore, the study put some recommendations and would help other researchers to take off similar or more advanced studies to be able to further explore the problems related with these people and would expand the experience to other parts of the country.

On the other hand, the study could be a potential reference to bring concerted efforts from interested people in the issues identified , stakeholders and respective communities so that the socio-economic problems of the target people would get clear understanding by their respective communities and other people in the area to coordinate efforts of all concerned people and institutions to be able to contribute for alleviating the problems stated in the study.

6. SUMMARY AND RECOMMENDATIONS

6.1 Summary

Epilepsy is a neurological disorder which affects people's life all over the world since early in the history of mankind. Early historical texts show that at a time when societies had become sufficiently organized to need written documents, concepts of epilepsy had often developed and these were frequently religious. Epilepsy was known as a natural disease and explained by Hippocrates in such a way that “A disease with natural causes like all other diseases, and its seat was in the brain”. This was taken as a major landmark for the medical history of epilepsy.

However, there is still much ignorance of how profound it influenced and changed public views. Withdrawing from society in order to reduce the experience of stigma which can greatly impact on the quality of life of PWE by making them feel more socially isolated, have less social opportunities and smaller social support networks.

This study sought to get perspectives from epileptic persons that live in the study area, different offices of local Government at wereda level, Traditional leaders and Elders. Moreover, the study was motivated by personal observation of the investigator and concerns reflected by some individuals who live in the study area.

In relation to the data collection it had been sought that participation of the target people being the main concept to undertake the study .Hence, the investigator felt duty-bound to apply it by involving people living with epilepsy in providing data that sought to ensure their involvement in issues that affect their lives. Communities’ views were as well sought.

Not only these ,the research spin around the four basic research questions thus: The Psycho social problems faced by epileptic persons among Me'enit ethnic groups assessed in the first question , the economic problems faced by epileptic persons assessed in the second question , the underlining reasons for epileptic persons to be isolated and evicted from their families and relatives at the study area was assessed in the third question and finally the roles to be played by different actors was assessed in the fourth question.

Accordingly total of fifty two (52) questionnaires were presented to PWE and filled in by the help of the local language translator in a face to face manner and six questions presented to 12 people who came from various community groups and government offices and discussed in a focus group discussion session with the help of local language translator and note taker .Additionally, 12 twelve (12) questions filled in by the investigator in an observation check list prepared to complement the data collected through questionnaires and focus group discussion.

In the mean time, it has been understood that ,there were several factors that came out from the study as regarding aggravating or improving the living situation of PWE in the target area. Among these age, maturity level, being illiterate, and cultural influences were taken as aggravating factors and the possibility of being observed by local Government ,other group of people and Nongovernmental organizations would be taken as an opportunities for mitigating the challenge through joint effort of all concerned people and institutions.

In conclusion, the PWE have had various kinds of social problems, psychological problems which most likely resulted from stigma and misconception and last but not least economic problems to help them participate in the social and economic activities in their day to day life. The empirical findings of the study has indicated that , there has been close relationship between poverty and being epileptic in the study area.

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6.2 Recommendations

The general objective of this study is to explore the socio economic problems of epileptic people among Me’enit tribe and seek for means to contribute for the livelihood improvement of the target people.

In order to achieve the major objectives of the study, the investigator has made intensive discussion with the target people, local community representatives, Government representatives and religious institutions representatives. As a result of the discussion and collected data through various data collection instruments, the investigator has drawn possible recommendations to respond to the basic research questions.

The recommendations have direct linkage with the major findings of the study and hence reflected the views and opinions of the people participated in the study. These are:

As indicated in the study findings , there has been high level of social exclusion on the PWE which in turn has put negative effect on the lives of the target people and has resulted for sever poverty and illness on the victims. To combat these problems, the investigator would recommend the importance of bringing together the efforts of various actors towards raising awareness of the general public and taking practical steps in creating access for basic social services.

In a similar fashion, the study has also identified that the PWE were facing various problems related with employment and having means of income to lead their lives. In this regard the investigator would recommend working on creating job opportunities and engage them in the production process like providing land to plough, provision of seed money to run small businesses and work on public perception towards the disease.

Furthermore, the study has also identified that, the underlining reason for PWE to be expelled from their birth place was circled around the long standing cultural beliefs. Therefore, the investigator would recommend for the local government to act on the issue in a long range and sustainable programs so that the public perception will get improved and the degree of social exclusion will be minimized.

Finally, the investigator has concluded that 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 Government structure, Non Government organizations, Religious institutions and elders to be able to bring sustainable change in the livelihood of the target people.

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Appendix A -

Interview Questions For People Living With Epilepsy

The purpose of this study is to gather data which are related to the socio economic problems of people living with epilepsy at Me'enit Goldia woreda and to show as how it has affected their livelihood.

Direction:

Dear respondent, in answering the questions you must be sure that your name and other personal information will not be written along side of your responses. There are three options and you are expected to respond to the option you think is appropriate. The questions are presented in a structured interview form and will be presented in a face to face manner. Thank you in advance for your cooperation.

I. Basic information on the profiles of the respondents

Respondents personal status	Alternatives							
	Put 'X' Mark in the space provided							
Age	(12-18)Yrs		(19-30)Yrs		(31-50)Yrs		51 and above	
Sex	Male		Female					
Educational status	Illiterate		Primary (1-4)		Primary (5-8)		Secondary	
Marital status	Single		Married		Divorced		Widowed	
Number of children	1-2		3-4		5-6		7 and above	
Religion	Christian		Muslim		Other			
Means of lively hood	Agriculture		Petty trade		Beggary		No	
Physical status	Strong		Fatally Injured		Mildly injured		weak but not injured	

Close ended Interview Questions for PWE

1. Do you think you can have marriage with a person free from epilepsy?

A. Yes B. No C .I don’t know

2. Do you feel people are carrying about your health?

A. Yes B. No C .I don’t know

3. Do you feel that you are socially excluded?

A. Yes B. No C .I don’t know

4.Do you feel you can participate in public, cultural, and religious Events?

A.Yes B. No C .I don’t know

5 .Do you feel that you are member of your families

A. Yes B. No C .I don’t know

6. Did you get access for education so far?

A. Yes B. No C .I don’t know

7. Do you believe education can improve your life?

A. Yes B. No C .I don’t know

8. Did you get health care services so far?

A. Yes B. No C .I don’t know

9. Do you believe that you can be cured if you get proper medication?

A. Yes B. No C .I don’t know

10. Do you have access for family planning services so far?

A. Yes B. No C .I don’t know

11. Do you have physical injury due to uncontrolled seizure?

A. Yes B. No C .I don’t know

12. Do you feel strange in public gatherings?

A. Yes B. No C .I don’t know

13. Do you have any experience of taking role in community services?

A. Yes B. No C .I don’t know

14. Do you feel comfortable living with other people who don't have acquired epilepsy?

A. Yes B. No C .I don't know

15. Do you know a person who committed suicide being epileptic?

A. Yes B. No C .I don't know

16. Do you feel depressed most of the time?

A. Yes B. No C .I don't know

17. Do you have personal goal to achieve in your life?

A. Yes B. No C .I don't know

18. Do you think everyone in the community is convinced to avoid an epileptic person from his/her village?

A. Yes B. No C .I don't know

19. Did you spend time chatting with your family members who have not acquired epilepsy to get support in your life time?

A. Yes B. No C .I don't know

20. Do you think epilepsy is medically treatable disease?

A.Yes B. No C .I don't know

21. Do you think epilepsy is contagious disease?

A. Yes B. No C .I don't know

22. Do you believe epileptic person should live in isolation from other family members?

A. Yes B. No C .I don’t know

23. Do you believe an epileptic person is a cursed person?

A. Yes B. No C .I don’t know

24. Do you believe an epileptic person can only be treated by purifications and incantations

A.Yes B. No C .I don’t know

25. Do you think epilepsy can happen because of evil spirit?

A.Yes B. No C .I don’t know

26 Epilepsy should be considered as a sacred untouchable disease

A.Yes B. No C .I don’t know

27. Do you have your own business to run?

A.Yes B. No C .I don’t know

28. Did you get employment at public and private sector so far?

A.Yes B. No C .I don’t know

29. Do you feel economically dependent of the public?

A. Yes B. No C .I don’t know

30. Do you think you can get employment at public and private sectors?

A. Yes B. No C .I don’t know

31. Can you afford sending your children to school?

A. Yes B. No C .I don’t know

32. Can you afford medical services?

A. Yes B. No C .I don’t know

33. Do you think employers have positive attitude towards hiring epileptic person at their company?

A.Yes B. No C .I don’t know

Appendix-B

Observation Check list

Objective

The purpose of gathering information through this check list is to triangulate and supplement the opinions of respondents by using various tools. Therefore, the availability and utilization of Social and Economic Services at Bala village.

	Indicators	status	
		Yes	No
	There are schools for children and adults in the village		
	There are health care facilities in the surrounding area of the village		
	Women in the village have family planning services		
	There are medical service provisions for epileptic people in the village		
	There is clean water facility for drinking and washing purpose in the village		
	There is plot of land for every house hold in the village		
	There are cattle and farming animals at every house hold in the village		
	There are community based institutions like edir ,iqoub and others in the village		
	Epileptic persons in the village are taking part in community based institutions		
	Epileptic person can participate in the community based institutions		
	There is credit facility for epileptic persons in the village		
	There are market possibilities to sell their products at the village/Kebele		

Appendix –C

Focus Group Discussion Questions

Objective

The objectives of conducting focus group discussion in the subject under study is to gather information on the socio-economic problems of people living with epilepsy at Me'enit Goldia woreda prepared for Government officials and various Community group representatives. Accordingly participants of the discussion have shared their opinions freely and trustfully so that the data gathered have been used to complement the information collected through various tools in the study.

Q.1 What is your opinion to the level of stigma and social marginalization applied on epileptic people in your surrounding?

Q.2 Do you feel that epileptic people need to live with their respective communities? If so, what do you think of the social role to be played by epileptic people in your surrounding?

Q.3 How do you see the level of confidence and emotional stability of PWE in their day to day activity as compared to other people?"

Q.4 How did the customary and religious beliefs practiced on people living with epilepsy?

Q.5 What do you think the income source of people living with epilepsy to lead their lively hood?

Q.6 What should be done by different community groups, governmental and nongovernmental organizations to improve the living situation of people with epilepsy in the study area?

Appendix-D

PROFORMA FOR SUBMISSION OF M.A. (RD) PROPOSAL FOR APPROVAL

Signature: ……………………………………………………………………

Name & : . ……………………………………………………………………

Address of Guide : ………………………………………………………………

……………………………………………………………

……………………………………………………………

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Name & Address of the student :

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Enrolment No. : …………………………………………………………………

Date of Submission: ……………………………………………………………

Name of Study Centre : ………………………………………………………

Name of Guide: …………………………………………………………………

Title of the Project: …………………………………………………………

Signature of the Student: ……………………………………………………

Approved/Not Approved

Date:………………………………

Appendix=E

DECLARATION

I hereby declare that the Dissertation entitle “A STUDY ON THE SOCIO-ECONOMIC PROBLEMS OF EPILEPTIC PEOPLE AMONG ME’ENIT TRIBE,THE CASE OF ME’ENIT GOLDIA WEREDA SNNPR ETHIOPIA” Submitted by me for the partial fulfillment of the M.A. in Rural Development to Indira Gandhi National Open University, (IGNOU) New Delhi is my own original work and has not been submitted earlier either to IGNOU or to any other institution for the fulfillment of the requirement for any course of study. I also declare that no chapter of this manuscript in whole or in part is lifted and incorporated in this report from any earlier work done by me or others.

Place :_________________ Signature:____________

Date : …………… Enrolment No………………

Name…………………………

Address……………………..

Appendix-F

CERTIFICATE

This is to certify that;

Mr.SELESHI GETAHUN MELISIE student of M.A. (RD) from Indira Gandhi National Open University, New Delhi was working under my supervision and guidance for his Project Work for the Course MRDP-001. His Project Work entitled "A STUDY ON THE SOCIO-ECONOMIC PROBLEMS OF EPILEPTIC PEOPLE AMONG ME'ENIT TRIBE, THE CASE OF ME'ENIT GOLDIA WEREDA SNNPR ETHIOPIA" which he is submitting is his genuine and original work.

Place: _______________ Signature______________________

Date : _______________ Name_____________________________

Address of the Supervisor__________

____

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ABSTRACT

This study sought to explore the socio economic problems of people living with epilepsy in Me’enit Goldia wereda at Bench Maji zone administration from the point of view of rural development .The study used qualitative research method to collect and analyze primary data from the target people and other community members.

Accordingly, structured interview questions were presented for the PWE and open ended questions for focus group discussion participants. Few of the PWE in the target area were pulled to gether and settled by Ethiopian Red cross Society and Mizan Aman town administration to the village called “BALA”. Many of them still are living in different towns in a vanguard manner. For this reason, the investigator chose to focus on those who were pulled to gether from towns and settled at the village though they are small in number. In spite of the small sample size, the investigator concluded that the people living in the village could possibly represent the whole population group affected by the disease. This was justified through the data collected using the various data collection instruments. Therefore, investigator has came in to conclusion that the main reasons for the problems related with these groups of people remains to the traditional and cultural beliefs of entrenched through the history of the people and requires concerted efforts of various group of people and institutions to work to gether in a sustainable manner.

ACKNOWLEDGMENTS

Thanks for GOD who helped me in all my endeavors to be in this position. My sincere gratitude goes to my advisor Dr. Milkesa Wakjira for his kindness in his guidance that helped me much to come up with this final paper. I am certain that his invaluable professional and technical assistance put me in this position.

I am deeply indebted particularly to my wife Meseret Yigrem and my children Mikel, Mihiret, Tewodros and the new baby girl Heran for their patience and tolerance during my study. I would also like to convey my sincere gratitude to my former colleagues Ato Kusia Bekele, Jember Woldemariam, Abraru Sherif and Eden Wondimu who supported me in many forms to complete this study. I am also highly indebted to my friends Ato Solomon Takele, Dr Kenenisa Dabi, Chora Teshome and Habtamu at IGNOU office Addis Ababa for their invaluable contribution and advice provided.

Finally, I would like to thank Ato Belay Tezera and all respondents at Me'enit Goldia wereda who helped me to conduct my interviews and discussions in an effective manner.

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ABBREVIATIONS AND ACRONYMS

AIDS-Acquired Immuno Deficiency Syndrome

BMZFEDD-Bench Maji Zone Finance and Economic Department

CSA- Central Statistics Authority

EU- European Union

FDRE-Federal Democratic Republic of Ethiopia

FGD- Focus Group Discussion

GTP-Growth and Transformation Plan

HIV- Human Immuno Virus

IGNOU-Indira Gandhi National Open University

NGO- Non Governmental Organization

PWE- People with Epilepsy

SNNPR- South Nations Nationalities Peoples Region

USDH- United States Department of Health

WHO- World Health Organization

1. INTRODUCTION

1.1 Background of the Study

Epilepsy is a neurological disorder that affects large group of people around the world. Anders Hildeman (2010) stated as the World Health Organization (WHO) estimates the point prevalence of active epilepsy is generally 4 to 10 per 1,000 people. The trend in developing countries ranges from 6 to 10 per 1,000 people. This illustrates, the estimated number goes to 50 million people in 108 countries in the world. The mean number of people with epilepsy per 1000 people is therefore 8.93. However, the incidence of epilepsy in developing countries is about twice that in developed countries, and about 80% of the world's epilepsy patients are living in developing countries.[1]

Depending on the above description on the incidence of epilepsy worldwide the estimation on the incidence of epilepsy cases in Ethiopia and the study area would be done respectively. Accordingly the populations of Ethiopia were 87,952,000 in the year 2014[2] and the incidences of epilepsy based on the ratio presented above were about 87,952 in the same year. Furthermore, this can also be taken to the

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[1] Anders Hildeman(2010),Early Predictors Of Seizure Outcome In Newly Diagnosed Epilepsy, Sydney :Chalmers University of Technology.

[2] Annual Statistical Abstract ,Central Statistics Authority (2014) ,Ethiopia

study area where the populations were found to be 133,556 in the year 2014 according to the data obtained from BMZFEDD[3]. Based on this proportion (10 per 1000 people) ratio since Ethiopia is one of the least developed country, and the possible estimation should be in the range between 133--140. However, according to the data related to epileptic incidences collected from the study area, the number exceeds the projected figure and found to be nearly 440 which is more than double of the normal estimation.

Furthermore, epilepsy is one of the world's most common neurological disorders, public understanding was so limited and the victims were facing problems related to health, other social services and economic deprivations. Parallel to other forms of marginalization practiced in many parts of rural Ethiopia, epileptic persons who live in Bench Maji Zone ,Me'enit Shasha and Goldia weredas were suffering from the worst kind of discrimination that was expressed in the form of evicting a ictim from his/her village. Moreover, the wider communities in the study area were not accepting epilepsy as any other medically treatable disease and have considered it as a catching disease. This implied , epilepsy in this society would be taken as a hereditary and contagious disease and the person

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[3] Bench Maji Zone Finance and Economic Department,2014.

affected by the disease was regarded as evil caller on the respective family .

Though it was not supported by research and empirical findings, the investigator has observed that there were high incidence of epilepsy in Me’enit tribe people that was largely associated with the cultural practice of child delivery which normally be carried out in unsafe and unprotected manner outside home with no support from any other skilled person or family member.

The FDRE government is taking various measures to improve peoples' health, productivity and skills. Among other benefits, these measures will increase the potential for government's policies, strategies and programs to realize their objectives. As indicated in the GTP (2010),the main initiatives that were expected to be realized in the strategic pillars are improving access to good quality higher and adult education ,very wide access to good quality primary health care services ,better access to safe water and sanitation facilities ,halting the spread of HIV/AIDS and other key infectious diseases ,improving food security and nutrition, and improved housing conditions [4]

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[4] FDRE, Ministry of Finance and Economic Development , Growth and Transformation Plan ,2010/11-2014/15, (2010),Addis Ababa

However, like any other socially marginalized people epileptic people who were denied of these rights and set aside suffering from extreme social and economic marginalization’s in their respective localities. These people have not been enjoying equal opportunities for social services like education, health and housing.

1.2 Statement of the Problem

Me'enit Shasha and Me'enit Goldia weredas are found in Bench Maji Zone/SNNPR; the people living in these weredas are known as Me’enit tribe people who have their own identity as a tribe and speak their own language and exercise their own culture.

As a matter of fact, if any member of Me’enit people regardless of age and sex found epileptic , the families, relatives and the whole community in the respective area would refuse to share any kind of social interaction with that person. For instance, if any one in a family found epileptic in these communities and the parents of the affected person tries to hide the fact and tolerate to live with them, the whole community put sanctions in their social life and it would largely affect their confidence and livelihood. For these cultural reasons, the families of the victims would evict them from their village mostly to towns.

After ones being expelled from their village, one can easily identifies them by their reckless personality and demonstration of un common behavior like shouting at people, crying and sleeping on streets in towns. Churches, mosques and market areas are the most common places in the towns for the victims to get shelter, food and clothes. Furthermore, this situation is more sever when it happens on woman, girls and children in general. Furthemore,the victims were facing various social problems like having no access for education, no access for health care services that would include family planning services and other medical facilities and housing to survive. Moreover, in relation to the income they may have, almost all of them are living in beggary in the places where they were evicted.

The problems of these people are not limited to starvation. Moreover, it requires much attention and care to protect them from further injury at the time of seizure. In actual fact, nobody would take initiative to support them when they found in seizure. Due to this reason, they frequently got injury in different parts their body. Physical damages were very common incidents happening in their day to day life, especially when they fall down around a fire, the flame burns any part of their body exposed to the flame. Based on the personal observation of the investigator, many of the victims who were living in Bala village were seen fatally injured. They didn’t get any medical service even first aid support from other community members whether they fall in a fire, in a gorge or in a roads etc.

In spite of these fact, some efforts were being done by Mizan Aman town administration and Ethiopian Red cross society Mizan Aman branch, they brought them together and to got them settled in a small village called "Bala". This action has helped few of the target people (twenty six households) at least to have small land and struggling for survival. However, pulling them to gether in one place has also been criticized by some people for the reason of further isolation from other community members.

Therefore, if the problems continue affecting the target people and no any support provided ,the issue will be aggravated much and will affect the development initiative of the nation in general and the study area in particular . Having sought deeply in the impact of the problem the investigator believed to undertake the study so as to reveal the social and economic problems of the target people and give recommendations to contribute for the improvement of their living situation and help them lead better life and take part in the social and economic activities of their locality. For this reason the investigator took the initiative to conduct the study considering that the study is timely and crucial so as to help improve their lively hood and enjoy better life.

1.3 Definition of Operational Terms

Antiepileptic drug (AED): a seizure-preventing drug carried to the brain through the bloodstream.

Cognition: the process by which knowledge is acquired; awareness, thinking, learning and memory.

Convulsion: involuntary muscle contractions common in generalized tonic-clonic seizures.

eCommunities: A place for all people affected by epilepsy to share their stories

Epileptologist – a neurologist who specializes in epilepsy treatment. This is usually only recommended if standard treatment isn't working or if diagnosis remains unclear

Epilepsy :is a medical condition that produces seizures that can affect mental and physical functions. It is also called a seizure disorder

Neurologist – a doctor who specializes in treating brain disorders, including epilepsy. A pediatric neurologist specializes in children's brain disorders.

Incidence: the frequency in which something occurs over a specified time period

Seizure: abnormal electrical discharge in the brain. Seizures can be related to injury, high fever, substance abuse,metabolic disorders and other health conditions such as diabetes, and are not always a sign of epilepsy.

Social Life – This is the time of life when having friends and fitting in may seem to be all a child is thinking about. Being “different” in any way, such as having epilepsy, is not easy.

Substance Abuse – Alcohol and drugs are dangerous for all children, but even more so for children who are prone to seizures and may be taking medication for epilepsy.

1.4 OBJECTIVES

1.4.1General Objective:

The general objective of this study is to explore the socio economic problems of epileptic persons among Me'enit tribe so as to seek for means of improving the livelihood of the target people.

1.4.2 Specific Objectives

- To point out the social problems epileptic persons are facing in the study area and promote social inclusion;
- To explore the economic problems of the target people and propose measures to be taken to improve their living standard;
- To contribute to the efforts being done by various actors in the study area so that the living condition of the target people will be improved;

1.5 Basic Research Questions

- What are the Psycho social problems faced by epileptic persons among Me'enit ethnic groups?
- What are the economic problems faced by epileptic persons among Me'enit tribe?
- What are the underlining reasons for epileptic persons to be isolated and evicted from their families and relatives at the study area?
- What should be done by Government, NGOs and community groups to help improve the living situation of the target people?

1.6 Scope of the Study

The problems related to marginalization and social exclusion of epileptic persons is understood as high in the two weredas of Bench Maji Zone administration as in other weredas of the administrative zone during the discussion carried out with various Government offices, Community based organizations and people living in the target wereda during problem identification. The problems of epileptic persons are mainly associated with socio cultural factors and deep rooted beliefs that, epilepsy is hereditary and contagious disease.

Though the problem is a common concern in the two weredas of Me'enit tribe people, the investigator has decided to delimit the scope of the study to one of the two weredas. This is actually done in order to make manageable the study interms of geographic area, time and availability of resources. Based on this fact, the scope of the study is delimited to one of the two weredas namely Me'enit Goldia wereda and the epileptic people who live in shay Kebele ,Bala village where those epileptic persons pulled to gether from Mizan Aman town and surrounding areas have settled.

1.7 Limitations of the study

There were a number of limitations in this study but the key ones are described in the following manner : the broadness of the topic for it was not specific to one type of decision and the depth of the problems faced by the target of people, the distance the target people are living from the area where investigator is living ,the data collection setting almost all respondents were not only less conversant with Amharic language but also apprehensive about it this has forced the investigator to work with a translator who can understand both the local language and Amharic . The other limitation was the expectation manifested by the target people for some kind of material or financial resource after the interview and discussion sessions.

1.8 Chapter Plan

This part of the study presents the major components of the study which were classified in to seven chapters. The first chapter shall be an introductory part to the study and comprises of eight sub topics. These are: Back Ground of the Study, Statements of the Problem ,Definition of Operational Terms, Objectives of the Study ,Basic Research Questions ,Scope of the Study, Limitations of the Study and finally the Chapter Plan .

The second chapter has dealt with the Literatures' reviewed in the course of the study. The review has covered Theoretical review and Empirical reviews done by different authors. Furthermore, people's perception about epilepsy in different countries have also been reviewed to enhance the knowledge and understanding of the investigator so as to give shape and focus for the study.

The third chapter has dealt with the Research Design under which Description of the Study Area, Population; Sampling Procedures, Types of and Data Collection Tools, Data Collection Process and Organization and finally the Data Analysis Methods were presented in the given order.

The fourth chapter has also dealt with the data Analysis and Interpretations. The datas were analyzed and interpreted in such a way that the responses collected from various groups of respondents were classified in to four Thematic areas which were :Psycho-Social Effects of , Perceptions and Beliefs, Economic Implications and finally the Roles to be Played by Various Actors have been presented in their order of importance.

The fifth chapter comprises the major findings of the study and the conclusions where as the last chapter comprises the summary and recommendations of the study.

Finally the report included the reference section under which bibliography and appendices put to gether as complementary part of the study.

2. REVIEW OF RELATED LITERATURES

The literature review includes concepts and definitions related to the problem under study and helps the investigator to have better understanding on the socio economic problems of epileptic persons in various cultures and countries. Accordingly, literatures that constitute some facts about epilepsy and its impact in the life of the victim and related documents reviewed by the investigator while undertaking the study and are presented in the following manner.

2.1 Theoretical Review

2.1.1Definition

Epilepsy is defined by different authors in a more similar way , as defined by Folarin Oluseye Abimbola (2010),it is “an umbrella term used for neurological disorders characterized by seizures. Since the seizures might originate in different locations of the brain, the symptoms can differ greatly between patients all diagnosed with epilepsy" Seizure in Epilepsy can be viewed in different forms and the usual symptoms of seizures are classified as uncontrolled motoric movements or spasms, convulsions, emotional or psychological sensations, loss of consciousness and more. These are usually caused by signal feedback oscillations between neurons.[5]

Similarly, as defined by National Center for Project Access(2013)

Epilepsy is a medical condition that produces seizures that can affect mental and physical functions. It is also called a seizure disorder. Many illnesses or severe injuries can affect the brain enough to produce a single seizure. When seizures continue to occur for unknown reasons or because of a problem that cannot be corrected, the condition is known as epilepsy.

2.1.2 What Causes Epilepsy?

Causes for epilepsy to happen in a person can be seen differently in different contexts. According to National Center for project center (2010) for instance in about seven out of ten people with epilepsy, no cause can be found. This is called idiopathic epilepsy. Idiopathic is a Latin word meaning "of unknown cause". Among the rest of the people with epilepsy, the cause may be any one of a number of things that can make a difference in the way the brain works. For example, head injuries or lack of oxygen during birth may damage the delicate electrical system in the brain. Other causes include brain tumors, lead poisoning, problems in

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[5] Folarin Oluseye Abimbola (**2010)**Classification of epileptic seizures using accelerometers, Chalmers university of technology

development of the brain before birth and infections like meningitis or encephalitis. Epilepsy can run in families but it is not contagious you cannot catch epilepsy from someone else and nobody can catch it from you.

2.1.3 What is Seizure?

Seizures occur due to brief disturbances in the normal electrical functions of the brain. Millions of tiny electrical charges pass between nerve cells in the brain and connect to all parts of the body. When someone has epilepsy, this normal pattern may occasionally be interrupted by short bursts of electrical energy that are much stronger than usual. This can cause muscle spasms or uncontrollable body movements, loss of consciousness or confusion. These physical changes are called epileptic seizures. Normal brain function cannot return until the electrical bursts stop. Seizures can occur in just one area of the brain (partial seizures) or may affect nerve cells throughout the brain (generalized seizures). Most last a few seconds or minutes.[6]

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[6] Folarin Oluseye Abimbola (**2010)**Classification of epileptic seizures using accelerometers, Chalmers university of technology

2.1.4 Types of Seizures

There are different types of seizures manifested by epilepsy patients, as defined by Abimbola (2010**),** seizures are classified in to two general forms; these are seizures by origin and seizures by motoric symptoms. According to the same author , classification of epilepsy symptoms are further done into two major classes depending on the initiation of the case. They are called partial-onset and generalized-onset seizures. Partial-onset seizures start in a specific area of the brain. The symptoms depend on the function of that specific area. If the seizure does not alter consciousness it is known as a simple partial seizure. Partial seizures that cloud consciousness and cause abnormal repetitious movements are known as complex partial seizures. Partial seizures are usually associated with some kind of damage to a part of the brain. Not only these, Generalized seizures are those seizures where the whole or large parts of the brain experience abnormal electrical activity. This kind of seizure is usually much more dramatic given that many of the brain functions are affected at the same time. In many of these types of seizures, the subject will not have any recollection of the seizure afterwards. On the other hand, Seizures by motoric symptoms are classified by its symptoms that affects motoric functions. For instance, tonic episode of a seizure is the phase of constant muscle contraction that comes due to the disease. If a tonic seizure affects the heart, it will stop beating due to the contraction of the heart muscle. Contractions are caused by oscillations of neuro-electrical signals with frequencies so high that the muscle fibers will not have time to relax in between each pulse. This causes the muscles to experience a constant contraction [7]

2.1.5 Superstitions, Religious Beliefs, and Concepts of Epilepsy

Religious beliefs are a very important aspect of the life of societies. It is a relatively recent development, and with many restrictions, that they are considered a private matter. In early history, when much still needed to be explained about life, the realm of religious beliefs was large and included matters of health and illness. Hippocrates' polemic against the belief that epilepsy in its variable appearances was sent by gods and should be treated by purifications and incantations (Hippocrates, around 400 BC) is recognizable in what was documented in a Babylonian cuneiform medical diagnostic series from the middle of the first millennium BC (Kinnier Wilson and Reynolds 1990). The Greeks referred to epilepsy as the Sacred Disease, and over the millennia, the disorder has been associated with prophets, mystics, diviners, and the like (Temkin, 1971). Hippocrates began his discourse on the "sacred disease" by refuting the connection between epilepsy and the divine; he argued against the widespread beliefs of prophetic and mystical powers

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[7] Anders Hildeman(2010),Early Predictors of Seizure Outcome In Newly Diagnosed Epilepsy, Sydney :Chalmers University of Technology

attributed persons with epilepsy and the disorder's divine causation. However, Hippocrates attempt to dissociate epilepsy and religion was unsuccessful. Subsequent religious figures were asked to heal people with epilepsy. The New Testament gospels of Matthew (17: 14-20), Mark (9: 14-29), and Luke (9:37-43), who was a physician; recount how Jesus cast out the evil spirit from a boy with epilepsy who just had a seizure, there by curing him. According to De Toledo & Lowe (2003) throughout the Middle-Ages and the Renaissance, religious and magical treatments of epilepsy predominated and in the nineteenth century the religiosity of persons with epilepsy was stressed by physicians. [8]

2.2 Empirical Review

2.2.1 How common is Epilepsy? The Trend in Selected Countries

Epilepsy is a very common neurological disorder that exists in a place where human population is found. It affects people of all ages, Nations and races all over the world. According to National Center for Project Access,(2010),there are records of it since biblical times. Many literatures put peoples' perception in a negative way which is common to all countries whether in developed or developing. However ,in this study the investigator has made review on the matter focusing on the situation of

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[8] Wolf P (2006) Descriptions of clinical semiology of seizures in literature. Epileptic Disord pp.35-37

the epilepsy and its perception in Nations/countries like United states of America, Europe, Asia, Africa and finally in Ethiopia.

2.2.1.1 Epilepsy in America

United States of America is one of the Nations that affected by Epilepsy and epilepsy is found the nation's fourth most common neurological disorder, after migraine, stroke, and Alzheimer's disease. As reported in The Institute of Medicine's report (2012) 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.[9]

Furthermore, an estimated 2.2 million Americans have epilepsy, with approximately 150,000 new cases diagnosed in the United States each year. This shows that approximately 1 in 26 people will develop epilepsy at some point in their lives, and the onset of epilepsy is highest in children and older adults. Yet living with epilepsy is about much more than just seizures. For people with epilepsy, the disorder is often defined in practical terms, such as challenges in school, uncertainties about

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[9] The Institute of Medicine's report (2012) , Epilepsy across the spectrum: promoting health and understanding

social situations and employment, limitations on driving, and questions about independent living. [10]

2.2.1.2 Epilepsy in Europe

The European Region of the World Health Organization comprises 53 countries, covering the usual ‘European’ countries west of the Ural but also the former Soviet Union Republics including the 5 Central Asian Republics. The European Union (EU) is a grouping of twenty seven independent states and founded to enhance political, economic and social co-operation and integration. According to WHO Global Campaign Against Epilepsy (2007)In Europe, at least 6 million people have epilepsy, and 15 million Europeans will have one seizure at some time in their lives. Nevertheless, in some countries of Europe, epilepsy is not recognized as a brain disorder, and up to 40% of people with this condition may be untreated. This regional report for Europe provides a panoramic view of the present epilepsy situation in the Region, outlines the initiatives taken by the Global Campaign partners to address the problems, define the current challenges and offers appropriate recommendations. It is an advocacy tool and an instrument for dialogue

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[10] Institution of Medicine(2012)Epilepsy Across the Spectrum: Promoting Health and understanding :Washington DC,National Academy of Sciences pp.2-3

with governments, consumer associations, nongovernmental organizations, academic institutions and development partners.

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 . Studies of the prevalence of epilepsy show that 1 out of every 20 or 30 persons in parts of the world with poor health conditions has epilepsy; in other parts, such as Europe, the prevalence is about 1 out of every 100 to 150. Thus 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 and may not keep track of the latest developments in the field of epileptology.[11]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.

2.2.1.3 Epilepsy Among Asian

A cross-cultural comparison in Europe showed that there were significant differences in perceive stigma among people with epilepsy

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[11] Global Campaign against Epilepsy. Out of the Shadows: an introduction to the Global Campaign and its demonstration projects. Heemstede: Global Campaign against Epilepsy, 2001.pp.5-9 Also accessible at http://www.who.int.

from various European countries. It is expected to have a greater cross-cultural difference in stigma between the Western and the Asian countries. According to Kheng-Seang Lim, Chong-Tin Tan (2014)**,** In the Various studies on social stigma or public attitude towards epilepsy, there were as high as (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.

When we look at experiences of various Asian countries we can see similarities in the people's perception about epilepsy, 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.

In a systematic review of public attitudes toward epilepsy, Asia and Africa were shown to be the two continents with the worst attitudes against employment in epilepsy where 50.0% and 80.0% of the published papers respectively reported more than 40% of participants with negative attitudes, as compared to none in North and South America, and Australia [12]

2.2.1.4 Epilepsy in Africa

The reaction to epilepsy in Africa is shaped by traditional indigenous beliefs which are surprisingly similar, in some way or other, throughout most of the African continent and result in severe psychological hardship. The African epilepsy sufferers have a hard time to achieve positive feelings about themselves and frequently suffer deprivations without protest. In 1970 Osuntokun & Odeku, reviewed 522 Nigerian epilepsy sufferers and observed that the patients suffered psychosocial handicaps including suicidal tendency because they themselves considered epilepsy a social disgrace. Moreover, modern treatment for epilepsy is often unavailable in Africa. The reason might be different in diverse situation but lack of treatment facilities take the major one, because the general belief that epilepsy is of supernatural causation and

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[12] Kheng-Seang Lim, Chong-Tin Tan(2014) **Epilepsy stigma in Asia: the meaning and impact of stigma** *Division of Neurology, Faculty of Medicine, University of Malaya, Malaysia*

therefore not treatable by Western medicine (Osuntokun & Odeku, 1970). [13]

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 (Carod-Artal &Vazquez-Cabrera, 2007). A person affected with epilepsy often demonstrate behavior of sudden impulsive onset and discharge of bursting seizures make the victim become visible as if in the hold of an eccentric power. This provokes powerful panic in those present and has most likely done much to be responsible for the belief that epilepsy is caused by evil spirits or other supernatural forces.[14]

An added cause cited by Mauritania Moorish populations is the diet; the term “iguindi” refers to all clinical manifestations including seizures attributed to excessive eating. In Nigeria, Africa’s most populous country, epilepsy is thought to be contagious, and that belief is even popular

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[13] Osuntokun, B.O. & Odeku, E.L. (1970). Epilepsy in Ibadan, Africa *Journal of Medical Nigerian Science, 1*: p 185

[14] Carod-Artal FJ, Vazquez-Cabrera CB. (2007). An anthropological study about epilepsy in native tribes from Central and South America. *Epilepsia* 48(5):p.886.

among medical school students. A belief of the Bini of Nigeria is that epilepsy is a disease where the heart gets blocked by foam, restricting circulation and resulting in a seizure.

In Uganda epilepsy is thought to be a result of a lizard spinning around in circles in the head disturbing the brain causing dizziness, usually followed by a seizure. In Malawi epilepsy is thought to be due to an insect moving inside the stomach. In Swaziland epilepsy is thought to be caused by sorcery, which sends evil animals or spirits into the body, causing convulsion (Andermann, 2011). A connection between the phases of the moon and convulsive attacks has been made since ancient times. It was, and still, is believed that either the new or the full moon is directly influencing and provoking seizure activity). Sub-Saharan Africa- and the continent of Africa as a whole- attach a huge social stigma to epilepsy). Prejudice against the disease is common, persons with epilepsy are usually stigmatized and even pronunciation of the word 'epilepsy' is a taboo (Jilek et al., 1999).[15]

The traditional indigenous beliefs and traditional treatment of epilepsy in Africa contribute to the under-utilization of the medical health services,

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[15] Jilek-Aall L. Morbus sacer in Africa: some religious aspects of epilepsy in traditional cultures. *Epilepsia,* 1999;40:382–6.

to discrimination and social isolation. In 1997 the Global Campaign against epilepsy was launched to bring epilepsy 'out of shadows' to reduce treatment gap and social and physical burden, educate health personnel, dispel stigma, and support prevention (Diop et al., 2003). Cultural aspects should be studied with regard to patients' perceptions, attitudes and practices in relation to epilepsy, as well as their socio-familial relations. Information and education of the public in general is important in order to enable and empower people to make informed choices.(WHO, 2004).[16]

2.2.1.5 Epilepsy in Ethiopia

Ethiopia is one of the least developed countries in the world and the incidence of epilepsy in less developed countries tends to be higher than in industrialized countries. 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,[2] but only 2–13% of people with epilepsy living in rural areas receive medical treatment. Berhanu S, Alemu S, Asmera J, and Prevett M (2008) .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

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[16] WORLD HEALTH ORGANIZATION 2004 Regional office for Africa: Regional Strategy for Mental Health, 2004.

treatment and cultural factors. The World Health Organization advocates the use of primary health care in less developed countries to improve access to treatment of chronic diseases, such as epilepsy .In Ethiopia, rural health centres, run by nurses and health officers are the focus of primary health care services to be given to the residing community. In line with health centre policy, patients who are unable to afford the cost of drugs and have the appropriate papers were given treatment without charge even for those patients having to pay for their treatment the cost of Phenobarbital is low.[17]According to the study conducted by Dawit Worku (2013)

It was estimated that 360 to 400 thousand epileptic Ethiopians are living with poor medication. The prevalence of epilepsy was 5.2/1000 inhabitants at risk, 5.8 for males, and 4.6 for females. The highest age-specific prevalence was found for ages 10-19 years. The annual incidence of epilepsy was 64 in 100,000 inhabitants at risk, 72 for males, and 57 for females. Generalized tonic-clonic seizures were the most common seizure type and occurred in 69 - 81%. 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

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[17] Berhanu S, Alemu S, Asmera J, Prevett M. Primary care treatment of epilepsy in rural Ethiopia. Ethiopian Journal of Health Development 2008;16: P.235

common associated disorder, found in 7.9 - 21% of the persons with epilepsy. EEG was recorded in 50 - 73% of patients in the capital city, Addis Ababa. 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.[18]

2.2.2 Public Perceptions in Some Selected Countries

Epilepsy as a natural disease is understood in many forms that in general reflect negative attitude towards the person affected by the disease. Some examples of these reflections are presented in the following manner as adopted from US Department of Health (2012) misunderstandings about epilepsy from around the world is presented in the following manner:[19]

- **In Cameroon** it is believed that people with epilepsy are inhabited by the devil. This does not mean that they are seen as evil, but that evil invades them and causes them to convulse from time to time.
- **In China**, epilepsy diminishes the prospect of marriage, especially for women. A survey of public awareness in 1992 revealed that

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[18] Dawit Worku (2013) **Resources, Quality Measures, and Epidemiology** Review Article: Epilepsy in Ethiopia Addis Ababa University, School of Medicine, Department of Neurology.

[19] US Department of Health; The World Health Organization(2012**)**

72% of parents objected to their children marrying someone with epilepsy.

- In some **rural areas of India**, attempts are made to exorcise evil spirits from people with epilepsy by tying them to trees, beating them, cutting a portion of hair from their head, squeezing lemon and other juices onto their head and starving them.
- **In Indonesia**, epilepsy is often considered as a punishment from unknown dark forces.
- **In Liberia**, as in other African countries, the cause of epilepsy is perceived as related to witchcraft or evil spirits.
- **In Nepal**, epilepsy is associated with weakness, possession by an evil spirit or the reflection of a red color. Bystanders who witness a seizure will often spray water on the forehead of the person experiencing the seizure of make him or her smell a leather shoe.
- **In the Netherlands** in 1996, a person was whipped and put into isolation because her seizures were thought to result from magic.
- **In Swaziland**, many traditional healers mention sorcery as the cause of epilepsy.
- **In Uganda**, as in many other countries, epilepsy is thought to be contagious and so people with epilepsy are not allowed to join the communal food pot for fear of others contracting epilepsy through that person's saliva.

2.2.1 Social Factors

2.2.1.1 Stigma and Misconception

Historical and media misrepresentations of epilepsy have been over whelmingly negative and consequently the condition has been clouded by misunderstanding, superstition and discrimination present over many centuries and across different cultures. This in turn increases the experience of stigma in PWE. 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 intimate relationships or maintain family relations. Consequently negative attitudes and lack of family support render the individual as being more vulnerable to psychosocial difficulties . 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 or are isolated within their family in an attempt to lessen the social stigma associated with the disorder and to increase marital prospects[20].

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[20] Quality of Life Issues in Epilepsy http://dx.doi.org/10.5772/58689 229

On a similar fashion ,as depicted on the works of Mary Jane (2012),People living with Epilepsy are stigmatized and socially excluded in many situations .Stigmatization leads to discrimination, and people with epilepsy experience prejudicial and discriminatory behavior in many spheres of life and across many cultures . A significant challenge for people with epilepsy, as well as for the epilepsy field, has been the multitude of ways that epilepsy is perceived and, in many cases, misperceived. As a consequence, people with epilepsy and their families may be faced with a lack of social support from extended family members; feelings of parental guilt; social isolation, embarrassment, and fear; and discrimination. Although efforts are being made to correct these misconceptions and to better inform people about the epilepsies, doing so remains a challenge. Both historically and cross-culturally, and with only rare exceptions, epilepsy has been represented as a stigma and, for many people with epilepsy worldwide; it is the continuing social reality.[21]

2.2.1.2 Effects on Marriage and Family Life

Like any other person, people living with epilepsy have a desire to establish a family life. This actually is not a simple task for many of them to accomplish it within their own community, the potential impact of epilepsy on the family is difficult to gauge and is likely to be variable

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[21] Mary Jane(2012),Epilepsy and Behavior Boston University, 715 Albany Street, T5W, Boston, MA 02118, USA

which would most affect the victim to feel loneliness. In addition to feelings of loneliness, as a consequence of Social isolation, emotional problems are the most common hindrances to marriage .Many of them have lacked close friends and unable to establish families in most cases (Temkin, 1971). Parents may be overprotective through fear of injury or death and they may harbor misconceptions about epilepsy and thus become socially isolated for fear of adverse public reactions.

The attitudes and understanding of families should therefore form a prominent part of any treatment programme.[22].

Little attention has been given to the possible impact on the family of a parent with seizures. Parents and potential parents with epilepsy often express doubts about their suitability for such a role and mothers may have the greatest concerns. Fears expressed include the potential inheritability of epilepsy and the possibility that antiepileptic drugs may lead to birth defects. As children grow older, parental vigilance may intensify as a watch is kept for any behavior or physical sign that might herald the onset of epilepsy in their child.[23]

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[22] Temkin O (1971) The falling sickness. A history of epilepsy from the Greeks to the beginning of modern neurology, 2nd edn, rev. Johns Hopkins University Press, Baltimore, MD

[23] Quality of Life Issues in Epilepsy http://dx.doi.org/10.5772/58689 229

2.2.1.3 Educational Aspects

Children with epilepsy have shown under achievement at school in comparison to their peers and are more prone to educational difficulties. These difficulties may arise as a consequence of a number of factors. Drug therapy and postictal confusion may slow cognitive functioning and impact on children's capacity to learn. Children who experience absence seizures in class can often be mistaken for daydreaming, consequently they may not take in all the material taught to them or their attentiveness and behavior in class may be misinterpreted by the teacher and result in adverse consequences. Children with more severe seizure types may miss time off school and may also be more prone to stigma if they have a seizure in class. Seizures can impair storage learned information and consequently frequent seizures are more likely to interfere with educational progress. [24]

2.2.1.4 Health Care Problems

Improving the lives of people with epilepsy and their families, to a large extent, begins with access to high-quality, patient-centered health care that facilitates accurate diagnosis and effective treatments and

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[24] McCagh J., Fisk J.E., Baker G.A. Epilepsy, psychosocial and cognitive functioning. Epilepsy Research, 2009; p. 230.

management. The many challenges that people with epilepsy and their families face are so diverse, even from a medical point of view, that although treatment must continue to be held to high standards, it nevertheless should be tailored to individual patient needs and characteristics, and no single health professional discipline can provide all of the elements required for high-quality epilepsy care. Historically, persuading health professionals to work across professional boundaries has been difficult. One of the challenges for government and institutional policy makers will be to devise organizational structures and incentive systems that make it easy—even attractive—for people from multiple professions to work together Even in an ideal system of care, the epilepsies will remain complex to diagnose and treat. While significant progress has been made in developing seizure medications with fewer adverse effects, as well as in refining medical devices and surgical techniques for select types of epilepsy, much remains to be done to reduce the sometimes lengthy delays in diagnosis and referral to more advanced levels of care, to improve care for those with refractory epilepsy, and to provide a better response to co morbidities, including mental health conditions.[25]

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[25] M.J. England et al. / Epilepsy & Behavior 25 (2012) P.266

2.2.4 Psychological Factors

Psychological factors of epilepsy are among the most common problems epileptic persons are facing in all over the world; accordingly, psychological effect of epilepsy, fears ,emotional disturbances ,anxiety and depression, Self-esteem and sense of mastery are among the many problems reviewed from various literatures and presented in the following manner.

2.2 .4.1 Psychological Effects

Epilepsy has negative effect on the life of a person affected by the disease. Most epileptic persons feel that they are helpless and hope less and psychologically inferior to their fellow age mates.

As explained by Thompson PJ (2010) , 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. [26]

2.2.4.2 Fears

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. For many people it is frightening to see a person having an epileptic attack, losing control of himself. The simplest way to prevent such fear is to avoid the person with epilepsy which could commonly happen in many parts of the world. Fear of social exposure of fits and feelings of disgrace often lead to social isolation many epileptic patients develop an extreme dependence upon their relatives as Abimbola (2010).

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[26] THOMPSON PJ (2010) The neuropsychology of epilepsy and its treatment. In: *Oxford Handbook of Clinical Neuropsychology* (Eds J Gurd et al), pp 637-661. Oxford University Press, Oxford.

2.2.4.3 Emotional Problems

Living with epilepsy means coping with an uncertain prognosis regarding seizure control. Epilepsy carries increased risks of mortality and morbidity. As stated by **Hermann B, Jacoby A** (2009) Having epilepsy may mean coping with additional hidden deficits such as language and memory problems, or with a dual diagnosis, a learning disability being the most frequent co-morbidity. 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. Potentially more damaging psychologically is the failure of surgical treatment (which can arise in approximately one-third of cases), particularly when this follows several years of freedom from seizures.

2.2.4.4. Anxiety and depression

Both anxiety and depression are common co morbid features in PWE yet psychopathology is undertreated and under diagnosed. According to Jane McCagh (2009),(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. Suicide is also far more common in PWE than in the general population. There is a reciprocal relationship between anxiety, depression and epilepsy such that those with anxiety and depression are more likely to experience epilepsy and those with epilepsy are more likely to experience anxiety and depression. The exact mechanism that underpins this relationship as yet is not fully understood. Consequently social isolation is very common in PWE. 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 have been inversely related to higher scores on measures of depression and anxiety in PWE.[27]

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[27] McCagh J., Fisk J.E., Baker G.A. Epilepsy, psychosocial and cognitive functioning. Epilepsy Research, 2009; pp. 1-14.

2.2.4.5 Self-esteem and Sense of Mastery

Unpredictability is central to living with epilepsy. Individuals may not know when a seizure will occur and often have difficulty accepting living with a chronic condition that may or epilepsy topics may not improve. This can cause PWE to feel that they lack control over their life, can 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. Knowledge has been found to mediate the impact on self-esteem.

As explained by Jane McCagh(2009) ,adolescents with more awareness of their condition report higher levels of self-esteem and educational interventions aimed at increasing knowledge have been successful at enhancing self-esteem in PWE . Low self-esteem is commonly reported in PWE and is often mediated by employability, with those being unemployed reporting poorer self-esteem. Over protective parental styles can work to reduce a sense of mastery and consequently make PWE less independent in adulthood .

2.2.5 Economic Factors

House hold income, individual income, employment and work opportunities for people living with Epilepsy are among the major economic problems they are facing. Literatures reviewed under this topic have shown much more similar contexts in various countries of people living with the disease. Majority of the people who are victims of the disease live under Sevier poverty. The following section describes about the living situation of the target people which is common for all that live in different countries.

2.2.5.1 Employment

Under this topic it is tried to review literatures by the investigator about availability of employment opportunities for people living with Epilepsy and those who have a history of epilepsy are prohibited by law from a variety of occupations. As described by McCagh J., Fisk J.E., Baker G.A. (2009) practices that discriminate against people with epilepsy are another major contributing factor to unemployment. In most cases it is common phenomena that PWE are unemployed and underemployed in relation to the general population all over the world. Seizure related variables contribute to this, PWE who experience frequent seizures have less chance of employment and so do those who experience tonic clonic seizures. Adequate seizure control, early age of onset, stigma, poor self-efficacy, poor social skills, education level, social isolation, cognitive deficits, negative attitudes of family members, employers and teachers have all been linked to unemployment and underemployment.

Work in general is not an easy task for these people because of various reasons . A major barrier is stigma which in turn may lower self-worth and discourage PWE from seeking employment, conversely being part of the workforce is also likely to increase self-worth. As well as individual feelings of stigma, professional stigma may affect employability in the work place. Perceptions of stigma in the workplace and experience of stigma have been found to be of a similar magnitude. Discrimination is apparent in relation to the availability of employment and employers[28].

However, internal work beliefs have been highlighted as an important factor in the successful inclusion of people with epilepsy into the workplace. According to McCagh J., Fisk J.E., Baker G.A. (2009), Self-worth, worry about safety at work, perceptions of the likelihood of injury in relation to self and others at work and attitudes of family members were primary factors in work status.[29]

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[28] McCagh J., Fisk J.E., Baker G.A. Epilepsy, psychosocial and cognitive functioning. Epilepsy Research, 2009; p.234

[29] McCagh J., Fisk J.E., Baker G.A., LoC.Cit

2.2.5.2 Feelings of Dependency

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 would resulted the patients to live in a sever poverty situation. Existing evidences suggest that people with epilepsy are experiencing high levels of unemployment and underemployment. 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.

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, by up to 50% in developed countries. The same is happening in developing countries and if seizures are not fully controlled, the un employment rate could 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 (Bishop & Hermann, 2000; Gumnit, 1997).

Similar to the above description of people living with epilepsy and their linkage with work, it has many functions aside from the financial rewards. It provides a way of structuring time and, more importantly, contributes to a person's identity and feelings of self-worth. According to Gumnit, 1977 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. If paid employment seems increasingly unobtainable, then alternatives should be sought to enable people to make a meaningful contribution to society.

2.2.5.3 Employers Attitude towards Epilepsy

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 Dr Steven stachtcher (2008) are given in the following manner, [30] 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.

2.2.3 Treatments of epilepsy

Epilepsy is most often treated with medication. According to National Center for Project Access,(2010),there are many seizure-prevention drugs (also known as anti epileptics or anticonvulsant drugs) available and it can sometimes take awhile to find the one that works best for each child.

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[30] Dr. Steven Schachter, MD, Harvard Medical School, Beth Israel Deaconess Medical Center, Adapted from Epilepsy.com. Dr. Steven Schachter, M.D

It is important to follow your doctor’s instructions about when and how much medication to give your child. The medication won’t work properly until it reaches a certain level in the body, and that level has to be maintained. The goal is to keep the blood level high enough to prevent seizures, but not so high that it causes excessive sleepiness or other unpleasant side effects. If medication doesn’t work, other options include surgery, a medical device or a very specialized, high-fat diet.

3. RESEARCH DESIGN AND METHODOLOGY

This part of the study describes the research methodology employed by the investigator to collect, organize, analyze, interpret and present the findings in the research process so as to come up with valid conclusions and recommendations. In view of that, the section comprises, the research methodology, the study area and context, population and the sampling techniques, the data collection instruments, the data collection process, data organization and analysis to carry out the study.

3.1 Methodology of the Research

The research employs qualitative research approach and case study method by which the opinion of the target people and community representatives that include religious leaders, elders, youths, women and government representatives is explored to deepen understanding about the socio economic problems of the target people so as to enhance public awareness and find out means to reduce the intensity of the problem endure in the target people.

The participants in this study are called respondents. The term is used to emphasize the role the participants played in the data collection process. Those invited were presented with information about the purpose of the study and would be interested to respond to the questions in a cooperated manner. General information about measures taken to guarantee confidentiality and informed consent were also given.

3.1 Study Area and Context

Me'enit Goldia wereda is one of the 10 weredas in Bench Maji Zone administration. The administrative zone is one of the fourteen zonal administrations in SNNPR and is located to the south eastern part of the country 561 kms away from Addis Ababa and 836 kms away from the regional capital Hawassa. The administrative zone comprises 10-weredas and 1 town administration, the total population size in the year 2014 G.C was 788,988 people as projected from the-2007 G.C census where 49.58% constitutes Men and 50.4% constitute Women. The administrative zone covers an area of 19,965 square Km and constitutes seven ethnic groups, of these, Me'enit tribe people are the focus of the study and reside in the two weredas namely Me'enit Goldia and Me’enit Shasha Weredas. These people have their own language, culture and identity which can make them peculiar as other ethnic groups in the area.

Me’enit Goldia , the target wereda of this study is bordered on south with Me'enit Shasha wereda, on the west by Debub Bench wereda, on the northwest by She bench wereda , and on the north and east by Kaffa Zone. Bachuma, the capital of the wereda is located 85 k.m to the south west of MizanTeferi; it is a small town where epileptic persons are also living in the same manner as they live in other towns. The woreda has 31 Kebeles with a total population of around 133,556 people of which 76,833 are male and 56,723 are female as projected from the 2007 G.C census in the year 2014G.C.[31]

There are many people affected by epilepsy in the target wereda and the reason for high prevalence of the disease is not studied so far. By and large due to cultural belief in this particular area epileptic persons have been considered as evil callers on their families, wider communities and their tribe as a whole. Thus, they do not allowed to live in their birth place because of the deep rooted belief entrenched towards epilepsy in the society which disfavor the patient and make them subject to expulsion.

After being casted out from their birth place, they live in a speckled manner around churches, mosques, market areas without any protection and care in different towns of the administrative zone. If they are once identified as epileptic patient no one shows interest to give them employment opportunities even for menial works in the towns. The marginalization usually continues in a different form affecting their lively hood where ever they go.

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[31] Bench Maji Zone Finance and Economic Department,2013G.C

3.2 Population of the Study

As indicated above, Me’enit tribe people are living in the two weredas of Bench Maji zone administration namely Me’enit shasha and Me’enit Goldia weredas. Some of the epileptic people who had been evicted from their village to the towns were gathered from Mizan Aman town and have settled in the village called ‘Bala’ which is found in shy Kebele at the study area. Even though some of the target people are pulled together to settle in this village, it is obvious that many more are left disorganized in various towns of the zone. Therefore, the populations of the study are defined as the people affected by epilepsy from the study area and living in and outside of the target wereda after being expelled by their respective families.

According to the data collected by Mizan Aman town administration Department of Labor and Social affairs, the total number of people affected by epilepsy that are living in different towns in the zone are found to be 444 along with their children. This number includes those people already settled in Bala village. The person living in the target area constitutes 26 households who have been identified as victims of epilepsy and lead their life in the village where there is no clean water, other social services like school, health post and etc. The total numbers of settlers in the village were 130 including their children. The total number of epileptic people therefore is 52 in this village and the children of these families have not acquired the disease but affected by the impact of the disease.

3.3 Sampling Procedures

As indicated above, the people living with epilepsy from the target wereda lead their life in a scattered manner after being evicted from their birth place in different towns of the administrative zone. Due to the nature of the subject and the study group, the investigator has decided to make the focus of the study on those people who already settled in the village called 'Bala' assuming that they can give depth information about the living condition of epileptic persons. These groups of people were important to undertake the study in a way they can best represent others who were living outside the village in a vagrant manner.

The sampling method employed to take on the study was a non probability sampling method and the selection of the key informants were done through purposive sampling technique which has given opportunities for the investigator to obtain the required data from the respondents in appropriate manner. Though, the population size in the study area found to be 130 the study focused to collect the data from 52 people who were epileptic in a fair representation of gender balance.

Alternatively, the investigator has also got the views and opinions of the different groups of people and Government representatives through focus group discussion in the target wereda. Accordingly 12 people are selected for the discussion and their composition looks like the following. 6 of them were representatives from traditional leaders, elders, and religious leaders and ‘6’ were representatives from various Government offices. When we look at the specific areas of their representation we can see that, representatives from wereda education office, wereda health office, wereda administration, wereda women, youth and children office, Finance and Economic and two representatives from religious institutions, two elder representatives at local level, two representatives from traditional leaders and a representative from Bench Maji Development Association has participated in the discussion.

3.4 Types of Data and Data Collection Instruments

The data collection tools chosen for this study were intended to include qualitative data collection instruments such as close ended questions through structured interview, focus group discussion and observation check list. Accordingly, the close ended questions were mainly used with the people affected by epilepsy in a face to face manner and the focus group discussion held with the representatives of government offices and various community groups selected from elders, religious leaders and traditional leaders in order to get their views and opinions on the matter.

Furthermore, the investigator had collected information through a check list by direct observation in the study area.

3.5 Data Collection Process and Organization

As can be seen in the above paragraph the data collection instruments employed were close ended questions through structured interview for the people living with epilepsy, focus group discussion with various community groups and Government representatives, check list to see the status of the availability and utilization of social and economic services in the target area which might be in use by the target people.

Correspondingly, the interview questions were presented to the epileptic persons living at Bala village in a face to face manner with the help of the local language translator and the recording was done at the spot and followed with final editing by the investigator. Not only this, the investigator has arranged a discussion time for the participants of the focus group discussion and conducted the meeting and captured the most important points of the discussion in a minute that reflects the views and opinions of the participants in the issue under study .

In relation to the data organization, the responses related to Psycho - social problems were organized in one category and presented in three tables, the responses related to public perception and beliefs in another category and presented in two tables, economic implications of epilepsy at house hold level in another category and presented in two tables. Furthermore ,the roles of various actors to mitigate the challenge of epileptic people were organized in another category and presented in two tables. This shows that the data collected through various instruments were organized and presented in different categories of thematic areas of the study to be able to respond to the basic research questions and objectives of the study.

3.6 Data Analysis methods

The data analysis of the study has employed univariate data analysis technique in which the investigator used multiple of single variables for analysis in the whole process of the study. It has also used Frequency distribution tables to show the percentage of respondents for each unit of analysis. This step came next to data editing, coding and computing of the scores.

Once the qualitative data collection were completed and appropriately scored for recurring themes and codes, It has also addressed the coding categories that were constructed from the concepts and themes pertinent to the review of literatures and basic research questions.

4. DATA ANALYSIS AND INTERPRETATION

This part of the study refers to the data analysis process and the corresponding interpretations. The data collected through various instruments were analyzed and interpreted to be able to respond to the research basic questions and presented in the following manner:

4.1 Data Analysis and Interpretation

The data analysis was done based on the thematic areas identified which were all set in reference with the objectives of the study and basic research questions namely: The Psycho social problems faced by epileptic persons among Me'enit People, the economic problems faced by epileptic persons among Me'enit tribe, the underlining reasons for epileptic persons to be isolated and evicted from their families and relatives, and the roles to be played by Government, NGOs and community groups to help improve the living situation of the target people. Accordingly, the responses collected through the various data collection instruments were classified in to major and interrelated thematic areas. These are: Psycho Social effects of epilepsy, Perception and Beliefs about epilepsy, Economic implications of epilepsy at house hold level and the roles to be played by different actors like Governmental and Non-governmental organizations and different community groups. In order to make the analysis responsive enough to the objectives of the research, the investigator has also critically examined the processed data in the form of frequency distribution techniques and re-categorized them to arrange categories with the help of master charts to avoid overlapping and duplication of data. The following section illustrates the data analysis based on the thematic areas identified and the interpretation followed the analysis.

4.1.1 Demographic Characteristics

The demographic characteristics of the respondents is presented in the following Table and shows the general characteristics the people affected by epilepsy and participated in the study by responding to the questions during data collection. Furthermore the table shows some characteristics of focus group discussion participants' interms of gender and age group.

Table-4.1 Profiles of Respondents

Typeof Respondents	**Respondents status at “Bala village”**			**Sample**			**Remarks**
	Male	**Female**	**Total**	**Male**	**Female**	**Total**	
Epileptic persons	26	26	52	26	26	52	All responders were between 30-60 years of age
Religious representatives		-		2	-	2	
Elders				2	-	2	
Traditional leaders				2	-	2	
Wereda Education office				1			
Wereda health office					1	1	
Wereda W/C/Yoffice					1	1	
Wereda F/E/D/ office				1		1	
Wereda Administration				1		1	
Bench Maji Development Association				1		1	
Total				**36**	**28**	**64**	

As indicated in the above Table 4.1, there were different categories people have participated in responding to the questions. The first category represents epileptic people and they were twenty six men and twenty six women, the other category represented various community groups represented from traditional leader,elders,religious institutions representatives and Government offices and a representative from Bench Maji Development Association. The age category of the respondents were between 30-60 years old .

4.1. Data Analysis and Interpretations

The responses given by all the respondents were coded and presented in a frequency distribution technique to make the data analysis easy and understandable. The thoughts and opinions of community groups and government representatives have also been merged with the responses of epileptic persons under each thematic area. Accordingly the above categorization of the responses, the data analysis and interpretation were presented in the following manner.

4.1.1 Theme1: Psycho-Social Effects of Epilepsy

This section has described the data collected through all the tools used in the study from different groups of respondents. The focus or center of analysis under this section has given more emphasis on the Psycho-Social effects of epilepsy. The thoughts and opinions of the respondents are categorized in to three different tables, the first table concentrates on questions related to 'social marginalization and stigma' applied on epileptic patients and the second table shows questions related to 'Access to Social services' like education and health . Finally the third table constitutes questions related 'Psychological problems of epileptic people' in the study area.

Table-4.2 Social marginalization and stigma

S.N	**Items**						
		Yes		**No**		**I don't know**	
		F	**%**	**F**	**%**	**f**	**%**
1	Access for a marriage with a person free from epilepsy			52	100%		
2	Public support for epileptic people health condition	8	15.38%	40	76.92%	4	7.69%
3	Social exclusion	52	100%				
4	Participation in public, cultural, and religious events			48	85.2%	4	7.69%
5	Feelings about family membership	6	11.53%	36	69.23%	10	19.23%

As indicated above in Table-4.2, opinions of epileptic persons in relation to social marginalization and stigma were assessed and five questions were presented in the order designated. Accordingly, the first question refers to the possibility of having marriage with non epileptic person and 100% of the respondents replied "NO" to the question. This implies that an epileptic person in the target area would not think of having marriage with non epileptic person. In question number two respondents were asked to give their opinion with regard to Public support for epileptic people health condition , 76.92% of the respondents have answered as d "NO", 15.38% have answered "YES" and 7.69% have responded as "I don't know". This shows that, majority of the epileptic persons in the study area feel that nobody is carrying about their health and well being. In question number three, opinions of respondents were assessed to know the level of social exclusion applied on them. For this question 100% of the respondents have felt that they were socially excluded and marginalized. In relation to taking part in public events as seen in question number four, 85.2% of the respondents have answered that they didn't take part in public, religious and cultural events. Finally in question number five Feelings of epileptic persons about family membership were assessed. Accordingly *69.23%* of the respondents have replied "NO", 19.23% said they don't know and 11.53% of them feels they are member of their respective families. These show that majority of the respondents did not feel that they are member of their respective non epileptic family members.

On the other hand, in the focus group discussion held at the target area participants were asked to give their opinion for the question "what is your opinion to the level of stigma and social marginalization applied on epileptic people in your surrounding?" the responses were captured in a minute and reflected their views in such a way that all the representatives from various community groups and government offices have agreed in common that there is high level social marginalization and stigma on the people affected with epilepsy in the target area. Not only have these it has also been verified by the observation checked list that the people affected by the disease are living in isolation at Bala village and around churches and market places in the nearby towns.

As can be understood from the above explanation, it has been verified by various groups of respondents that majority of them have agreed in the matter and said, there is high level of social marginalization and stigma applied on them from the wider communities of the same ethnic group.

Table 4.3 Access for Social Services

S.N	**Items**	**Level of responses**					
		Yes		**No**		**I don't know**	
		F	**%**	**F**	**%**	**f**	**%**
1	Access for education			52	100%		
2	Importance of education	36	69.23%			16	30.76%
3	Health care services	12	23.07%	40	76.92%		
4	Believing on medication	12	23.07%	32	61.53%	8	15.38%
5	Access for family planning services			52	100%		
6	physical injury	44	84.6%	8	15.38%		

The above Table 4.3 has questions related to availability and use of social services by the people living with epilepsy in the study area and the responses indicated in the Table are described in the following manner. For question number 1,100% of the respondents have said, they have no access for education so far and for question number 2, 69.23% of the respondents have said “YES” and 30.76% of the respondents said “I don’t know”. This shows that majority of the respondents knew that education can improve their lively hood. For question number 3, it was assessed the use of health care services by the patients. Accordingly 76.92% of the respondent said “NO” and 23.07% of them said “YES”. On the other hand for question number 4, 61.53% of the respondents said “NO”,23.07% of them said “YES” and 15.38% of them have also said “I don’t know” . From the responses given, we can see that majority of the respondents have no access for health care services and most of them don’t believe epilepsy can be cured with proper medication. Furthermore 100% of the respondents don’t use family planning services to manage their family size. Similarly, in question number 6 it has been tried to assess the level of injury they may have due to uncontrolled seizure and 84.6% of the respondents said “YES” and 15.38% said “NO”. This implies that many of them have injuries at their different body parts.

On the other hand ,in response to the question stated above ,participants of the focus group discussion have had similar opinion that epileptic persons have no or limited access for social services like education and health care services. This has also been verified by the observation check list filled by the investigator in such a way that infrastructures for social services are not established in the target area to make use of the services in a coordinated manner.

Table 4.4 Psychological problems of being epileptic

S.N	**Items**	**Level of response**					
		Yes		**No**		**I don't know**	
		F	**%**	**F**	**%**	**f**	**%**
1	Feeling of strangeness	44	84.61%			8	15.38%
2	Assuming roles in community activities			52	100%		
3	living with other people who are free from epilepsy	6	11.53%	46	88.46%		
4	Feeling of Suicide			40	76.92%	12	23.07%
5	Feeling of depression	52	100%				
6	Having personal goal	6	11.53%	46	88.46%		

In most cases epileptic patients have been observed as they have psychological problems in the views of the public at large and it has been manifested in different forms in the day to day life of the victims. As can be seen in Table-4.4, in question number one respondents were asked to reply on the feelings of strangeness on public gatherings, 84.61% of them have responded "YES" and 15.38% have responded "NO". This implies that majority of them have had feelings of strangeness in public gatherings and few of them didn't even know what strange means. In question number two, they were asked to know whether they had taken roles in community activities so far or not. For this question 100% of the respondents have said they did not take any role in community activities so far. This implies that the mainstream community didn't want to give them the chance of sharing social life and the epileptic people themselves did not try to challenge the trend in their localities. In question number three, it was asked to assess their confidence to live with people free from epilepsy , correspondingly,88.46% of the respondents have replied as “NO” to the question and 11.53% have said “YES”. This implies that, majority of the people with epilepsy have had no confidence to live with other people who are free from epilepsy. In Question number four, it was asked that whether they knew a person who has committed suicide being epileptic ,and the responses were summarized in a manner that 76.92% of them said “YES” and 23.07% have said “NO”. This implies that feeling of committing suicide is common and many of them knew a person who committed suicide because of the psychological suffering that came out of being sufferer by the disease. The last question in this section was about assessing the views of the PWE with regard to having personal goal in life .Accordingly, very few of them 11.53% have replied as “Yes” and 88.46% of them have replied as “NO”. These show, majority of PWE have not had any personal goal in life.

On the other hand, during the FGD conducted with community groups and government representatives, views of the participants were assessed for the question presented as “How do you see the level of confidence and emotional stability of PWE in their day to day activity as compared to other people?” few of the participants said , “PWE are like any other normal person in accomplishing their day to day activities” and majority of the participants said “PWE are mentally abnormal persons and are emotionally disturbed and have no confidence in their life”

In general, the responses from the FGD and interview questions have shown that, PWE are considered as mentally ill and emotionally disturbed people who are exposed for various forms of psychological problems like fear, anxiety and depression. Furthermore, these happened as a consequence of social marginalization and stigma they are experiencing in their day today life.

4.1.2. Theme 2: Perceptions and beliefs

As any traditional community Me’enit people are also living in a context of traditional beliefs which guides the way of their life in their localities. Not only this, superstations and religious beliefs are also among the kind of beliefs that shape the society to continue as it now. Under this section of the study, the investigator has assessed the perception of local people about ‘Epilepsy’ in Me’enit communities with reference to the traditional beliefs and religious beliefs about the case. Accordingly, the first Table has contained issues related to traditional beliefs and the second Table has constituted issues related to religious beliefs. Furthermore, the same issues were discussed at the FGD session and the participants’ views and opinions were discussed in order to triangulate the responses of the PWE with the FGD participants to come to conclusion.

Table-4.5 Traditional beliefs

S.N	Items	Level of response					
		Yes		No		I don't know	
		F	%	F	%	F	%
1	Evicting an epileptic person from his/her village	36	69.23%	16	30.76%		
2	Having chat with family members who have not acquired epilepsy	8	15.38%	44	84.61%		
3	Epilepsy is Medically treatable disease	4	7.69%%	40	76.92%	8	15.38%
4	Epilepsy is contagious disease	44	84.61%	4	7.69%	4	7.69%

There were four questions presented in Table 4.5 to the respondents, the first question referred, to assess the attitude of PWE about the practice of being evicted by their families from their village and the responses were bestowed as 69.23% of the respondents replied "YES" and 30.76% replied "NO". This indicates that, still majority of the PWE have been convinced that the mainstream communities would continue the practice. However, there be some improvement on their perception towards the public attitude of avoiding the victim because significant number of respondents replied as "NO" the question. In question number two, they were asked to respond to the question aimed at assessing the confidence and the opportunity they have to share ideas with people who were free from epilepsy. Correspondingly, 84.61% of them replied as "NO" and 15.38% have replied as "YES". This implies that, majority of them have not had any opportunities to deal with social issues with their relatives. In the third question they were asked to respond to the question that focused on the medical treatment of epilepsy. 84.61% of the respondents replied as “NO” and 15.38% have replied as “I don’t know”. This implies that majority of the PWE didn’t consider epilepsy as a medically treatable disease. In the same Table, respondents were asked about the disease in a way to assess their opinion whether it is contagious or not. Accordingly, 57.69% of the respondents replied as “YES” and 42.30% have replied as “NO”. This implies, PWE have had different opinions on this regard. Though majority of them believed that it is contagious disease and significant number of the respondents believed that it is not contagious, they explained this in example and said ,we have children that have not acquired epilepsy.

Table-4.6 Religious beliefs

S.N	**Items**	**Level of response**					
		Yes		**No**		**I don’t know**	
		F	**%**	**F**	**%**	**F**	**%**
1	Being cursed person	44	84.61%	8	15.38%		
2	Treatment by purifications and incantations	44	84.61%	8	15.38%		
3	Epilepsy happens due to evil spirit	48	92.30%	4	7.69%		
4	Epilepsy is considered as a sacred or untouchable disease	44	84.61%	8	15.38%		

Similarly, Table 4.6 has contained four questions to assess the opinions of PWE and their perception about religious beliefs. Accordingly, it was stated in question number one that epileptic person is considered as a cursed person; accordingly, 84.61% of the respondents have replied

“YES” and 15.38% have replied as “NO”. These shows, majority of the PWE were convinced that they had acquired epilepsy because they were cursed. The second question also refers to the treatment type in a spiritual sense and it was presented as treatment can only be through purifications and incantations. The same way as above, 84.61% of the respondents have replied “YES” and 15.37% have replied “NO”. This has also capitalized the above response in such a way that epilepsy can only be treated through purifications and incantations.

Furthermore, question number three states that epilepsy happens in a person due to evil spirit. Accordingly, 92.30% of the respondents have replied “YES” and 7.69% have replied “NO” for the question. This indicates, almost all people living with epilepsy thought that epilepsy would happen due to evil spirit and not for some other reason. The last question stated that, it was considered as untouchable disease. Similarly 84.61% of the respondents have replied “YES” and 15.38% have replied “NO” for the question. This shows, insignificant number of the respondents believed as a normal disease and quite large number of the respondents have taught as untouchable disease.

On the other hand, in a question presented as “How did the customary and religious beliefs practiced on people living with epilepsy?” The FGD participants shared their views from different angles and finally those who came representing different community groups and religious institutions reached in consensus among themselves that epilepsy is a disease caused by evil spirit and can only be treated with purifications and incantations. For this reason a person affected by the disease should be placed in untouchable situation far away from other community groups. However, participants of the FGD who came from the Government offices argued that epilepsy should be considered as a natural disease and could be treated as any other disease through hospitalization and medication.

4.1.3Theme 3: Economic implications

Observably epilepsy would affect the income of the person affected by the disease in many ways. One way of affecting their income as observed by the investigator was the attitude of the employers towards epilepsy took the larger share. Moreover, the following two Tables constitutes issues related to economic implications of epilepsy at house hold level. Table one consists of questions related to employment and epilepsy and Table two consists of questions related to capacity to buy services.

Table 4.7 - Employment and epilepsy

S.N	Items	Level of response					
		Yes		No		I don't know	
		F	%	F	%	f	%
1	Having one's own business to run			52	100%		
2	Employment at public and private sectors			52	100%		
3	Feeling of dependency on the general public	36	69.23%	16	30.76%		
4	Do you think you can get employment at public and private sectors?			48	92.30%	4	7.69%

Employment opportunities were not an easy task for people living with epilepsy , in Table 4.7 issue number one it was assessed whether epileptic persons run their own business or not . Accordingly 100% or all respondents have replied "NO" for the issue raised and it implied that none of them run their own business. In the same way on issue number two, it was assessed to know their views whether they can get employment at public and private sectors or not . In a similar fashion 100% of the respondents replied "NO". This shows employment has been a very difficult challenge for people living with epilepsy. Moreover, Issue number three states about the feelings of dependency on the general public. Accordingly, 80.76% of the respondents replied "NO" and 19.23% replied "YES". This means majority of the people living with epilepsy in the target area felt as they were highly dependent on the public at the towns. The fourth issue indicated in the table assessed about the possibility of getting employment at public and private sectors and the corresponding responses were seen as 92.30% of the respondents said "NO" and 7.69% of them said "YES". These imply that the target people in the study area would have not had the opportunity of getting employment at the public and private institutions.

Table 4.8 – Capacity to buy public services

S.N	Items	Level of response					
		Yes		No		I don't know	
		f	%	f	%	f	%
1	Affording schooling expenses	12	23.07%	40	76.92%		
2	Affording medical services			52	100%		
3	Employers attitude	6	11.53%	46	88.46%		

In a similar manner Table 4.8 has contained three different but interrelated issues that were related to the capacity of the people living with epilepsy to buy public services. Hence issue number one assessed opinions of the PWE about affording schooling services for their children. In this regard 76.92% of the respondents said "NO" and 23.07% replied "YES". These implied, majority of the target people didn't cover schooling expenses for their children. Similarly, issue number stated about affording health services and the responses were summarized in such a way that 100% of the respondents were not able to afford the health care services at public and private institutions. The other issue raised in the Table was about employers attitude towards epilepsy and the responses were summarized in such a way that 88.46% have replied as "NO" and 11.54% have replied "YES". These implied, PWE have taught, employers have no interest to give them employment opportunities for people living with epilepsy. On the other hand, questions that have similar content were asked to focus group discussion participants in the form of “What do you think the income source of people living with epilepsy to lead their lively hood?”

4.1.4 Theme 4: Roles of various actors to mitigate the challenge

As can be seen indifferent parts of the study, the psychosocial and economic problems of epileptic people is more of external to the patients and requires concerted efforts of all concerned parties such as Government, Non Governmental organizations ,Religious institutions and traditional institutions need to play constructive roles to alleviate their problems and help them live better life. Views and Opinions of these stake holders have been obtained during the focus group discussion and the summary of their views and opinions is presented in the following manner:

4.1.4.1 Government Role

As per the discussion held, government representatives have reflected their views in the following manner:

> They suggested that problems related to the target group should get attention as much as possible in all the local government plans and programs.

They have also agreed to promote awareness raising on the rights of the target people .

Propose resource mobilization strategies and stakeholders cooperation in order to avail social and economic services to make use of them by the target people.

Agree to organize public awareness raising events to enhance the knowledge of the public in the problem underlined by the target people.

Suggested means to strengthen the works of bringing together those who live in different towns of the zone in a vanguard manner to a place where they can get public services and improve their livelihood.

Agree to work with Traditional institutions and Religious institutions to enhance public perceptions to fight the tendency of mistreatment of epileptic persons and reduce stigma.

4.1.4.2 Religious Institutions Role

During the FGD held at the study area, the views and opinions of religious institutions' one from the Orthodox Christian church and the other one from Mekaneyesus church suggested that,the issue under discussion was not an issue that can simply taken to their respective followers to take for a positive actions on changing the trend towards people living with epilepsy . However, on gradual basis, they agreed to recognize and promote the problems of PWE to be understood by their respective followers and institutions under the curtain.

4.1.4.3 Traditional leaders Role

Two representatives of traditional leaders who have been culturally recognized and respected by the wider communities and two other participants who were elders and recognized by the local communities had taken part on the FGD session conducted in the study area. Accordingly, they have thoroughly discussed on the roles that can be played by them to contribute for the mitigation of the challenges faced by the target people. Finally, they came in to consensus that, the deep rooted belief of avoiding an epileptic person from their respective villages could not be changed in a short period of time; however, they have shown commitments to take personal responsibilities to contribute for others to understand the problems of the target people rather than considering them as an evil caller person to their families.

5. MAJOR FINDINGS AND CONCLUSIONS

The major findings of the study were drawn from the data analysis and interpretation process completed in the previous chapter. The proceeding chapters had precisely and objectively verified the issues raised in the research basic questions. Accordingly, the main findings of the study are presented in a logical order, these are:

5.1 Major Findings

- An epileptic person in the target area did not consider the possibility of having marriage with non epileptic person;
- The PWE has believed that there is high level of social marginalization and stigma applied on them from the wider communities in the study area;
- There was good understanding on the PWE about the importance of education to improve their livelihood;
- Majority of the target people have injuries at their different body parts.
- Infrastructures for social services were not established in the target area to make use of the services ;
- Majority of them have had feelings of strangeness in public gatherings ;
- The mainstream communities didn't show interest to give them the chance of sharing social life with PWE.

- Majority of PWE have not had any personal goal in life.
- PWE were considered as mentally abnormal and emotionally disturbed persons who did not have confidence in their life;
- Majority of the PWE didn’t consider epilepsy as a medically treatable disease.
- Majority of the PWE believes that epilepsy is contagious disease however.
- Majority of the PWE were convinced that they had acquired epilepsy because they were cursed and can only be treated through purifications and incantations.
- Almost all people living with epilepsy in the target area were convinced that epilepsy would happen due to evil spirit;.
- Employment has been a very challenging task for people living with epilepsy and majority of them were living on beggary so that they feel that they were highly dependent on the public in the towns.
- Majority of the target people couldn’t cover schooling expenses for their children;
- 100% of the respondents were not able to afford the health care services at public and private institutions
- PWE have taught, employers have no interest to give them employment opportunities in towns.

5.2 Conclusions

This study was initiated by the investigator after personal observation on the target area and discussion conducted with various people, government representatives, Bench Maji Development Associations staff members and some epileptic persons who live at the study area in relation to the people affected with epilepsy and living on Mizan Aman town streets.

Like any other people living with epilepsy in different places of developing nations, the people living with epilepsy in the study area were facing extreme form of discrimination by their respective families and the wider communities that made the victims highly vulnerable for severe poverty and illness. Although the problems related with these people have multifaceted forms, however, the investigator has focused on the social, psychological and economic problems of the target people that would greatly affect their livelihood.

As indicated in the research findings ,there have been various issues to be addressed related to the people affected by epilepsy in the target area and the intensity of the problem requires further study and intervention by various actors who have interest and willingness to support them . Furthermore, the study put some recommendations and would help other researchers to take off similar or more advanced studies to be able to further explore the problems related with these people and would expand the experience to other parts of the country.

On the other hand, the study could be a potential reference to bring concerted efforts from interested people in the issues identified , stakeholders and respective communities so that the socio-economic problems of the target people would get clear understanding by their respective communities and other people in the area to coordinate efforts of all concerned people and institutions to be able to contribute for alleviating the problems stated in the study.

6. SUMMARY AND RECOMMENDATIONS

6.1 Summary

Epilepsy is a neurological disorder which affects people's life all over the world since early in the history of mankind. Early historical texts show that at a time when societies had become sufficiently organized to need written documents, concepts of epilepsy had often developed and these were frequently religious. Epilepsy was known as a natural disease and explained by Hippocrates in such a way that "A disease with natural causes like all other diseases, and its seat was in the brain". This was taken as a major landmark for the medical history of epilepsy.

However, there is still much ignorance of how profound it influenced and changed public views. Withdrawing from society in order to reduce the experience of stigma which can greatly impact on the quality of life of PWE by making them feel more socially isolated, have less social opportunities and smaller social support networks.

This study sought to get perspectives from epileptic persons that live in the study area, different offices of local Government at wereda level, Traditional leaders and Elders. Moreover, the study was motivated by personal observation of the investigator and concerns reflected by some individuals who live in the study area.

In relation to the data collection it had been sought that participation of the target people being the main concept to undertake the study .Hence, the investigator felt duty-bound to apply it by involving people living with epilepsy in providing data that sought to ensure their involvement in issues that affect their lives. Communities' views were as well sought.

Not only these ,the research spin around the four basic research questions thus: The Psycho social problems faced by epileptic persons among Me'enit ethnic groups assessed in the first question , the economic problems faced by epileptic persons assessed in the second question , the underlining reasons for epileptic persons to be isolated and evicted from their families and relatives at the study area was assessed in the third question and finally the roles to be played by different actors was assessed in the fourth question.

Accordingly total of fifty two (52) questionnaires were presented to PWE and filled in by the help of the local language translator in a face to face manner and six questions presented to 12 people who came from various community groups and government offices and discussed in a focus group discussion session with the help of local language translator and note taker .Additionally, 12 twelve (12) questions filled in by the investigator in an observation check list prepared to complement the data collected through questionnaires and focus group discussion.

In the mean time, it has been understood that ,there were several factors that came out from the study as regarding aggravating or improving the living situation of PWE in the target area. Among these age, maturity level, being illiterate, and cultural influences were taken as aggravating factors and the possibility of being observed by local Government ,other group of people and Nongovernmental organizations would be taken as an opportunities for mitigating the challenge through joint effort of all concerned people and institutions.

In conclusion, the PWE have had various kinds of social problems, psychological problems which most likely resulted from stigma and misconception and last but not least economic problems to help them participate in the social and economic activities in their day to day life. The empirical findings of the study has indicated that , there has been close relationship between poverty and being epileptic in the study area.

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6.2 Recommendations

The general objective of this study is to explore the socio economic problems of epileptic people among Me'enit tribe and seek for means to contribute for the livelihood improvement of the target people.

In order to achieve the major objectives of the study, the investigator has made intensive discussion with the target people, local community representatives, Government representatives and religious institutions representatives. As a result of the discussion and collected data through various data collection instruments, the investigator has drawn possible recommendations to respond to the basic research questions.

The recommendations have direct linkage with the major findings of the study and hence reflected the views and opinions of the people participated in the study. These are:

As indicated in the study findings , there has been high level of social exclusion on the PWE which in turn has put negative effect on the lives of the target people and has resulted for sever poverty and illness on the victims. To combat these problems, the investigator would recommend the importance of bringing together the efforts of various actors towards raising awareness of the general public and taking practical steps in creating access for basic social services.

In a similar fashion, the study has also identified that the PWE were facing various problems related with employment and having means of income to lead their lives. In this regard the investigator would recommend working on creating job opportunities and engage them in the production process like providing land to plough, provision of seed money to run small businesses and work on public perception towards the disease.

Furthermore, the study has also identified that, the underlining reason for PWE to be expelled from their birth place was circled around the long standing cultural beliefs. Therefore, the investigator would recommend for the local government to act on the issue in a long range and sustainable programs so that the public perception will get improved and the degree of social exclusion will be minimized.

Finally, the investigator has concluded that 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 Government structure, Non Government organizations, Religious institutions and elders to be able to bring sustainable change in the livelihood of the target people.

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Appendix A -

Interview Questions For People Living With Epilepsy

The purpose of this study is to gather data which are related to the socio economic problems of people living with epilepsy at Me'enit Goldia woreda and to show as how it has affected their livelihood.

Direction:

Dear respondent, in answering the questions you must be sure that your name and other personal information will not be written along side of your responses. There are three options and you are expected to respond to the option you think is appropriate. The questions are presented in a structured interview form and will be presented in a face to face manner.

Thank you in advance for your cooperation.

I. Basic information on the profiles of the respondents

Respondents personal status	Alternatives							
	Put 'X' Mark in the space provided							
Age	(12-18)Yrs		(19-30)Yrs		(31-50)Yrs		51 and above	
Sex	Male		Female					
Educational status	Illiterate		Primary (1-4)		Primary (5-8)		Secondary	
Marital status	Single		Married		Divorced		Widowed	
Number of children	1-2		3-4		5-6		7 and above	
Religion	Christian		Muslim		Other			
Means of lively hood	Agriculture		Petty trade		Beggary		No	
Physical status	Strong		Fatally Injured		Mildly injured		weak but not injured	

Close ended Interview Questions for PWE

1. Do you think you can have marriage with a person free from epilepsy?

A. Yes B. No C .I don’t know

2. Do you feel people are carrying about your health?

A. Yes B. No C .I don’t know

3. Do you feel that you are socially excluded?

A. Yes B. No C .I don’t know

4.Do you feel you can participate in public, cultural, and religious Events?

A.Yes B. No C .I don’t know

5 .Do you feel that you are member of your families

A. Yes B. No C .I don’t know

6. Did you get access for education so far?

A. Yes B. No C .I don’t know

7. Do you believe education can improve your life?

A. Yes B. No C .I don’t know

8. Did you get health care services so far?

A. Yes B. No C .I don’t know

9. Do you believe that you can be cured if you get proper medication?

A. Yes B. No C .I don’t know

10. Do you have access for family planning services so far?

A. Yes B. No C .I don’t know

11. Do you have physical injury due to uncontrolled seizure?

A. Yes B. No C .I don't know

12. Do you feel strange in public gatherings?

A. Yes B. No C .I don't know

13. Do you have any experience of taking role in community services?

A. Yes B. No C .I don't know

14. Do you feel comfortable living with other people who don't have acquired epilepsy?

A. Yes B. No C .I don't know

15. Do you know a person who committed suicide being epileptic?

A. Yes B. No C .I don't know

16. Do you feel depressed most of the time?

A. Yes B. No C .I don't know

17. Do you have personal goal to achieve in your life?

A. Yes B. No C .I don't know

18. Do you think everyone in the community is convinced to avoid an epileptic person from his/her village?

A. Yes B. No C .I don't know

19. Did you spend time chatting with your family members who have not acquired epilepsy to get support in your life time?

A. Yes B. No C .I don't know

20. Do you think epilepsy is medically treatable disease?

A.Yes B. No C .I don't know

21. Do you think epilepsy is contagious disease?

A. Yes B. No C .I don't know

22. Do you believe epileptic person should live in isolation from other family members?

A. Yes B. No C .I don't know

23. Do you believe an epileptic person is a cursed person?

A. Yes B. No C .I don't know

24. Do you believe an epileptic person can only be treated by purifications and incantations

A.Yes B. No C .I don't know

25. Do you think epilepsy can happen because of evil spirit?

A.Yes B. No C .I don't know

26 Epilepsy should be considered as a sacred untouchable disease

A.Yes B. No C .I don't know

27. Do you have your own business to run?

A.Yes B. No C .I don't know

28. Did you get employment at public and private sector so far?

A.Yes B. No C .I don't know

29. Do you feel economically dependent of the public?

A. Yes B. No C .I don't know

30. Do you think you can get employment at public and private sectors?

A. Yes B. No C .I don’t know

31. Can you afford sending your children to school?

A. Yes B. No C .I don’t know

32. Can you afford medical services?

A. Yes B. No C .I don’t know

33. Do you think employers have positive attitude towards hiring epileptic person at their company?

A.Yes B. No C .I don’t know

Appendix-B

Observation Check list

Objective

The purpose of gathering information through this check list is to triangulate and supplement the opinions of respondents by using various tools. Therefore, the availability and utilization of Social and Economic Services at Bala village.

	Indicators	Status	
		Yes	No
	There are schools for children and adults in the village		
	There are health care facilities in the surrounding area of the village		
	Women in the village have family planning services		
	There are medical service provisions for epileptic people in the village		
	There is clean water facility for drinking and washing purpose in the village		
	There is plot of land for every house hold in the village		
	There are cattle and farming animals at every house hold in the village		
	There are community based institutions like edir ,iqoub and others in the village		
	Epileptic persons in the village are taking part in community based institutions		
	Epileptic person can participate in the community based institutions		
	There is credit facility for epileptic persons in the village		
	There are market possibilities to sell their products at the village/Kebele		

Appendix –C

Focus Group Discussion Questions

Objective

The objectives of conducting focus group discussion in the subject under study is to gather information on the socio-economic problems of people living with epilepsy at Me'enit Goldia woreda prepared for Government officials and various Community group representatives**.** Accordingly participants of the discussion have shared their opinions freely and trustfully so that the data gathered have been used to complement the information collected through various tools in the study.

Q.1 What is your opinion to the level of stigma and social marginalization applied on epileptic people in your surrounding?

Q.2 Do you feel that epileptic people need to live with their respective communities? If so, what do you think of the social role to be played by epileptic people in your surrounding?

Q.3 How do you see the level of confidence and emotional stability of PWE in their day to day activity as compared to other people?”
Q.4 How did the customary and religious beliefs practiced on people living with epilepsy?

Q.5 What do you think the income source of people living with epilepsy to lead their lively hood?

Q.6 What should be done by different community groups, governmental and nongovernmental organizations to improve the living situation of people with epilepsy in the study area?

Appendix-D

PROFORMA FOR SUBMISSION OF M.A. (RD) PROPOSAL FOR APPROVAL

Signature: ………………………………………………………………….

Name & : . …..Milkesa Wakjira .(PhD)

Address of Guide : ………………………………………………………….

………………………………………………………….

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Enrolment No. : .089132473.

Date of Submission: ..3rd November,2014.

Name of Study Centre: ………………………………………………………….

Name of Guide: Milkesa Wakjira.(PhD)

Title of the Project: . A STUDY ON THE SOCIO-ECONOMIC PROBLEMSOF EPILEPTIC PEOPLE AMONG ME’ENIT TRIBE THE CASE OF ME’ENIT GOLDIA WEREDA SNNPR /ETHIOPIA.

Signature of the Student: ……………………………………………………….

Approved/Not Approved…………………………………………………….

Date:…3rd Nov,2014

A Study on The Socio-Economic Problems of Epileptic People Among Me’enit Tribe,

The Case of Me'enit Goldia Wereda/SNNPR/Ethiopia

A Proposal for the Partial Fulfillment of Master of Arts Degree in Rural Development

Prepared by: Sileshi Getahun-

Submitted to: Indira Gandhi National Open University

3rd, November, 2014

Hawassa/

SNNPR

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CHAPTER 1

1.1 INTRODUCTION

The World Health Organization (WHO) estimates the point prevalence of active epilepsy (i.e. people with continuing seizures or the need for treatment) as generally 4 to 10 per 1,000 people, and in developing countries from 6 to 10 per 1,000 people. It is also estimated that at least 50 million people in the world have epilepsy as 43.7 million people were reported to have epilepsy from 108 countries covering 85.4% of the world in a WHO survey. The mean number of people with epilepsy per 1000 population is 8.93. This varies from 7.99 in high-income countries to 9.50 in low-income countries. However, the incidence of epilepsy in developing countries is about twice that in developed countries, and the WHO estimates that about 80% of the world's epilepsy patients are in developing countries.[32]

Based on this estimate ,the projected number of epileptic persons and the incidence of epilepsy in the study area would be calculating by using the ratio 10 per 1000 people since the country is found in developing nation's category. Accordingly the number from the total population of the wereda which is 133,556 would be expected to be 134 . This is the

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[32] Early Predictors Of Seizure Outcome In Newly Diagnosed Epilepsy, The University of Sydney ,August 2010

normal and acceptable number of incidence in the study area. However, according to the data collected from the study area ,the number exceeds the projected one and found to be more than 440 which is more than double of the normal estimation.

As understood from literatures, some known causes of epilepsy are genetic abnormalities, strokes, brain tumors, brain defects, head trauma and infectious diseases. However, for about half of all the epileptic seizures, their causes are still not completely understood.

Bench Maji is one of the fourteen zonal administrations in SNNPR ,it is located to the south eastern part of the country 561 kms away from Addis Ababa and 836 kms away from the regional capital Hawassa. It also comprise 10-weredas and 1 town administration ,the total population size in the year 2014 G.C was 788,988 people as projected from the-2007 G.C census where 49.58% constitutes Men and 50.4% constitute Women.

The administrative zone is covering an area of 19,965 square Km and constitutes seven ethnic groups who live in relative peace and harmony for centuries . Of these people Me'enit tribe are the focus of the study and reside in the two weredas namely Me'enit Goldia and Me’enit Shasha

Weredas. These people have their own language, culture and identity which can make them peculiar as other ethnic groups in the area.

Me’enit Goldiya , the target wereda of this study is boardered on south with Me'enit Shasha wereda, on the west by Debub Bench wereda, on the northwest by Shebench wereda , and on the north and east by Kaffa Zone. Bachuma , the center of the wereda is located 85 k.m to the south west of MizanTeferi ,it is a small town where epileptic persons are also living in the same manner as they live in other towns. The woreda has 31 Kebeles with a total population of around 133,556 people of which 76,833 are male and 56,723 are female as projected from the 2007 G.C census in the year 2013G.C.[33]

The target wereda is known and strongly believed by the investigator that there is high level of social marginalization which put negative influence on the lively hood of the people affected by epilepsy. In this particular area there is a widely spreaded belief which considers epileptic person as evil callers on their families, wider communities and their tribe as a whole.[34]

There are people affected by epilepsy that live in this wereda at Chat Kebele which is 9 k.ms to the South of Bachuma. The total population

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[33] Bench Maji Zone Finance and Economic Department,2013G.C

[34] Bench Maji Zone Finance and Economic Department , 2013G.C

of the kebele is 1,817 of which 1,030 are male and 787 are female. The kebele has 5 villages and the people affected by epilepsy are pulled together from Mizan Aman town in the village called Bala where no any non-epileptic person is living.

Though it is not supported by research the incidence of epilepsy in Me'enit tribe people is as high it happens as in other people in the administrative zone and it is related with the cultural practice of child delivery which usually be carried out in unsafe and unprotected manner outside home with no support from any other skilled person or family as understood from personal observation.

These people are not allowed to live in their birth place because of the deep rooted belief entrenched towards epilepsy in the society which disfavor the patient and make subject for expulsion from his/her respective area. After being evicted from their birth place, they live in a scattered manner around churches, mosques, market areas without any protection and care. They don't have any opportunities for jobs, even for menial works in the town if once identified as epilepsy patients. The marginalization continues having different form affecting their lively hood even in the towns.

The Federal Democratic Republic Government of Ethiopia in its Growth and Transformation plan indicated that, "Improving citizens' living standards and development of their human potential ,is a key strategic pillar of the GTP".

The FDRE government will take various measures to improve peoples' health, productivity and skills . Among other benefits ,these measures will increase the potential for government's policies ,strategies and programs to realize their objectives. AS indicated in the GTP ,the main initiatives that are expected to ensure that this strategic pillar is realized are "improved access to good quality higher and adult education ,very wide access to good quality primary health care ,better access to safe water and sanitation facilities ,halting the spread of HIV/AIDS and other key infectious diseases ,improving food security and nutrition, and improved housing conditions" [35]

However, there are quite a lot people who are denied of these rights and set aside suffering from social and economic marginalization's in their respective localities. Among those people, epileptic persons in the study area are the one experiencing even the worst form of discrimination and eviction. These people are not getting equal opportunities for social services like education, health and housing. Not only these, they are not also benefitting from the country's economic development and considered as the most unreachable and marginalized people.

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[35] FDRE, Ministry of Finance and Economic Development , Growth and Transformation Plan ,2010/11-2014/15, (2010),Addis Ababa

1.2 STATEMENT OF THE PROBLEM

Me'enit Shasha and Me'enit Goldia weredas are found in Bench Maji Zone/SNNPR; the people living in these weredas are known as Me’enit tribe people who have their own identity as a tribe and speak their own language, culture and lead their own peculiar way of living.

Similar to other forms of marginalization practiced in many people considered as low cast in the respective communities, epileptic persons who live in Bench Maji Zone ,Me’enit shasha and Goldia weredas are suffering from the worst kind of discrimination that is expressed in the form of avoiding a person from his/her village and leaving aside due to his/her ill health. Within these people, there has been a wide spread and deep-rooted wrong belief that epileptic person should be marginalized and not allowed to live in that community. The wider community in the study area are not accepting epilepsy as any other medically treatable disease and consider it as a transmittable disease. Epilepsy in this society is therefore ,believed as a hereditary and contagious disease and the person affected by the disease is regarded as evil caller on the respective family and the larger community in general.

Nevertheless , Epilepsy can happen in a any person at any time in any place regardless of age and sex. Furthermore, If any person regardless of age and sex found epileptic in Me’enit tribe, the families , relatives and the whole community in the respective area would refuse to share any kind of social communication with that person. For instance ,If a father or mother of those persons affected by the disease are trying to hide the fact and tolerate to live with them ,the whole community put sanctions in their social life that would largely affect their confidence and livelihood.

According to personal observation of the investigator, it has been learned that a person affected by epilepsy used to be killed by his/her own family in a mysterious way, like pitching a person from a hill in to a river or deep gorges . However, in recent times , the kind of measures being taken by the people changed and they usually practice evicting a person from his/her village to towns or distant areas believing that the person will have no chance to get back home again.

After ones being expelled from their village, they will automatically assimilate themselves with the people living in a similar situation in Mizan Aman and the nearby towns. Churches, mosques and market areas are the most common places in the town for the victims to get shelter, food and clothes. Furthermore, the situation is found more Sevier when it happens on woman, girls and children in general.

Since these people are subject for marginalization and multiple form of social exclusion from their own community, nobody cares and consider them as a human being that, they have feelings, emotions and needs for survival. Moreover , the desperate way of living make them hopeless and vision less, their sexual behavior is rampant and resulted to have more children that forced to live on a street.

On the other hand , in times of seizure, they frequently got injury in different parts their body. Physical damages are the most common incidents that are happening in their day to day life, especially when they fall down in a fire, it burns any part of their body exposed to the flame. It is observed by the investigator that many of the epileptic persons are highly got injuries on their face around their eyes, neck and the most sensitive body parts. They don’t get any medical service and even first aid support from other community members whether they fall in a fire, in a gorge or in a roads etc…

Currently, there are some efforts being done by Mizan Aman town administration to gether with the Ethiopian Red cross society Mizan branch ,to bring some of them together and get settled in a small village called "Bala". This action has helped few of the target people at least to have small land and strive for survival. However, pulling them to gether in one place is also been criticized by some people in a way that doesn't help to get them live with their respective families and the wider communities.

For this reason the investigator believed to undertake the study so as to call for concerted efforts to be made from different actors to improve the hardship situation of the people affected by epilepsy in order to help them survive ,getting better social and economic services and plays their role as a citizen of this nation to contribute for the achievements of local and national development programs.

Therefore, the study is timely and crucial to explore the socio-economic problems of the target people so as to give valuable recommendations that would help improve their lively hood and enjoy better life .

1.3 OBJECTIVES

1.3.1General Objective:

The general objective of this study is to explore the socio economic problems of epileptic persons among Me’enit tribe so as to seek for means of improving the livelihood of the target people.

1.3.2 Specific Objectives

- To point out the social problems epileptic persons are facing in the study area and promote social inclusion;
- To explore the economic problems of the target people and propose measures to be taken to improve their living standard;
- To contribute to the efforts being done by various actors in the study area so that the living condition of the target people will be improved;

1.4 Basic Research Questions

- What are the Psycho social problems faced by epileptic persons among Me’enit ethnic groups?
- What are the economic problems faced by epileptic persons among Me’enit tribe?
- What are the underlining reasons for epileptic persons to be isolated and evicted from their families and relatives at the study area?
- What should be done by Government, NGOs and community groups to help improve the living situation of the target people?

1.4 DELIMITATION OF THE STUDY

The problems related to marginalization and social exclusion of epileptic persons is understood as high in the two weredas of Bench Maji Zone administration as in other weredas of the administrative zone during the discussion carried out with various Government offices, Community based organizations and people living in the target wereda during problem identification. As it is widely accepted by society in the study area the problems of epileptic persons are mainly associated with socio cultural factors and deep rooted beliefs that, epilepsy is hereditary and contagious disease.

Though the problem is a common concern in the two weredas of Me'enit tribe people, the investigator has decided to delimit the scope of the study to one of the two weredas. This is actually done in order to down size the study to manageable geographic size and to the time and resource the investigator can have to complete the study.

Based on this fact, the scope of the study is delimited to one of the two weredas namely Me'enit Goldia wereda and the epileptic people who live in shay Kebele of the same wereda where those epileptic persons pulled to gether from Mizan Aman town and surrounding areas.

The study will also be delimited to collect educational datas from sample schools going back three years from the current academic year to be able to see the progress in the participation of the target people in the selected schools.

1.6 BASIC ASSUMPTIONS

There were assumptions taken in to consideration in the course of identifying the problem to make the study a reality. These assumptions had motivated the investigator to carry out the study in the target area. To mention some, the respondents of the study will be open and transparent in explaining the facts related to the problem and be willing to cooperate with the investigator in the course of the study.

There can be sufficient data in the target schools which can help the investigator to draw conclusion out of it and the respective government institutions will also be cooperative enough to facilitate conditions for conducting an interview and focus group discussions in the study area.

Furthermore, the results of the study will possibly call attention of many other academicians, civil society organizations, Government and Non-governmental organizations in order to mitigate the challenge the target people are facing.

CHAPTER 2.

2.REVIEW OF RELATED LITERATURES

The literature review includes concepts and definitions related to the problem under study and helps the investigator to have better understanding on the socio economic problems of epileptic persons in various cultures and countries. Accordingly, literatures that constitute some facts about epilepsy and its impact in the life of the victim and related documents reviewed by the investigator while undertaking the study and are presented in the following manner.

2.1 Theoretical Review

2.1.1Definition

Epilepsy is defined by different authors in a more similar way , as defined by Folarin Oluseye Abimbola (2010),it is “an umbrella term used for neurological disorders characterized by seizures. Since the seizures might originate in different locations of the brain, the symptoms can differ greatly between patients all diagnosed with epilepsy" Seizure in Epilepsy can be viewed in different forms and the usual symptoms of seizures are classified as uncontrolled motoric movements or spasms, convulsions, emotional or psychological sensations, loss of consciousness and more. These are usually caused by signal feedback oscillations between neurons.[36]

Similarly, as defined by National Center for Project Access(2013)

Epilepsy is a medical condition that produces seizures that can affect mental and physical functions. It is also called a seizure disorder. Many illnesses or severe injuries can affect the brain enough to produce a single seizure. When seizures continue to occur for unknown reasons or because of a problem that cannot be corrected, the condition is known as epilepsy.

2.1.2 What Causes Epilepsy?

Causes for epilepsy to happen in a person can be seen differently in different contexts. According to National Center for project center (2010) for instance in about seven out of ten people with epilepsy, no cause can be found. This is called idiopathic epilepsy. Idiopathic is a Latin word meaning "of unknown cause". Among the rest of the people with epilepsy, the cause may be any one of a number of things that can make a difference in the way the brain works. For example, head injuries or lack of oxygen during birth may damage the delicate electrical system in the brain. Other causes include brain tumors, lead poisoning, problems in development of the brain before birth and infections like meningitis or

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[36] Folarin Oluseye Abimbola (**2010)**Classification of epileptic seizures using accelerometers, Chalmers university of technology

encephalitis. Epilepsy can run in families but it is not contagious you cannot catch epilepsy from someone else and nobody can catch it from you.

2.1.3 What is Seizure?

Seizures occur due to brief disturbances in the normal electrical functions of the brain. Millions of tiny electrical charges pass between nerve cells in the brain and connect to all parts of the body. When someone has epilepsy, this normal pattern may occasionally be interrupted by short bursts of electrical energy that are much stronger than usual. This can cause muscle spasms or uncontrollable body movements, loss of consciousness or confusion. These physical changes are called epileptic seizures. Normal brain function cannot return until the electrical bursts stop. Seizures can occur in just one area of the brain (partial seizures) or may affect nerve cells throughout the brain (generalized seizures). Most last a few seconds or minutes.[37]

2.1.4 Types of Seizures

There are different types of seizures manifested by epilepsy patients, as defined by Abimbola (2010), seizures are classified in to two general forms; these are seizures by origin and seizures by motoric symptoms. According to the same author , classification of epilepsy symptoms are

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[37] Folarin Oluseye Abimbola (**2010)**Classification of epileptic seizures using accelerometers, Chalmers university of technology

further done into two major classes depending on the initiation of the case. They are called partial-onset and generalized-onset seizures. Partial-onset seizures start in a specific area of the brain. The symptoms depend on the function of that specific area. If the seizure does not alter consciousness it is known as a simple partial seizure. Partial seizures that cloud consciousness and cause abnormal repetitious movements are known as complex partial seizures. Partial seizures are usually associated with some kind of damage to a part of the brain. Not only these, Generalized seizures are those seizures where the whole or large parts of the brain experience abnormal electrical activity. This kind of seizure is usually much more dramatic given that many of the brain functions are affected at the same time. In many of these types of seizures, the subject will not have any recollection of the seizure afterwards. On the other hand, Seizures by motoric symptoms are classified by its symptoms that affects motoric functions. For instance, tonic episode of a seizure is the phase of constant muscle contraction that comes due to the disease. If a tonic seizure affects the heart, it will stop beating due to the contraction of the heart muscle. Contractions are caused by oscillations of neuro-electrical signals with frequencies so high that the muscle fibers will not have time to relax in between each pulse. This causes the muscles to experience a constant contraction [38]

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[38] Anders Hildeman(2010),Early Predictors of Seizure Outcome In Newly Diagnosed

2.1.5 Superstitions, Religious Beliefs, and Concepts of Epilepsy

Religious beliefs are a very important aspect of the life of societies. It is a relatively recent development, and with many restrictions, that they are considered a private matter. In early history, when much still needed to be explained about life, the realm of religious beliefs was large and included matters of health and illness. Hippocrates' polemic against the belief that epilepsy in its variable appearances was sent by gods and should be treated by purifications and incantations (Hippocrates, around 400 BC) is recognizable in what was documented in a Babylonian cuneiform medical diagnostic series from the middle of the first millennium BC (Kinnier Wilson and Reynolds 1990). The Greeks referred to epilepsy as the Sacred Disease, and over the millennia, the disorder has been associated with prophets, mystics, diviners, and the like (Temkin, 1971). Hippocrates began his discourse on the "sacred disease" by refuting the connection between epilepsy and the divine; he argued against the widespread beliefs of prophetic and mystical powers attributed persons with epilepsy and the disorder's divine causation. However, Hippocrates attempt to dissociate epilepsy and religion was unsuccessful. Subsequent religious figures were asked to heal people with epilepsy. The New Testament gospels of Matthew (17: 14-20), Mark

(9: 14-29), and Luke (9:37-43), who was a physician; recount how Jesus cast out the evil spirit from a boy with epilepsy who just had a seizure, there by curing him. According to De Toledo & Lowe (2003) throughout the Middle-Ages and the Renaissance, religious and magical treatments of epilepsy predominated and in the nineteenth century the religiosity of persons with epilepsy was stressed by physicians. [39]

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[39] Wolf P (2006) Descriptions of clinical semiology of seizures in literature. Epileptic Disord pp.35-37

CHAPTER 3

3. RESEARCH METHODOLOGY AND METHODS

As specified in the above part of the proposal, the major intention of this study is to show how epilepsy is affecting the life of a person acquiring the disease among Me'enit tribe people in Bench Maji zone namely, Me'enit Goldia and Me'enit shasha weredas.

The research employs qualitative research approach by which the opinion of the target epileptic people and community representatives that include, religious leaders and traditional leaders, elders, youths, women and government representatives will be collected and analyzed to understand the extent of the problems the target people are facing and the attitudes of the people affected by the disease and the larger communities in the study area.

To sum up, the study uses descriptive method to clearly put the social and economic problems of the target people in understandable manner by taking the epileptic people living in one area pulled to gether from towns with the intention to give them opportunities to work and get other social services by creating access for social services like education and health. Case study method which is one form of descriptive research method will be employed to get opinions of the target people.

Accordingly, this section presents the population, the sample, the sampling technique used, the data collection instruments, the data analysis techniques and the interpretation method of the major findings respectively.

3.1 UNIVERSE OF THE STUDY

As indicated above, Me'enit tribe people are living in the two weredas of Bench Maji zone namely Me'enit shasha and Me'enit Goldia weredas, however, due to the time and resource limitations, the scope of the study is restricted only to one of the weredas which is known as Me'enit Goldia wereda and the Persons identified as epileptic from this area are living in different parts of the administrative zone and lead their life in pleading around churches and mosques.

Of course some of these are pulled together by Mizan Aman town administration and Ethiopian Red cross society mizan branch to one of the kebeles in Me'enit Goldia wereda called Shay Kebele. Therefore, the population of the study is defined to be the people affected by epilepsy and living in and outside the target wereda after being expelled by their respective families.

3.2 SAMPLE

After clearly defining the population, the study employs non-probability sampling technique to select the sample from two different population groups that can fairly represent the population under study. Accordingly, the first group consists of fifteen people who will be wrested from traditional and religious leaders, elders, youths and women in the target wereda and the selection will be done by close consultation of the local government authorities assuming that, they can represent the wider community and feelings and feelings of the people in the area. The second group consists of eighteen epileptic people who will be a mix of Married people [men and women], youths [female and male] in equal proportion.

3.3 Data Collection Instruments/Tools

The data collection tools chosen for this study are designed to include qualitative data collection instruments. Accordingly, the investigator uses semi structured interview and focus group discussions from the different sample groups. The semi structured interview will be conducted mainly with the people affected by epilepsy and the focus group discussion will be carried out with the representatives of various community groups such as elders, religious leaders, traditional leaders, and youth and women representatives.

3.4 DATA ANALYSIS

As stated above, the data collected through the various data collection instruments would be scrutinized and coded in a logical manner for analysis. This entail , the data analysis will be done effectively if it is properly organized. Statistical methods would be the possible ways to do the data analysis task to be able to generate findings of the study to come up with valid conclusion and recommendation at the end of the study.

3.5 TABLES

The study will have various tables that will have relevant statistical calculations such as percentage. These tables will have proper numbers in each chapter in ascending order . (i.e. Chapter I will have Table 1.1, Table 1.2 etc; Chapter 2 will have Table 2.1, Table 2.2 etc.). Table number will be followed by Table title which should be as brief as possible while conveying the matter contained in the table clearly.

1.6 CHAPTER PLAN

This part of the proposal conveys the major problems reflected in the study keeping in mind the objectives of the study and the basic questions of the research in mind so that the reader can easily understand the flow of the idea and would capture the main points of the study .

The first chapter shall be an introductory part to the study indicated in the title of the research. In this chapter, an attempt shall be made to describe the socio -cultural and economic problems of the people's affected by epilepsy in Me'enit tribe people in Bench Maji zone administration and explores to what extent the wider communities in the study area have negative attitude towards the patients and the disease itself. Chapter two will be , review of related literatures in relation to the disease and its impact on the persons affected socially and economically will be reviewed in this chapter. The third chapter shall deal with the research design and methodology of this research and conceptual framework of the study. The forth chapter shall present the data analysis and interpretation based on the social and economic profile of the sample taken for this study .The fifth chapter shall deal with major findings and conclusions of the study and the six chapter deal with Summary and Recommendations of the Study.

The last part of the study will deal with the reference section of the study and which include Bibliography, various forms of questionnaires which will be used in the study .

References Section

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Appendix=E

DECLARATION

I hereby declare that the Dissertation entitle “A STUDY ON THE SOCIO-ECONOMIC PROBLEMS OF EPILEPTIC PEOPLE AMONG ME’ENIT TRIBE,THE CASE OF ME’ENIT GOLDIA WEREDA SNNPR/ ETHIOPIA” Submitted by me for the partial fulfillment of the M.A. in Rural Development to Indira Gandhi National Open University, (IGNOU) New Delhi is my own original work and has not been submitted earlier either to IGNOU or to any other institution for the fulfillment of the requirement for any course of study. I also declare that no chapter of this manuscript in whole or in part is lifted and incorporated in this report from any earlier work done by me or others.

Place: Addis Ababa, Saint Marry University Signature:…………………..

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Appendix-F

CERTIFICATE

This is to certify that;

Mr.SELESHI GETAHUN MELISIE student of M.A. (RD) from Indira Gandhi National Open University, New Delhi was working under my supervision and guidance for his Project Work for the Course MRDP-001. His Project Work entitled "A STUDY ON THE SOCIO-ECONOMIC PROBLEMS OF EPILEPTIC PEOPLE AMONG ME'ENIT TRIBE, THE CASE OF ME'ENIT GOLDIA WEREDA SNNPR ETHIOPIA" which he is submitting is his genuine and original work.

Place: _______________ Signature______________________

Date : _______________ Name_____________________________

Address of the Supervisor__________

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