

JIMMA UNIVERSITY

COLLEGE OF SOCIAL SCIENCES AND HUMANITIES

DEPARTMENT OF SOCIOLOGY

M A IN SOCIOLOGY (SPECIALIZATION IN SOCIAL POLICY)

***Investigating the Socioeconomic Situations of Epileptic Children:-The
Case of Me'nit Shasha Woreda, West Omo Zone, SNNPR, Ethiopia***

A thesis submitted to Jimma University, Department of Sociology, in partial fulfillment of the requirements for the Degree of Master of Arts in Sociology (Specialization in Social Policy)

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Declaration

I Genet Damte, declare that the thesis entitled, “Socioeconomic situations of epileptic children in the case of *Me’nit Shasha Woreda, West Omo Zone, SNNP Region of Ethiopia*” submitted by me to the award of the Degree of Master of Art in Sociology (Specialization in Social Policy) at Jimma University, is the product of my original work, and has not been presented for the award of any academic degree, diploma, the fellowship of any other University or organization. This work has also accredited the views of the research participants. To the best of my knowledge, I have fully acknowledged the materials and pieces of information I used in the study.

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Certification

This is to certify that this thesis entitled: “*Socioeconomic situations of epileptic children in case of Me’nit Shasha Woreda, West Omo Zone, SNNPR of Ethiopia*”, prepared by Genet Damte Aynemar and submitted in partial fulfillment of the requirements for the award of the Degree of Master of Arts in Sociology complies with the regulation of the University and meets the accepted standards concerning originality and quality.

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Abstract

Epilepsy is a complex disorder, which involves much more than seizures, and significant social, economic, and quality of life implications. This study aimed to investigate the socioeconomic situations of epileptic children in the case of Me'nit Shasha Woreda, West Omo Zone, and SSNPR of Ethiopia. To address these objectives, both quantitative and qualitative research methods were employed. The sample of this study comprises; epileptic children, community elder, Labor and Social Affairs, and the woreda administration. Thus, 60 epileptics were selected by using non-probability (purposive) sampling techniques. A cross-sectional study design was employed in this study. The necessary data for this study were collected from both primary and secondary sources. In-depth interviews, key informant interviews, case studies, survey, and participant observations were used. The qualitative data were analyzed thematically and triangulated alongside quantitative data. As the quantitative study findings demonstrate, various factors affect epileptics' quality of life. Among these food shortage 50 (83.3%), stigma and discrimination 52 (86.6%), poor relation with others 35 (58.3%), and drug shortage 48 (80%) are the major. Besides, qualitative findings also indicated food scarcity, a shortage of suitable houses, seizure frequency, and a shortage of clean water for washing have major implications on patients' quality of life. The study findings also revealed that epilepsy resulted different social problems on epileptics such as discrimination from family and the communities 60 (96.8%), discrimination from educational opportunities 44 (71%), excluded from social relation 51(85%) and excluded from physical activities 48 (80%). There are some interventions by the woreda administration, MTU, LSAO, and community elder to address socioeconomic situations of epileptics in the study area.

In conclusion, stigma, discrimination, food scarcity, a shortage of suitable houses, seizure frequency, and a shortage of clean water for washing have determinant implications on epileptics' quality of life. The main implication of this study is the need to eliminate stigma, discrimination, improve drug access, provide safe water for washing, sufficient food, and suitable housing services may have a significant to enhance the quality of life of epileptics.

Keywords: Children, Duration of disease, Depression, Discrimination, Epilepsy, Perceived stigma, Seizures frequency, Social stigma, Living situations, Quality of life.

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Abbreviations and Acronyms

AEDs	Anti-epileptic Drugs
AMSH	Amanuel Mental Specialized Hospital
AHO	Africa Health Organization
APA	American Psychological Association
CWE	Children with Epilepsy
E.C	Ethiopian Calendar
EP	Epilepsy Foundation
HRC	Human Right Commission
HRQOL	Health -Related Quality of Life
ILAE	International League against Epilepsy
LSAO	Labor and Social Affairs Office
MOH	Minster of Health
NGOs	Non-governmental Organizations
QOLCWE	Quality of Life of Children with Epilepsy
SNNPR	Southern Nations Nationalities and People's Region
UNICEF	United Nations International Children's Emergency Fund
WHO	World Health Organization

Chapter One

Introduction

1.1. Background of the Study

Epilepsy is a term used to describe a group of neurological disorders that are characterized by recurring unprovoked paroxysmal seizures (Cicero, 2004). Epilepsy is the most prevalent major neurological disorder in children, impacting half a million children in the United States alone (Russ, Larson, & Halfon, 2012). It is one of the most common causes of symptomatic disease in children. Epileptic seizures are the clinical manifestations (signs and symptoms) of aberrant neuronal activity in the brain that is excessive and/or hyper-synchronous and usually self-limited (Mula & Sander, 2016).

Childhood epilepsy rates have differed across developed and developing countries. According to a nationwide study, the incidence rate of childhood epilepsy (1-12 years) in Italy is significant (102/100,000) (Giussani et al., 2014). As cited in Meeraus, Petersen, Chin, Knott, and Gilbert (2013) study the rate of childhood epilepsy has decreased in high-income nations in recent decades, but there is a lack of updated population data on the incidence and prevalence of epilepsy (Fisher et al., 2014). According to the nationwide cohort study epilepsy affects 0.5-1% of children population in America and it is the most common chronic illness in children (Aaberg et al., 2017). Approximately 1 out of 150 children diagnosed with epilepsy during the first 10 years of life, with the highest incidence rate is observed during infancy (Aaberg et al., 2017).

It is estimated that 10.5 million children under the age of five have active epilepsy in Saudi Arabiya, accounting for nearly 25% of the global epilepsy population (Rabie, Al Asmari, Al-Barak, Al-Rashed, & Mare, 2016). Around 40% of epilepsy cases in young children happened in the 3.5 million people who are affected with epilepsy each year in Saudi Arabiya (Rabie et al., 2016). Active epilepsy impacted 4.4 million persons in Sub-Saharan African countries, with a high frequency among adults and children (Rabie et al., 2016).

According to a Chinese study, factors such as the parents educational level, mental development, age at commencement of illness, seizure frequency and length of disease, and AEDs side effects all have significant ($p=0.05$) impact on the patient's quality of life (QOLCWE) (Yong, Chengye, & Jiong, 2006).

It is difficult to determine how many Ethiopian children suffer from epilepsy and how many of them have access to basic needs (such as adequate food, shelter, water, and cloth), and social services such as educational opportunities as well as health care services due to the lack of information, and it is less studied. The incidence of epilepsy in Ethiopia is high (Tekle Haimanot, 1997). High incidence in combination with prevalence of epilepsy in the study area comparable to that in the rest of the world may be explained by a high degree of spontaneous remission of epilepsy and/or a high mortality due to epilepsy (Tekle Haimanot, 1997).

About 510 epileptics were banished from Me'nit Shasha woreda into various rural and mainly urban centers into zone and beyond over the last 15 to 10 years since the practice of killing the victims was changed into a relatively more favorable form of discarding the patients (Doffana & Hawassa, 2009). From this, the total number of children was 65 (Doffana & Hawassa, 2009). The banished epileptics mainly live as an outcast in various woredas, including Shebench woreda, Zozzo, Dehub Bench, Debere work, Guraferda, and Mizan Amen town. The data gathered from the woredas office shows that about 80 (31 males and 29 females) epileptic children were living in a temporary epileptic camp at Jemmu, Era Menit, Cheru, and Kera kebele (Woreda Report, 2020). The number of epileptics living outside the camp is not known.

Currently, to solve these problems the woredas office is striving in collecting those banished epileptics from nearby towns such as Mizan Teferi and Zozzo and builds some temporary epileptic shelters for them. The majority of epileptics living in a temporary epileptic camp have suffered from different challenges including poor accessing basic needs like adequate food, safe shelter, safe water, cloth, and social services like drug shortage, and generally living in unfavorable conditions. Furthermore, they were discriminated against and isolated from their family relationships, networks, support, and reside in a separate house. As a result of the above researchers' reasoning, the current study was undertaken in Me'nit Shasha woreda, particularly in

a temporary epileptic camp at Jemmu, Era Me'nit, Kera, and Cheru kebele to investigate their socio-economic problem.

1.2. Statement of the Problem

Epileptic patients were immediately killed and thrown into the forest in the past in the Me'nit community, but with the intervention of government, the society changed its punishments of these patients such as forcefully banishing them from the community (Doffana & Hawassa, 2009). Epileptic patient could not continue living with non-epileptic family and the community once they found epileptic (Doffana & Hawassa, 2009). After banishment and discrimination epileptics were suffered a lot of problems like poor access to basic needs and social services which affect their socio-economic and health situations (Doffana & Hawassa, 2009) and (Murugan & Workineh, 2020).

Epileptic seizure have significant consequences on economic, health, psycho-social, and physical aspects of life if not treated, according to several pieces of literature (Bidu, 2004) and (Murugan & Workineh, 2020). The psycho-social consequences are stress, depression, despair, social isolation, stigma, discrimination, low self-esteem, humiliation, and guilt (Sharon, 2011). Because epilepsy is viewed as a highly contagious, trans-generational, and embarrassing condition by many people (Kabir, Iliyasu, Abubakar, Kabir, & Farinyaro, 2005) which is linked to a lack of awareness and poor community attitudes around epilepsy (Shehata, 2016) and (Murugan & Workineh, 2020). Studies revealed stigma and social discrimination associated with epilepsy have a greater impact on patients' lives more than the condition itself (Shehata, 2016; Murugan & Workineh, 2020; and Assaye, 2020).

Various scholars such as Rabie et al. (2016), Tanriverdi, Mutluay, Tarakçi, Güler, and Iscan (2016), Lawal, Anyebe, Obiako, and Garba (2014), Duko, Ayalew, and Toma (2020), Tomlinson, Buch, Armstrong, and Kennedy (2019), and Subki et al. (2018) have undertaken studies on epilepsy at a global level. Majority of the studies were more concerned at institutional and health aspects. For example, in the Asser Region, a research on the prevalence and causes of epilepsy among school children was done (Rabie et al., 2016) ; a study conducted on the impact of epilepsy on preschool children and their families (Tanriverdi, Mutluay, Tarakçi, Güler, &

Iscan, 2016), and a hospital-based study conducted on socioeconomic challenges of patients of children with neurological disorders in Nigeria (Lawal, Anyebe, Obiako, & Garba, 2014) can be mentioned studies that focused at institutional level. A study on epidemiology of headaches among patients with epilepsy (Duko, Ayalew, & Toma, 2020), a study on epilepsy surgery (Tomlinson, Buch, Armstrong, & Kennedy, 2019), and a study on impact of pediatric epilepsy on children and their families in Saudi Arabia (Subki et al., 2018) are all studies that focused on health dimensions.

The same is true in Ethiopia, research conducted on epilepsy was more focused on health dimension and communities perceptions. For example, a study in Addis Ababa Saint Amanuel Mental Specialized Hospital, focused on epileptic patients' quality of life and associated issues Mesafint, Shumet, Habtamu, Fanta, and Molla (2020), and studies on quality of life and associated factors among epileptic patients on treatment follow-up at a public hospital in Ethiopia's in North Wollega Zone, Northeast Ethiopia (Kassie et al., 2021) might be mentioned from some health-related studies. According to Mesafint et al. (2020) findings patients suffered from epilepsy have poor quality of life than both the general population and many other chronic disease sufferers. An institutional cross-sectional study findings conducted by Kasse et al. (2021) also revealed that only around half of the epileptic patients have a good health-related quality of life. In addition, multiple variables including family history, uncontrolled seizure, and poor drug adherence were associated with quality of life among epileptic patients.

A study on the socioeconomic and health situations of epileptic patients, as well as the attitudes of the surrounding population toward epilepsy, were undertaken in Mizan-Teferi Town, Bench Maji Zone (Murugan & Workineh, 2020) as an example of current Ethiopian studies. The findings indicated that a lack of knowledge and negative attitudes among non-epileptic people towards epilepsy causes stigmatization and discrimination of people diagnosed with epilepsy on a daily basis.

Furthermore, compared to studies on the socioeconomic dimension of epilepsy in other countries, Ethiopian studies on the socioeconomic dimension of epilepsy were a few. For instance, Kassie, Kebede, and Duguma (2014), Shibre, Alem, Tekle-Haimanot, and Medhin (2006), Henok and Lamaro (2017), Murugan and Workineh (2020), Doffana and Hawassa (2009), and (Assaye, 2020) were conducted studies on epilepsy. A study conducted by Doffana

& Hawassa (2009) focused on epileptic children, health, psycho-social wellbeing and human rights among the Me'enit of Bench-Maji of Southwest Ethiopia. The study find outs the main cause of epilepsy, which is more prevalent among the Me'enit compared to other ethnic groups, is related to traditional treatments women receive during child labor that exposes the fetus to physical damage.

A study assessed knowledge, attitude, and practices of epileptic patients towards their illness at Gonder, and Mekelle city (Kassie et al., 2014). The study has showed that the majority of the respondents have medium knowledge and better attitude towards epilepsy and its treatments. They also have medium knowledge about the first aid measures to be taken for seizing patients. A study examined knowledge and attitudes among Me'nit community towards epilepsy (Henok & Lamaro, 2017). The study findings indicated that participants' level of knowledge about and attitude towards epilepsy was not satisfactory. In addition to this, study investigate community's belief towards epilepsy and the socio-cultural challenges of the epileptic patient in Me'nit Golidya Woreda (Assaye, 2020). The findings showed that as result of wrong belief, and miss information on etiological causes, and community's negative view towards victims, patients suffered from epilepsy experienced poor social interaction and social discrimination that made their lives more difficulty.

The above-mentioned several studies was focused on community's views, attitude, and health dimensions of epilepsy. Only one study conducted by Doffana and Hawassa (2009) focused on epileptic children, health, psycho-social wellbeing and human rights among the Me 'nit of Bench-Maji of Southwest Ethiopia. But small attention was paid to the quality of their life, their living situations, and social consequences of epilepsy, and governmental and non-governmental organizational interventions in addressing the problems. In terms of methodological gap, the above researchers were conducted their study more with qualitative methods, for instance Assaye and Doffana and Awassa conducted their study by using only qualitative methods, but the current study was conducted by a mixed research methods. As far as know there was no adequate study concerning socioeconomic situations of epileptic children in the current study area notably in Jemmu, Era Me'nit, Cheru, and Kera kebele, to the researcher's knowledge.

Therefore, this study was conducted to fill the above research gap by investigating socioeconomic situation epileptics Me'nit Shasha Woreda, West Omo Zone, SSNPR of Ethiopia.

1.3. Research Questions

The study was conducted to answer the following research questions.

1. What are the factors that affect epileptic children's quality of life in the study area?
2. What are the living situations of epileptic children's in the study area?
3. What are the social consequences of epilepsy on epileptics in the study area?
4. What are the interventions undertaken by government and non-government organizations (NGOs) in enhancing the socio-economic conditions of epileptic children in the study area?

1.4. Objective of the Study

1.4.1. General Objective

The overall objective of this study was to investigate the socioeconomic situations of epileptic children in case of Me'nit Shasha Woreda, West Omo Zone, and SSNPR of Ethiopia.

1.4.2. Specific Objectives

In keeping with the above general goal, this study focuses on the following specific goals:

- To examine factors affecting epileptic children's quality of life in the study area
- To investigate the living situations of epileptic children's in the study area
- To identify the social consequences of epilepsy on epileptics in the study area
- Identify interventions undertaken by government and non-government organizations (NGOs) in enhancing the socio-economic conditions of epileptics in the study area.

1.5. Significance of the Study

The findings of this study will be helpful in providing insight for government, and non-governmental organizational intervention to improve the situations of epileptics. First, the findings of this study will serve as essential inputs for policymakers by looking into major areas of concern such as social stigma and discrimination, patients living situations, and their quality of life. Second, it will be helpful for various stakeholders like Women's, Children and Youth Office, Labor and Social Affairs Office, community elders, religious institutions, health office, woredas, and zonal government to take action in solving epileptics problems by providing basic needs like adequate food, suitable shelter, cloth, water, and sufficient drug services for patients.

Thirdly, this study will be serve as reference for a researcher who may conduct further studies on epilepsy-related issues.

1.6. Scope of the Study

The scope of this study was investigating socioeconomic situations of epileptic children who live in a temporary epileptic camp in Me'nit Shasha Woreda (at Jemmu, Era Me'nit, Kera, and Cheru kebele). Specifically, it examined factors affecting epileptic's quality of life; living situations of epileptics; social consequences of epilepsy, and intervention undertaken by government and non-government organizations (NGOs) to address the problem. In terms of time, it was a short time study. Methodologically, this study employed a mixed research method.

1.7. Limitation of the Study

As a novice researcher, the researcher experienced numerous obstacles while conducting this study. To name a few, the researcher suffered a time shortage problem. Another problem was a shortage of organized documents on epileptic children, particularly in the Ethiopian context. To overcome this challenge, most literature was cited from developed countries. Furthermore, the researcher also suffered language barriers. To overcome this, the researcher employed a data collector who speaks both the native (Mantegna) and Amharic languages. Data was collected from epileptics through direct translation by the data collector. In doing so, necessary data were collected from the patients. As a result, the aforementioned problems have their effect on data quality, but by following the above strategies helped to minimize the effect.

1.8. Conceptual Definition of Key Terms

A child: A child means every human being below the age of 18 years (Borrel, Dabideen, Mekonen, & Overland, 2013).

Active Seizures (AS): Epilepsy that caused two or more unprovoked seizures on different days in the year before the assessment date (Cicero, 2004).

Camp: a temporary living shelters for epileptic children established by woredas government bodies.

Age Category: Epileptics aged 6 up to 18 was included in this study.

Discrimination: Means excluding a person, denying benefits, or imposing burden (HRC, 2008).

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

Epileptic Seizures (ES): Define as the transient occurrence of signs and/or symptoms due to abnormal excessive neuron activities in the brain (Fisher et al., 2014).

Stigma: Stigma is a major cause of discrimination and exclusion: it affects people's self-esteem, disrupt their family relationships, and limits their ability to socialize and obtain housing, and job opportunities (Van Boekel, Brouwers, Van Weeghel, & Garretsen, 2013).

Social Stigma/ Public Stigma: Actual episode of discrimination against an epileptic solely on the ground of the disease (Scamber, 1989).

Social Isolation: is a state of being cut off from normal social networks, which can be triggered by factors such as loss of mobility, unemployment, or health issue (Steens et al., 2020).

Quality of Life (QL): Is the degree to which an individual is healthy, comfortable, and able to participate in or enjoy life events (Jenkinson, Kennedy, & Jones, 2008).

Perceived Stigma/ Felt Stigma: Shame associated with being an epileptic and the fear of encountering stigma by other people (Scamber, 1989).

1.9. Operationalize Terms

The researcher discussed independent and dependent variables, as well as the indicators utilized in this study to assess variable and their level of measurement. The variables and degree of measurement utilized in this study are listed below.

Box 1: Variables and their level of measurement

Concept	Variable	Indicator	Measurement
Demographic factors	Age	The number of year a respondent lived.	Scale/ratio
	Sex	Sex of the respondent (male, female).	Nominal
	Religion	The type of religion the respondents following.	Nominal
	Ethnicity	The type of ethnic-group the respondent's belonging	Nominal
Social factors	Educational level	The maximum grade the respondent has completed	Ordinal
Factors affecting epileptics quality of life	Factors affecting the quality of life of epileptics	Total test score on certain statement reflecting factors affecting quality of life of epileptics	Scale/ratio
Living situations of epileptics	The living situations of epileptic	Total score on certain statement reflecting the living situations of epileptics	Ordinal

1.10. Organizations of the Paper

The contents of the thesis are divided into six main chapters. Introduction, statement problem, research question, objectives of the study, delimitation, significance, and study challenges, and operational definitions are included under the first chapter. The second chapter is all about the literature review. The third chapter discusses research methods, such as the study area, study population, data sources, research design, sampling techniques, and data collection instruments as well as ethical considerations. Data analysis, presentation, and interpretation are presented in the fourth chapter. Under chapter five, major study findings and discussions were presented. Finally, under chapter six conclusions and recommendations were presented.

Chapter Two: Literature Review

The definitions and meanings of epilepsy are presented in this section. These sections included the work of previous studies conducted throughout the world. Factors affecting epileptic's quality of life and social consequences of epilepsy related issues are presented. Lastly, both theoretic framework and conceptual frameworks presented under this section.

2.1. Definitions and Meanings of Epilepsy

Epilepsy is defined by the International League against Epilepsy as a disorder marked by an enduring predisposition to create epileptic seizures that has biological, cognitive, psychological, and social effects on the lives of epileptics (Fisher et al., 2014). Group of Experts Proposed the Operational (Practical) Clinical definition, epilepsy intended as a disease of the brain defined by any of the following conditions (ILAE, 2014).

- At least two spontaneous (or reflex) seizures that happen within 24 hours of each other.
- One unprovoked (or reflex) seizure with a risk of subsequent seizures comparable to the overall recurrence risk (at least 60%) following two unprovoked seizures over the next ten years.
- An epilepsy syndrome is diagnosed.

Epilepsy is referred to as “Biriyo” in Me'nit (Yemitil Beshita in Amharic, meaning literally, a disease that makes one fall down). Among the Me'nit, the word “Biriyo” is a very popular and, of course, a much feared term (Doffana & Hawassa, 2009). The term is understood as a disease known by a complex of symptoms that are displayed during the outward manifestations of the epileptics. Some of its symptoms are when a person falls down amidst a crowded or a group of people, his feet being stiff, his body jerking, his mouth foaming white saliva, his eye turning red, and the patients carries special odor during seizure (Doffana & Hawassa, 2009).

2.2. Empirical Literature

2.2. 1. Factors affecting Epileptics Quality of Life

Quality of life is “the degree to which a person’s cognitive, emotional, social and spiritual experience of life is positive”. It is a broad concept consists of the subjective assessment of his or her physical health, psychological state, and level of independence, social relationships, and their relationships to the environment (WHO, 1998).

2.2. 1. Lack of Social Relation

Social bonds are at the center of our daily living and are an essential determinant of our quality of life. If you have close friends and confidants, friendly neighbors and supportive co-workers, you are less likely to experience sadness, loneliness, low self-esteem and problems with drugs, eating or sleeping (Helliwell & Putnam, 2004). This ‘social capital’ has been found to impact positively on health, morbidity, and mortality.

Many epidemiological studies have revealed that major determinants of quality of life: were unemployment, social interactions, family relationships, and experiential activities, are at considerable risk in patients with epilepsy (Hamiwka et al., 2009). Moreover, epileptic patients have an increased risk of having impaired social cognitive skills and suffering from communication problems, and interpersonal difficulties. Therefore, it is, important that a partnership between educators, family members, and health care providers be instituted so that a plan for academic success as well as safety plan, management of emotional or behavioral dysregulation and active social integration be developed and evaluated on an ongoing basis (Loring, Meador, & Lee, 2004).

2.2.2. Perceived Stigma and Marginalization

For children, epilepsy is still stigmatized (Wagner et al., 2009) and cause low self-esteem compared to children with others chronic conditions such as asthma/diabetes (Soria et al., 2008). It can be trigger mental problem and reduce their quality-of-life (Vona, Siddarth, Sankar, &

Caplan, 2009). Epilepsy, with its acute and vary visible manifestations gives difficulty contexts in children (Soria et al., 2008).

Children with epilepsy have to cope with unpredictable seizure with take away their control over their body and mind. This results uncertainty, vulnerability, marginalization from peer, possibility of stigma (Valery et al., 2009) and potential bullying (Hamiwka et al., 2009). Study conducted in Ethiopia indicated that patient with perceived stigma were twice more likely to have poor quality of life compared to patient who did not perceived stigma (Kassie et al., 2014).

In practical terms, the stigma associated with epilepsy, and the insensitivity of others, are also stressors that affect the emotional and adaptive behavioral responses in these children. It is our experience that many of the children with whom we come in contact are excluded from activities with classmates, teased and bullied, and sometimes suspended from school because of behavioral issues. These factors further reinforce the child's negative view of him/herself and alienate the child from the usual social and learning experiences that promote self-esteem, and normal social development (Loring et al., 2004).

Stigma and discrimination associated with epilepsy affects the patient in different ways (Murugan & Workineh, 2020). It makes them to feel guilty, mentally ill, stress, and depressed. This stigma is a result of the unpredictable seizures and social isolation due to the negative attitude of society and including poor access education, lack of job opportunity, the difficulty of finding a marriage partner (Murugan & Workineh, 2020).

2.2.3. Co-morbidity Factors

Regarding co-morbidity, out of the total respondents had experienced anxiety and depression symptoms 33.5%, 32.8%, respectively. It indicated that patients who had co-morbid anxiety were about 4.4 times more likely to have a poor quality of life as compared to patients who had no anxiety as well as patients who had co-morbid depression were 9.6 times more likely to have a poor quality of life as compared to patients who had no depression (Kassie et al., 2014).

2.2.4. Clinical Factors

Clinical factors such as frequency of seizure, duration of disease, age at onset, and using two or more anti-epileptic drugs have negative consequences on the patient's quality of life. Some study findings indicated that frequency of seizure was another factor associated with a poor quality of life. Most of the respondents (54.9%) had one or more seizure attacks per month. Those who had seizure frequency greater than or equal to one seizure/month were twice more likely to have poor quality of life as compared to patients with no seizure in one year period 61.9% (Kassie et al., 2014). Regarding duration of illness among study subjects 35.2% had duration up to five years, followed by 34.2% eleven years and above. Concerning age at onset of illness 38.8% found between 10-19 years and 35.4% found between 20-29 years (Kassie et al., 2014).

2.2. 5. Side Effects of Anti-epileptic Drug

AEDs are a potentially effective treatment for epilepsy. Side effects are, however, common and the negative consequences necessitate treatment ranging from minor interventions to very expensive hospitalization (de Kinderen et al., 2014). In approximately 25% of the patients, side-effects lead to treatment discontinuation and have a substantial, negative impact on the quality of life.

2.2. 6. Lack of Basic needs and Services

Children with epilepsy who reside in the African continents are faced with some of the greatest challenges in receiving adequate care (Wilmshurst, Kakooza-Mwesige, & Newton, 2014). The burden of the disease is exacerbated by a high incidence of acquired causes and a large treatment gap. A skill team to identify and care for children with epilepsy is lacking. Many patients are managed by psychiatric services thus, potentially compound the stigma associated with epilepsy. Children with epilepsy in poor areas have reduced opportunities for educational as well as future employment and marriage. The stigma often arises from the cultural beliefs about the cause of epilepsy is thought to be a biomedical illness affecting the brain, but is the thought to be caused by spiritual beliefs and is sometimes contagious. When epilepsy is heavily stigmatized, the social

and economic morbidity of the conditions influenced every aspect of the person's life, thus limiting opportunities for education, employment marriage, and poor housing quality, food insecurity, poverty, and physical vulnerability (Wilmshurst et al., 2014). The fact that epileptic children are automatically expelled from the society means that they miss out on educational chances. In a research undertaken by previous studies, major sanitary concerns, insufficient supply of AEDs, poor educational access, and inadequate living space were identified (Doffana & Hawassa, 2009)

2. 3. Living Situations of Epileptics

A previous study conducted Doffana and Hawassa (2009) had visited the epileptic outcasts living in the temporary shelters at Mizan and Bachuma towns. As they observed the living shelters of these outcasts and discussions with them and the various offices revealed that the epileptic community faces an alarming crisis in access to basic services. For example, a key concern is a scarcity of water (both drinking and washing), as seen by the severe sanitation problems and hygienic quality of the epileptic community (Doffana & Hawassa, 2009). Majority epileptics were live in low conditions due to poor accessing basic needs, particularly food. As the study conducted by Murugan and Workineh (2020) indicates that many epileptics live in absolute poverty and low socio-economic situations they lead their life by engaging on begging food from the market, at church, and mosque.

2.4. Social Consequences of Epilepsy

Epilepsy results in different challenges for epileptics. They suffered problems such as discrimination, stigmatization, engaging in risky behavior, can't share their family and community resources, and others due to their conditions.

2.4. 1. Stigmatization and Discrimination

Stigmatization of epilepsy is often exacerbated by misconceptions and misunderstandings of the condition. In certain cultures, and communities in Africa, it is believed that epilepsy is a spiritual condition. Other beliefs are that children and adults with epilepsy are sexually deviant, antisocial,

aggressive, and mentally ill (Williams, Nefdt, & Wilmshurst, 2015). As a result of these beliefs, epileptics are often discriminated against, resulting in social isolation, exclusion, and lack of support from communities.

The fear that epilepsy may be contagious has resulted in children being excluded from communities and expelled from schools. Participation in physical activities and social engagement with peers is particularly important during childhood development. Concern for the child's safety may lead to restrictions on normal school activities, which most children take for granted. This increases the child's sense of social isolation. Isolation from these important social learning experiences further enhances a negative perception of self, informing the child, that he or she is 'not normal' at the time in life when being 'normal', not 'different' is highly valued (Loring et al., 2004).

2.5. Theoretical Frameworks

To have a better understanding on the socioeconomic situations of epileptic children, this paper was examined a theoretical framework.

2.5.1. Historical Origin and Development of Stigma Theory

The stigma theory proposed by Erving Goffman was selected for this study because it explain stigma and discrimination as result of disease in general and epilepsy in particularly. This theory explains why individuals face stigma, prejudice, marginalization, and social isolation in the community. Stigma is a characteristic that has the ability to undermine individual possession, resulting in the avoidance of an individual's social identity (Goffman, 2009). It was used as a mark of shame in the 16th and 17thC. Stigma was firstly defined by Goffman and widely used as a model (framework) by scholars to explain stigma, discrimination, and marginalization attached with epilepsy (Goffman, 2009). Goffman's broad definition of stigma incorporates many contemporary discredited attributes, including what he defined as "tribal stigmas" (e.g., race, ethnicity, and religion), "physical deformities" (e.g., deafness, blindness, and leprosy), and "blemishes of character" (e.g., homosexuality, addiction, and mental illness).

In his book *Stigma* (1963), Goffman argues that stigma is a relationship of devaluation in which one individual is disqualified from full social acceptance. His research focused on the problems generated by stigma for individuals and groups and on the coping mechanisms they employ. Stigma can take many forms. It can result from physical deformity, documentary details (such as a prison record), or context (associating with “bad company”), or it can be ascribed (by default—e.g. father is a child molester so son could also be one), or achieved (by becoming a delinquent). Stigma is inherent in theories of deviance and non-conformity. It can also be retrospective, or after the event (as in the case of Lindy Chamberlain being portrayed as “evil”). Stigma, therefore, is about applying a label to describe someone’s perceived (or otherwise) non-conformist, degenerate or simply different behavior. The value of Goffman’s definition of stigma lies in its applicability as a conceptual framework, a prototypic blue print for the analysis of stigmatizing illness conditions. Stigmatization appears in the medical context very often. It can be apparent for patients with infectious diseases (AIDS, Hepatitis-B) or for those with physical deformities (loss of a limb, crippled). It can arise because of chronic illness (a “weak” or “sickly” person) or from one’s medical record, which may prevent future employment. Inherent in the process of stigmatization is the issue of social control.

Stigmatization is a social phenomenon leading to the marginalization of a specific member or group of the community. Stigma leads to discrimination and loss of dignity as a result of prejudices by other members of society. The community developed a negative attitude towards children with mental illness because they perceived the disease as incurable, unpredictable, contagious, and dangerous. Why the researcher select mainly stigma analytical framework to discuss it with socio-economic situations of epileptics was because of some it’s significant for patients and policy intervention. Epilepsy-related stigma and discrimination have a powerful complication on the patients living situations, their quality of life, social relations, and access to basic needs like food, cloth, shelter, and water. Besides, it leads to psycho-social consequences social isolation, withdrawal, low self-esteem and affects their social network. Furthermore, it determines patients' access to social services like treatment, health care services, and education opportunities.

Chapter Three: Research Methodology

3.1. Description of the Study Area

Until 2016 West Omo Zone has a part of Bench Maji Zone. West Omo Zone has become an independent zone in 2018 compressing Me'nit Shasha, Me'nit Golidya, and Berro, Maji, and Surma woreda. This study was conducted in Me'nit Shasha woreda, West Omo Zone. For this study the researcher use the map of the Bench Maji Zone because the newly established zone (West Omo Zone) has no its own structural map still.

Dominantly, the woreda has comprised of the four largest ethnic groups like Me'en, Bench, Amhara, and Dezzi. Me'nit Shasha woreda is bordered on the south by Maji, on the north by Debub-Bench, and Me'nit Golidya, on the northwest by Berro, on the west by Guraferda, on the east by Keffa zone, and on the southeast by the Omo River which separates it from Debub-Omo Zone. It is located at a distance of 945 km from Hawassa and 675.28 km from Addis Ababa. Me'nit Shasha woreda are located at a distance from the zonal center of Bench Maji Zone (Mizan Teferi town) of 115 km.

Epilepsy cases have been found in both Me'nit Shasha and Me'nit Golidya woreda, however Me'nit Shasha woreda was chosen for this study because of the research gap. A previous study conducted by Doffana & Hawassa (2009) only visited and assessed the conditions of epileptic children in Mizan and Bachuma town, but they did not visit and assess the situations of epileptic children in Me'nit Shasha woreda (Doffana & Hawassa, 2009).

About 80 epileptic children were housed in a makeshift shelter at Jemmu, Era Me'nit, Kera, Kera, and Cheru kebele (Woreda Administration Reports, 2021). The woreda office in partnership with the zonal gathered and re-settled epileptic patients who are banished and discriminated from family and the community and live in Mizan-Aman town, Zozzo, and Deberewerk by preparing a temporary epileptic shades. At Jemmu kebele there were temporary epileptic sheds which is built by the woreda office in 2018. Within this camp there are 25 epileptic children. It was located at 5 kilometer far from the Jemmu town.

At Era Me'nit kebele about 20 epileptics is living in a shelter which is prepared by the woreda office in 2014. It was located at 8 km far from the Jemmu town. In Cheru kebele there are 17 children with epilepsy cases are living in house opportunity provided by the woreda government in 2020. It was far from 10 kilometer from the capital town of Jemmu. Although 18 epileptics are live in a temporary house at Kera kebele from 2013. Those epileptics were support and guided mainly by the woreda office and accessed some living houses, food services, a few educational opportunities, and drug services from woreda sector and others.

Figure 3.1. Map of Bench Maji Zone

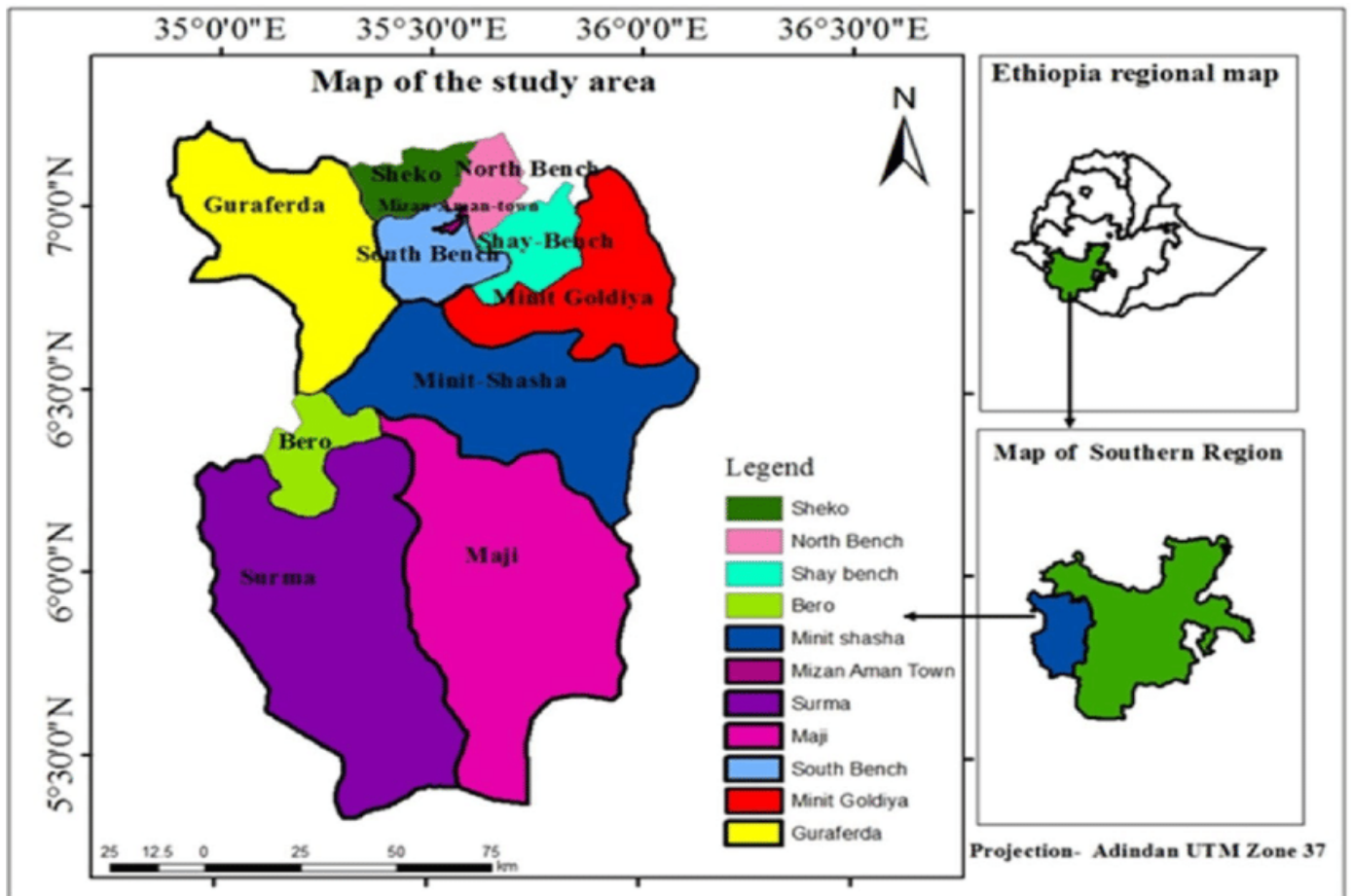


Figure 2: Source Uploaded by Alemayehu, Ayele, Valsangiacomo, and Ambelu (2020)

3.2. Research Methods

Both quantitative and qualitative research methods were employed. The researcher employed a mixed research methods to address the research objective. Particularly research objectives such as factors that affect epileptic's quality of life and the living situations of epileptics were invited the researcher to study this study by a mixed method. Moreover, it helped the researcher to collect data both by qualitative and quantitative methods and that also increases data accuracy, reliability, and validity. A mixed research method is one in which a researcher integrates components of quantitative and qualitative research method (e.g., the use of qualitative and quantitative viewpoints, data collecting, analysis, and tools) for breadth and depth study (Guetterman, 2017). According to Chih-Pei and Chang (2017); Creswell and Creswell (2017), both quantitative and qualitative research method are effective, there are limitations to both they can be extremely effective in combination with one another. The limitation of quantitative research is expensive, time-consuming, and presents a limited understanding of consumer needs. However, qualitative research has many limitations which include possible small sample sizes, potential bias in answers, self-selection bias, and potentially poor questions from researchers (Lauren Christiansen, 2021).

3.3. Research Design

A cross-sectional study is a type of research design in which data is collected from many different individuals at a single point in time. Due to time and economic relevancy a cross-sectional study design was employed. Based on the purpose Blumberg, Cooper, and Schindler (2005), classified three types of research design such as exploratory, explanatory and descriptive. The descriptive research design was selected because it provides an opportunity to describe the situation; it is a theory-based research that allowed the researcher to provide insight; data collected for descriptive research is helpful in decision-making because the data is obtained from a large population.

3.3. Study Population

This research was conducted in Me'nit Shasha woreda, West Omo Zone. In Me'nit Shasha woreda there are 16 kebele, from this only Era Me'nit, Cheru, Jemmu, and Kera kebele were selected for the current study. That kebele was selected by the researcher purposely based on the availability of a temporary epileptic camp and the living situations of epileptics. The study population is all affected epileptic children in a temporary epileptic camp in the above four selected kebele. Around 80 epileptic children were residing in a temporary epileptic shelter in the selected kebele (Woreda Administration Reports, 2021). The box below show the profile of epileptics.

Box 2. The profile of epileptic Children

Kebele	Era Me'nit	Jemmu	Kera	Cheru	Sex		Total
					Male	Female	
	-	-	-	-			-
Epileptic children	20	25	18	17	43	37	80

Sources: Woreda Administration Report, 2021

3.4. Target Population

The target population of this study were epileptic children found age 6-18 years, who used anti-epileptic drugs for at least two months, and non-epileptic communities such as community elder, woreda administrator, and the Labor and Social Affairs Office. The researcher selected this age group because they are able to describe their situations.

3.5. Source of Data

The information was gathered from both primary and secondary sources. The primary data was collected from both affected epileptic children, non-affected communities such as community

elders, woreda administrator, and the Labor and Social Affairs Office. The primary data was supported by the available secondary sources such as published and unpublished documents and related articles.

3.6. Inclusion and Exclusion Criteria

Affected epileptic children age between 6-18 years of both sexes, were included. Epileptics who have treated the disorder for at least two months with AEDs were included. Besides, epileptics who can explain their situations in detail were included in the qualitative study. However, epileptics age below 6 years and patients who treat epilepsy with AEDs less than two months were excluded. Because children in this age group was unable to explain their situations and to know any change in seizure severity after they use drug and the adverse effect of a drug on their health conditions.

3.7. Sampling Techniques and Procedure

The research was used only a non-probability sampling technique. Non-probability sampling is defined as the sampling technique in which the researcher selected samples based on the subjective judgment of the researcher rather than random selection. The sample strategies used were purposive sampling techniques. The researcher selected the respondents based on the criteria such as their age and the month they use the drugs. In this process 60 epileptics are chosen by using purposive sampling techniques from 80 epileptics to fill a survey.

3.8. Study Variables

Dependent variable

Duration of disease, seizure severity, depression, perceived stigma, discrimination, quality of life, and drug access was used as dependent variables.

- Independent variables
- Socio-economic situations of epileptic children

3.9. Data Collection Methods

For the study, the following data collection methods were used:

1. Survey

For epileptic children, questionnaires (both closed-ended and open-ended) were used as the primary data gathering method. The questionnaires were focused on factors impacting epileptic children's quality of life, epileptic's living situations, implications of epilepsy, and governmental and non-governmental organizations'. The survey were covered all of the above-mentioned specific research objectives.

However, there are a variety of qualitative data collection methods such as an in-depth interview, key informant interviews, case study, and observations. This all qualitative data gathering methods were employed.

2. In-depth Interviews

One of the qualitative data gathering strategies is an in-depth interview. In-depth interviews were used to address all of the above-mentioned research goals. Interview guides were developed for the informants. For this purpose, the researcher was selected at least 13 epileptics. The interview was taking 30-45 minutes for each patient. The researcher then continued interviewing until the saturation point was reached. At the time of interviewing tape-recording, and field note-taking were implemented.

3. Key Informant Interviews

To obtain data from experienced persons, a semi-structured interview guide was used. In the study, the interview data were used to supplement quantitative data collected by a survey. Three key informant's from non-epileptic communities (1 from Labor and Social Affairs, 1 from community elder, and 1 from the woreda administration) were selected.

4. Observations

Additional data for this study was gathered through participate observation. The researcher studied their situations such as sanitary problems, hygiene, and access to cloth, water, housing, and educational services.

3.10. Methodological Triangulation

Box 3. Summary of methods and instruments used

Specific objectives	Study unit	Observation unity	Data collection methods
To examine factors affecting the quality of life of epileptics	Epileptic children	Sample of epileptic children in 4 kebele	In-depth interview Survey Case study, Observation
To investigate the living situations of epileptics	Epileptic children	Sampled epileptic children from 4 kebele	In-depth interview Survey , Observation
To examine the social consequences of epilepsy	Epileptic children	Sampled epileptic children selected in 4 kebele	Survey
To identify intervention undertaken by government and non-governmental organizations (NGOs) in enhancing the socio-economic conditions of epileptic children	Both epileptic children and key informants	Community elder, woredas office, epileptic children, and Labor and Social Affairs Office	Key informant interview In-depth interview

3.11. Method of Data Analysis

Both quantitative and qualitative data can be analyzed in different methods based on the research objectives. Data collected through survey was first coded and entered into a computer, and analyzed by using descriptive data analysis such as frequency table and percentages. Besides, qualitative data was analyzed by creating codes for each response and categorize the data based on their similarity. Thematic analysis is one of the most common form of analysis in qualitative research. It focused on identifying, analyzing, and interpreting pattern or themes within qualitative data. The procedure employed to analyze qualitative data was data collecting, organization and arranging, summarizing, edit, and reporting.

3.12. Ethical Considerations

The coordinator of Research and Graduate Studies of the College of Social Science and Humanity Jimma University approved the researcher's application for ethical clearance. The letters were used to get permission from concerned bodies to conduct the study. The privacy and confidentiality of all respondents were respected such that all responses were confidential and anonymous. This study was conducted by keeping patient's values, respecting their interests, and creating an enjoyable environment in which children are able to speak and share their views. The aim of the study, for example was stated to the participants, and permission was asked from respondents to complete the questionnaire or participate with interview guide. The participants were also told that the information they submitted would not be shared with anybody else. Furthermore, the researcher ensured that children are safe and not exposed to a different form of abuse. As a result, the information provided by the participants was utilized only for the purposes of the study. Generally, any idea that could affect the respondents was handed in a very careful manner.

Chapter Four: Data Analysis and Presentation

Both quantitative and qualitative data were analyzed and presented in this chapter. Descriptive statistics were employed in this study to present quantitative data collected via a survey. Furthermore, qualitative data gathered from key informant interviews, in-depth interviews, case studies, and observations were presented in theme analysis, categories, and direct quotation following the research objective.

Data collected from both quantitative and qualitative sources were presented in four distinct sections. The respondents' socio-demographic backgrounds are presented in the first section. The second section described and presented, factors affecting patients' quality of life. In the third section, the living situations of epileptic patients are analyzed and presented. Fourthly, the consequences of epilepsy on epileptics are presented. Finally, interventions undertaken by government and non-governmental organizations addressing the issues are described.

4.1. Socio-demographic Background of the Respondents

This section analyzes and presents respondents' socio-demographic characteristics using a frequency table and percentage. In this manner, the age, sex, education, religion, and ethnic background of the respondents are presented.

Table 4.1. Socio-demographic Characteristics of the Respondents

Age-category	Frequency	Percentage
6-9	2	3.3
10-13	7	11.7
14-17	20	33.3
18	31	51.6
Total	60	99.9
Sex-category		
Male	31	51.6
Female	29	48.3

Total	60	99.9
Educational Level		
Cannot read and write	44	73
Can read and write	16	27
Total	60	100.0
Religious type		
Orthodox	15	25
Muslim	12	20
Protestant	16	26.6
Traditional religion followers	17	28.3
Total	60	99.6
Ethnicity		
Meen	41	68.3
Keffa	5	8.3
Sheko	7	11.6
Bench	7	11.6
Total	60	99.8

Sources: Field Data, 2021

According to Table above 4.1, majority of patients who took part in this study were children age 18 and 14–17, about 31 (51.7%) and 20 (33.3%), respectively. The remaining children age 10-13 are accounted 7 (11.7%), and children age 6-9 are accounted 2 (3.3%).

In terms of gender distribution, Table above showed, males made up 31 (51.6%), although females are represent about 29 (48.3%). Majority of respondents 44 (73.3%) were unable to read and write, whereas about 16 (27%) of epileptics were able to read and write. As Table 4.1, revealed a bout 17 (28.3%) of epileptics were participated from Traditional religious followers, 16 (26.6%) were from Protestant, 15 (25%) Ethiopian Orthodox and 12 (20%) were from Muslims. Out of 60 respondents, the majority of 41 (68.3%) of respondents were Meen and the remaining epileptics were from Sheko, Bench, and Keffa about 11.6%, 11.6%, and 8.3%, respectively.

4.2. Factors Affecting Epileptics Quality of Life

According to Spring (2012) quality of life embodies overall well-being and happiness, including access to educational opportunities, absence of military conflict or threats, as well as good physical and emotional healthy.

4.2.1. Food Access, Duration of Disease, Seizure Frequency and Physical Injury

This section deals with factors that affected the quality of life of epileptics. Data gathered using various instruments showed that there was a variety of factors that influence patients' quality of life. Such as access to food, a long duration of disease, seizure frequency, and physical injury to name a few.

Table 4.2. 1. Food Access, Duration of Disease, Seizure Frequency and Physical Injury

Have you accessed food from governmental organizations?	Response	Frequency	Percentage
	Yes	31	51.6
	No	29	48.3
	Total	60	99.9

Duration of disease	1-2	12	20
	3-4	37	61.6
	Above 4	11	18.3
	Total	60	99.9
Seizure frequency	1-2	23	38.3
	3-4	29	48.3
	No seizure	3	5
	4 and above	5	8.3
	Total	60	99.9
Vulnerability to physical injury	Yes	39	65
	No	21	35
	Total	60	99.9

Source: Field Data, 2021

Table 4.2. 1, showed 31 (51.6%) of respondent were access food and the rest 29 (48.3%) of respondents were not access food from governmental organizations in the camp.

The researcher has been done an in-depth interview with an epileptics regarding food access. 18-year-old male epileptic patient (from Era Me'nit kebele) who took part in an in-depth interview state as follows:

“Accessed to food for survival, is a severe problem. I usually do not access food. As a result, I became hungry, forcing me to move and beg food from the town (Jemmu). I have lived a life similar to the previous one. Before this, I begged meals at several hotels, cafes, and restaurants in Mizan-Aman town”.

Another female epileptic victim who has age of 17 from Cheru kebele explain food access during an in -depth interview in the following way.

“I have suffered food shortage that is a critical problem for me. There was no food distribution timely from concerned bodies. Once it is provided and now it was stopped for two weeks. No access to it regularly because of this I have suffered the feeling of discomfort and weakness”.

The above two statements indicates that epileptics were not accessing food in the study area. As a result, they were subjected to hunger, discomfort, and weakness which affect their quality of life.

Table above 4.2,1, showed that a significant number of 37 (61.6%) of respondents have experienced the disease 3-4 years and the remaining 12 (20%) of respondents have experienced 1-2 years. Finally, 11 (18.3%) of respondents were experienced above 4 years. Based on this data, one can be remembered that the majority of patients are experienced a long duration of disease.

Table presented above in 4.2.1, indicated that majority 29 (48.3%) of respondents have experienced 3-4 seizures within a day. About 23 (38.3%) of the respondents have experienced 1 - 2 seizures within a day. About 5 (8.1%) patients have experienced seizure 4 and above within a day. Finally, 3 (4.8%) of epileptics have not experienced seizures. This data suggested that a significant number of epileptics were experienced more seizure severity. Seizures frequency is one factor that affects epileptics' quality of life.

The researcher collected data from epileptic child related to seizure frequency. In an in-depth interview epileptic child of 17-year-old female (Kera kebele) state as follows:

“I was diagnosed with epilepsy at the age of seven years old. I have experienced numerous seizures after being diagnosed. I faced two or three seizures with a day at least. Due to a shortage of therapy and low obtaining necessities such as food and safe drinking water. Furthermore, famine, hunger, and depression are all increased my seizure frequency”

From this statement, it is clear that epileptics in the research area have experienced a seizure regularly it may be due to various factors such as poor accessing basic needs like food and clean water for drinking.

Further, another 18 year old female epileptic patient who has participated (from Era Me ‘nit kebele) described the issue as follows:

“When I used antiepileptic drugs, most of the time I have suffer more seizures. Because there is a shortage of accessing basic needs particularly adequate food and clean water for drinking that are important things to control seizures besides drugs. After I stop it, now I have suffered one or two seizures with a day, but before that I have frequent suffered it”.

The statement above indicated that patient suffered more seizure severity in the study area it may be because of poor accessing food and clean water for drinking.

Some epileptics are suffered physical injury as a result of frequent seizures. They have limited or no access to help from others during an active seizure because the sickness was once thought to be contagious in their native group. According to Table 4.2.1, a considerable proportion of respondents 39 (65%) suffered physical injure during an active seizure, but 21 (35%) of epileptics were not experienced. If you answered "Yes," what kind of physical damage did you sustain? They highlighted wounds, bleeding, and amputation or loss of body parts such as the finger.

According to in-depth interview with 18 year old male epileptics (Jemmu kebele) mentioned the problem as follows:

“Epilepsy is a bad disease because you cannot know where, when, and how might the seizure occur. Look this! I have lost my right face during the fire burn”.

The following life history was taken from one epileptic female (*Era Me’nit kebele*) concerning the physical harm she suffered

Case Regarding Physical Injury

I was living in this temporary epileptic camp for six months. I have been living on the street in Mizan-Aman town for two years before moving here. When I was preparing the lunch for my family in my original homelands, I suddenly felt down on fire. I'll never forget that time! When this event occurred, I was alone because my family member were away. I was crying for help from others, but no one was interested in helping me. Because the community thinks that epilepsy is a transmittable and contagious disease through touching patients' bodies and interacting with patients, no one approached me. Take a look at my finger! I lost my finger due to a lack of support.

4.2.2. Access to Anti-epileptic Drug and Information from Health Care Services and Side Effects of Antiepileptic Drug

Getting anti-epileptic drugs in the health care services was relevant in terms of diminishing seizure frequency and improving patients' health conditions, but there is a gap in accessing drugs from health care services. Besides, awareness creation activities on the disease prevention, controlling, effective utilization of the drug, are crucial to eliminating seizure and its consequences on patient's life, but there is a gap in follow-up services.

Table 4.2.2. Access to Anti-epileptic Drug and Information from Health Care and Side effects of Antiepileptic Drug

Have you accessed anti-epileptic drug from health care services?	Response	Frequency	Percent
	Yes	28	46.6
	No	32	53.3
	Total	60	99.9
Have you accessed information and advice from health care services?	Yes	19	31.6
	No	41	68.3
	Total	60	99.9
Anti-epileptic drugs caused problems on your health condition?	Yes	20	33.3
	No	8	13.3
	Total	28	46.6

Source: Field Data, 2021.

The preceding Table 4.2.2, indicated about 28 (46.6%) of patients are accessed anti-epileptic drugs from the health care services. The remaining 32 (53.3%) of respondents did not access drugs services from health care services. Factors influence access to drug in health care services is lack of income, and shortage of medical services. From these numbers, the majority of 20 (33.3%) of respondents are reported issues related to drug on their health conditions and a few 8 (28.7%) of respondents were not. The most common identified problems of anti-epileptic drug are fatigue, headache, loss of body weight, drowsiness (loss of sleep), dizziness (loss of body balance), and so forth.

Respondents were questioned about obtaining information and advice from health care services. According to chart above 4.2.2, majority 41 (66.1%) of respondents are not received information and advice from health care services. Only 19 (30.6%) of respondents are received information and advice from health care services. This data demonstrates that a significant number of epileptics were not access information and advice from health care services.

Although qualitative data gathered by the researcher from an epileptic child on access to medical treatment and care from health services is indicated low. An 18-year-old male epileptic (from Jemmu kebele) who participated in an in-depth interview explains the issue as follows:

“For three years, I have been an epileptic patient. For me, epilepsy or biriyo is not a curable disease, but the seizure severity can be managed by the anti-epileptic drug. Because I have used the drug for three months, but still know I have faced a few seizures. The problem is that a shortage of drug and follow-up services from healthcare providers. I have not used the drug for 4 months. The drug are not provided regularly in the health care for me”.

Anti-epileptic drugs have been provided for epileptics by the woredas government, Labor and Social Affairs Office cooperation with health office at free charge, but there is a gap accessing the adequate and continuous drug. . The researcher conducted an in-depth interview with 17 year old male epileptics from Cheru kebele. He explained the issue as follows:

“I have accessed some drug that is provided by the government in the hospital, but it was not adequate. Due to poor accessing it I have experienced more seizure that affect my happiness in a camp”.

According to statement above, epileptics have suffered drug and follow-up services shortages from health care. In order to minimize the severity of the seizure and enhance patients' quality of life and adequate and accessible provision of drug and follow-up services in health care is critical.

4.2. 3. Experience of Stigma from Non-epileptics

Patients' quality of life was also determined by stigma related to epilepsy. Epilepsy-related stigma was a serious implication on patients' quality of life more than the disorder. They develop the fear of being discriminated against. As a result, they develop poor interpersonal relationships, vulnerable to psychological problems, and feeling of inferior (Shehata, 2016; Murugan & Workineh, 2020).

Table 4.2.3. Experience of Stigma from Non-epileptics

Have you experienced stigma from non-epileptic children?	Frequency	Percent
Yes	46	76.6
No	14	23.3
Total	60	99.9

Source: Field Data, 2021

According to Table 4.2.3, about 46 (76.6%) of the respondents have encountered stigma from non-epileptics. The remaining 14 (32.3%) of respondents were not. These numbers demonstrated that a large number of epileptics were subjected to stigma from non-epileptics. Epileptic patients have frequently experienced stigmatization and social isolation due to the commonly held misconception of epilepsy among the communities which directly or indirectly affects epileptics' quality of life (Shehata, 2016; Murugan & Workineh, 2020; and Assaye, 2020).

4.2.4. Participation in Religious Centers

Religious institutions are important social institutions that foster individuals' social relationships, social skills, good spirit, ethical personalities, and freedom from psychological problems. Regarding this, a significant number of epileptics were discriminated against from religious places.

Table 4.2.4. Epileptic Children Participation in Religious Center

Have you worship with non-epileptic children at same churches or mosques?	Frequency	Percent
Yes	24	40
No	36	60
Total	60	100.0

Source: Field Data, 2021

As described in Table 4.2.4, a large number of respondents 36 (60%) were not worshipping alongside non-epileptic children in the same churches or mosques. The rest of the respondents 24 (40%) were worshipping with non-epileptics at the same church or mosque. The respondents were asked to provide their reason why they were discriminated against from religious places. The repeated raised idea by the majority of respondents is that epilepsy is perceived as contagious, evil eyes, and demonic possession.

4.2.5. Epileptics Relationship with non-epileptic Children's

Stigma attached with epilepsy increases patients to have poor interpersonal relationship and affect the many aspect of their lives (Murugan & Workineh, 2020). Many epileptics were have no relationship with non-epileptics due to their condition in the study area.

Table 4.2.5. Relation between Epileptics and Non-epileptic Children

What it looks like your relationship with non-epileptic children?	Frequency	Percent
Mid	25	41.6
None	35	58.3
Total	60	99.9

Source: Field Data, 2021

As presented in Table, 4.2.5, showed a large number of 35 (58.3%) of the respondents have no relationship with non-epileptic children. But a few 25 (41.6%) of the respondents have a moderate or mid relationship with non-epileptic children.

4.2.6. Main Problems Affecting Patients Quality of Life

In a temporary epileptic camp, patients' quality of life was affected by a shortage of the drug in health care, stigma, discrimination, a shortage of food, and a shortage of safe water (for washing and drinking). The major factors that influence patients' quality of life are presented in the table below.

Table 4.2.6. Main Problems Affecting Patient's Quality of Life

What problems are affecting your quality of life?	Frequency	%	Total frequency	Total %
A shortage of food	50	83.3	50	83.3
A shortage of drug services	48	80	48	80

A Shortage of clean water for washing	12	20	12	20
Stigma and discrimination	52	86.6	52	86.6

Source: Field Data, 2021

According to Table, 4.2.6, a large number of respondents are exposed to stigma and discrimination, a shortage of food, and shortage of drug services in health care 52 (86.6%) ,50 (83.3%), and 48 (80%) respectively. About 12 (20%) of respondents are responded to a shortage of safe water for washing. Foods is not sufficiently provided to epileptics in the camp. An interview with youngsters is done by the researcher. In an in-depth interview, 18-year-old male epileptic child (from Cheru kebele) described this problem as follows:

“I was living in this camp for a maximum of two years. Access to adequate food was a major issue. In one month, the woredas administration supplies some food services such as maize and rice. But the food was insufficient because of this I was subjected to hunger and malnutrition”.

In addition to, food shortage epileptics are suffered problem related to accessing clean water for washing. An in-depth interview is conducted by the researcher with 17 year female epileptic child from Cheru kebele. She described this issue as follows:

“Access to clean water for washing was a major difficulty. In the camp, there are no clean water services for washing. Due to this, I have to wash my bodies and clothes with affected water by searching around the camp”.

4.2.7. Access to Suitable House

Furthermore, epileptics have faced challenges concerning obtaining suitable house services. They have accessed house service from the woredas government, but it was not suitable and conducive for living. An 18-year-old male epileptic youngster who participated in an in-depth interview (from Jemmu kebele) described this problem as follows:

“Living in a temporary epileptic shelter has its advantages, it used to protect me from other natural hazards such as cold, rain, and sun, among others. But a maximum of 7-8 patients was

living in one shelter. The houses were overcrowded, deteriorating, and about to collapse. In the shelter, there is no good sleeping place”.

Another 18 year female epileptic patient also described the issue as follows:

“In one epileptic shelter (class), both male and female epileptic sufferers were living. It harmed the life of a girl patient. Male epileptic patients abuse alcoholic substances (Teji) and rape female patients. I have been abused by an epileptic patient in the camp. Still, no one can take action on these concerns, and this is happening in my life right now”.

Data obtained from field observation also verify the above facts. They were living in cramped, overcrowded, and low-quality houses which unfit for human habitation. Besides, some houses have no doors and windows due to this the patients were exposed to various natural problems. Furthermore, both epileptic females and males were living together in one house. There was no separate house for the patients. Additionally, epileptic youngsters in the study region have poor accessing cloth. The patients have were dressed unclean, deteriorated, and low-quality cloth.

4.3. Living Situations of Epileptics

4.3.1. Access to Adequate Food, Safe Water for Drinking and Washing, Conducive Shelter and Anti-epileptic Drugs

Getting sufficient and adequate food is a serious problem for many epileptics. Majority patients were not access adequate food from governmental organizations.

Table 4.3.1. Access to Adequate Food, Safe Water for Drinking and Washing, Conducive Shelter and Anti-epileptic Drugs

Have you accessed adequate food from governmental organization?	Response	Frequency	Percentage
	Yes	20	33.3
	No	40	66.6
	Total	60	99.9

Have you got clean water for drinking in a camp?	Response	Frequency	Percent
	Yes	18	30
	No	42	70
	Total	60	100.0
Have you got clean and safe water for washing in a camp?	Yes	18	30
	No	42	70
	Total	60	100.0
Have you accessed conducive shelter from governmental organization?	Yes	17	28.3
	No	43	71.6
	Total	60	99.9

Sources: Field Data, 2021

The Table above 4.3.1, indicated a significant number of 40 (66.6%) epileptics did not get adequate food from governmental organizations, but a few 20 (33.3%) epileptics accessed. For this number, one can be remembered that many epileptics were not access adequate food from governmental organizations.

In the study area, epileptics are suffered problem in relation to accessing safe and clean water for drinking. The Table above 4.3.1, revealed many 42 (70%) of the respondents did not get clean water for drinking and only 18 (29.0%) of epileptics are get clean water for drinking. From this data, one can understand that a large number of epileptics were suffered a shortage of clean water for drinking.

As Table above 4.3.1, indicated majority 42 (70%) of the respondents are not accessed clean and safe water for washing in a temporary epileptic camp. But only a few 18 (29.0%) of the respondents are accessed clean and safe water for washing in epileptics camp. This data revealed that significant number of epileptics are not accessed clean and safe water for washing.

An in-depth interview conducted with 17-year-old male epileptic patients (from Era Menit kebele) has described the problem as follows.

“I have suffered problem accessing to clean water for washing in this camp. For me, the shortage of clean water for washing was a major problem. I wash my body and clothes with contaminated water as a result, it developed extra health problems on my body”.

Standard, conducive, and suitable house services is significant for good life. But regarding to this majority epileptics were not access proper and congenial house services. As Table above 4.3.1, showed that a large number 43 (71.6%) of the respondents were not access conducive shelter from governmental organizations. But the remaining 17 (27.4%) of the respondents are accessed conducive houses from governments. This data demonstrate that most patients are not accessed conducive and safe housing services from governmental organizations.

An 18 year-old epileptic men from Kera kebele who participated in an in-depth interview describe the problem as follows:

“I was living in this shelter for six months. Before this, I used to on a street in Mizan-Aman town. When I compared the houses to previous (street life), this residence is better, but not suitable. Take a look at those houses! The houses have no windows or doors. I have no option but to live in this shelter to protect myself from the cold, rain, and sun. The woredas authorities pledged to rebuild the house four months ago, but nothing has been done”.

According to the statements above, epileptics are not accessed appropriate and quality shelter. This jeopardizes their living conditions in the research region.

Another 18 year-old female epileptic child who participated from Kera kebele in the study during an interview section describe the issues as follows:

“Temporary shelters are dangerous for epileptics, especially ladies. Female and male epileptic patients were living together in one house or class in physical proximity. Due to this, I have faced sexual violence by epileptic patients within a camp. But out of fear, I don't report it. As a result, I lose my security”.

From the above statement, one can understand that epileptic's particularity, females were suffered conducive housing problem as result they were vulnerable to sexual abuse.

4.3.2. Treatment Methods

There's no cure for epilepsy, but the disorder can be managed with medication and other strategies. AEDs are effective medication in terms of eliminate and managing seizure frequency when they use the prescription appropriately (Ann Pietrangelo, 2018). The table below are present epilepsy treatments.

Table 4.3.2. Treatment Methods

In which method you treat the disease?	Frequency	Percentage
Anti-epileptic drug	35	58.3
Traditional medicine	14	23.3
Both	11	18.3
Total	60	99.9

Source: Field Data, 2021

As Table above 4.3.2, indicated about 35 (58.3%) of the patients were treated the disease by using antiepileptic drug. The rest of the respondents were treat by using antiepileptic drug and traditional healing approach 14 (23.3%) and 11 (18.3%), respectively. Furthermore, they also mentioned some other treatments such as using holy water, pasting, praying, and fire use due to the drug shortage.

4.3.3. Major Problems Affecting Patients Living Situations

The following Table below presents main problems affecting epileptics living situations in a temporary epileptic camp. Problems related to a shortage of food, a shortage of clean water for drinking and washing, and a lack of suitable house are mainly identified by majority.

Table 4.3.3. Main Problems Affecting Epileptics Living Conditions

Currently, what major problems are affects your living situations?	Frequency	Percent	T F	T%
A shortage of food	49	81.6	49	81.6
A shortage of clean water for drinking	40	66.6	40	66.6
A shortage of clean water for washing	38	63.3	38	63.3
A shortage of conducive houses	42	70	42	70

Source: Field Data, 2021

As depicted above Table 4.3.3, indicates about 49 (81.6%) of epileptics have suffered from food and conducive houses shortage. About 42 (70%) of epileptics are suffered from a shortage of conducive houses and clean water for drinking. About 40 (66.6%) of the patients were suffered from clean water for drinking and washing shortage. Lastly, about 38 (63.3%) of epileptics were suffered from shortage of clean water for washing.

4.3.4. Access to Toilet and Sanitation Problems

In qualitative study, epileptics also mentioned the problem of toilet and sanitation issues. An 18-year-old female epileptic patient (from Era Me'nit kebele) who participated in an in-depth interview describe the issues as follows:

“Lack of toilet and sanitation concerns is a huge problem in a camp. I usually go to the forest and defect in an open field. There were no restroom facilities within a camp. Not only this, but also I suffered a shortage of soap to retain my hygiene. The community surrounding a camp was hesitant me because of sanitary difficulties. In a camp, access to sanitation supplies and toilet facilities was also a major issue”.

Data gathered by observation also showed that epileptics are low accessing toilet and sanitation materials services. During field observation, there is no toilet services provision in the camp due to this the patients were defecated in the field or going to the forest. Also, most epileptics have not protected their sanitation because of poor accessing clean water for washing and soap from concerned bodies in the study area.

4.4. Social Consequences of Epilepsy

The researcher analyzed the social implications of epilepsy in the study area. Most epileptics are suffered from a lot of problems such as discrimination from family’s relations, stigma and discrimination, poor engagement with non-epileptic children, and discrimination from various activities.

4. 4.1. Discrimination from Families Relations, Educational Opportunities and Various Activities

All epileptics in the study area were live in a separate shelter far from their families without accessing their family care, support, love, and without sharing resources with them. This consequences epileptics being vulnerable to access housing, social services like care, seeking treatments, and educational opportunities. Many epileptics did not have access educational opportunities due to the stigma, discrimination, seizure factor, and lack of school opportunities, and scarcity of resources. Furthermore, children with epilepsy are discriminated against from different activities due to their conditions.

Table 4.4.1. Discrimination from Family Relation, Educational Access and Various Activities

Have you suffered discrimination from your family’s relation?	Response	Frequency	Percent
	Yes	60	100.0
	Total	60	100.0
Have you suffered discrimination from the educational opportunities?	Yes	44	73.3

	No	16	26.6
	Total	60	99.9
Due to the seizures what problems do you suffered?			
Withdrawal from families and the communities		60	100.0
Discriminated from social engagement with non-epileptics		51	85
Excluded from participation in physical activities		48	80
Excluded from educational opportunities		44	73.3

Source: Field Data, 2021

As depicted in Table 4. 4. 1, almost all of the respondents have suffered discriminated from their family’s relation. They were totally discriminated and stigmatized from their family relation. As presented in above Table 4.4.1 a significant number 44 (73.3%) of the respondents were discriminated against from education opportunities. The remaining 16 (26.6%) of respondents were not discriminated against from educational opportunities. They cited a variety of factors, including their health condition, a lack of assistance from others during the active seizure, frequency of seizures, a shortage of food and cloth, and lack of school materials.

As shown in above Table, 4.4.1, a significant number of the respondents have faced different problems due to the seizure. Such as withdrawal from family and the communities 60 (100.0%) discriminated from social engagement with non-epileptics 51 (85%), excluded from participating in physical activities. About 44 (73.3%) of epileptics are excluded from educational opportunities.

Furthermore, data collected from key informant interviews (woredas government) also indicates that a significant number of epileptics were not getting an educational chance. For example,

epileptic children at Era Me'nit kebele have accessed some educational possibilities. However, epileptics in Jemmu, Kera, and Cheru kebele have not accessed. According to him, the main causes are mainly due to the material, budget constraint, and lack of dependent school, stigma, and discrimination. But know the woredas was working with zonal and other offices to provide educational opportunities for all.

4. 4.2. Attitude of Epileptics towards Epilepsy

The majority of patients agree that epileptics were live with their family after diagnosis because, after discredit, banishment, discrimination accessing basic needs and treatment services were varied difficult. The disorder crates many consequence on the life the patients. For instance, it increases social isolation, stigma and discrimination, food and safe water for drinking shortage.

Table 4.4. 2. Attitude of Epileptics towards Epilepsy and Implication of Epilepsy

Do you think that epileptics should live with their families after being epileptic?	Frequency	Percent
Yes	50	83.3
No	10	16.6
Total	60	99.9

Source: Field Data, 2021

As depicted in Table above 4.4. 3, the majority 50 (83.3%) of the respondents said “Yes”. After being diagnosed with epilepsy, epileptics should live with their families. Because epileptics were suffered a lot of problems such as low accessing food, a shortage of clean water for drinking and washing, cloth, and other problems after discrimination. But only 10 (16.6%) of respondents were responded "No".

Similar to this, data collected from key informant age of 35 during in -depth interview section show as:

“Of course, epilepsy is a contagious or transmittable disease, and as a result, non-epileptic community has previously banished and discriminated against epileptics, but this has now decreased. It is, in my opinion, immoral, anti-human, criminal, and unlawful. The communities were now living with the sick as a result of the availability of some information about the disease and how to prevent it. Epileptics should not be discriminated from their families after being affected. Because they were facing severe problems related to accessing basic needs (such as food, water, shelter, cloth, education opportunity, and others)”.

4.5. Government and Non-governmental Organizational Interventions

Key informant from woreda administration, revealed that some interventions are carried out by both government and non-governmental organizations. For example, there are some governmental intervention by woreda administrative, Labor and Social Affairs, and Mizan Tepi University in managing the socioeconomic difficulties of epileptics living in a temporary epileptic camp. They provide some basic needs such as food, living shades, cloth, water, and social services like education and drug services to the patients, but they do not provide sufficient and satisfactory services for children with epilepsy that required additional governmental attention to solve various socio-economic challenges, to improve patients living situations, and their quality of life in the study area. Besides, the community elders were undertaking some interventions like providing food and cloth, but it was not adequate.

Data collected from key informants from LSA Offices indicates that they delivered necessities, such as food, clothing, and drug services corroborating with the health office. The LSA Office responded that patients were not receiving enough care from the offices. As he points out, the government does not treat this sickness like other diseases (such as HIV/AIDS). For instance, individuals with HIV/AIDS can live with their families and the community, but epileptics cannot, particularly in the Me'nit community. The patients are completely discriminated against and ostracized from family and the community.

As a result, the patients in a temporary epileptic camp are accessed limited basic needs and live in poor socioeconomic conditions. Furthermore, he stated that it was critical to establish a

distinct office or club with a regular budget that provides long-term and continuous assistance to patients by engaging in other activities such as resource mobilization. Additionally, the government bodies should work with the local communities particularly on social stigma and discrimination associated with the disease in the communities.

Moreover, the researcher interview one non-epileptic community from community elder. As he informed that they were supplying some basic needs such as food and clothing for the patients. According to the community elder, throughout the holiday season, by mobilizing the communities, they were aiding the patients who reside in a temporary epileptic camp. He suggested that they were not accessing sufficient support that needs additional intervention.

The researcher conducted a key informant interview with the woreda administrator. He described that they were providing the basic needs (such as shelter, food, and cloth), and services (like AEDs, awareness creations, and a few educational opportunities). As he stated, the woreda was unable to provide sufficient and consistent necessities for patients use to obstacles such as financial, logistic, and human resource deficiencies. Similar to this, MTU is undertaking some activities like providing food, cloth, and sanitation materials for them, but know it was interrupted.

4.5.1. Access to Basic Needs from Governmental Organization

Access to fundamental needs such as food, clothing, water, and shelter is critical for human life. Human survival was extremely difficult and impossible without accessing such necessities. However, the inability to meet fundamental demands has a significant impact on the patient's personal development, healthy, happiness, well-being, and quality of life. In this regard, epileptics in the research area have suffered problems accessing to basic needs. Furthermore, being a youngster with no means of income makes them difficult to meet their basic demands. Almost all of patients were surviving depending on government and non-government organizations, but there is a gap in accessing these basic needs from those organizations.

4.5.2. Access to Services from Governmental Organizations

Qualitative data collected from the informants indicated that they were accessing a few services such as counselling services, educational opportunities, and drugs services from the governmental organizations.

1. Accessing Counseling Services

Epileptic youngsters are interviewed about accessing counselling services from health care services. This stated by an 18-year-old female epileptic child from Kera kebele who participated in an in-depth interview as follows:

“I have an epileptic illness for at least 2 years. I have accessed counselling services from health care services, but it’s not adequate”.

Furthermore, epileptics in the research area had limited access to counselling services from government organizations.

2. Access to Educational Opportunities

A lack of educational possibilities not only affects patients' current living situations, but also jeopardizes their future quality of life and socioeconomic status in the communities. The educational changes are significant in terms of developing fundamental skills and knowledge. Furthermore, educational opportunities allow children to learn basics facts about epilepsy, its causes, how to treat it, and how to avoid its negative effects. In relation to the previously mentioned benefits of education many epileptics did not access educational opportunities in the study area. The researcher observe that a considerable number of epileptics from Jemmu, Cheru, and Kera kebele are denied from educational possibilities. Only epileptics at Era Me'nit kebele have access a few educational opportunities.

3. Access to Anti-epileptic Drugs

According to the data acquired from epileptics, they were accessing some medicine in the health care systems. As they stated, AEDs (Phenobarbital) were used in health care services. The

researcher also interviewed one key informant from Labor and Social Affairs Office about how epileptics access to AEDs. He elaborated this as follows:

“We collaborated with health offices and set up a system via which epileptic children could obtain free medications. They were able to obtain phenobarbital treatments from the health care system by identifying and sending the patient's name to the hospital. The medications have no negative effects on the patient's health. Some patients' were show improvement after they use it. The most difficult challenge was not drug shortage, but the patients were most of the time have used alcoholic elements such as Wine (Teji). As a result, the medications were not always successful for everyone. The patients have been using medicines for about two years and continue to do so”.

From this statement one can understood that epileptics were accessing some drug service. But the medication is not effective for those who use alcoholic element.

Chapter Five: Discussions

The current study find outs several factors that affected patients' quality of life. They are suffered stigma from non-epileptics, stigma and discrimination, food shortage, duration of disease, seizure frequency, a shortage of drug, a shortage of safe water for drinking and washing, and physical harm. This study findings has consistence with several studies done by Kassie et al. (2014), Momen, Abareian, and Malamiri (2019) , Nasir et al. (2020), Murugan and Workineh (2020) ,and Doffana and Hawassa (2009). For example, a cross-sectional study conducted in public hospital in North Wollo Zone indicated that seizure frequency, duration of disease, side effects of AEDs, depression, physical injury, and deformities were have its own negative implications on patient's quality of life (G. M. Kassie et al., 2014). Study conducted Kassie et al. (2014) indicated that patients with perceived stigma were twice more likely to have a poor quality of life compared to a patient who did not perceive stigma. In the present study, the respondents were asked about stigma; the majority 46 (76.6%) of patients were suffered perceived stigma from non-epileptic children and a few 14 (23.3%) were not. The current study findings has consistence with the study finding done by (G. M. Kassie et al., 2014) . Perceived stigma is the most dangerous factor that affected the quality of life of children who suffered from

mental illness. Because it increases psychological problems such as fear, rejection, depression, discrimination, stigma, and poor elation with others.

In relation to drug availability, study conducted by Doffana and Hawassa (2009) at Mizan and Bachuma indicated that there was no regular and continuous provision of the drugs. This finding has consistency with the current study finding because the majority 32 (53.3%) of epileptics in this study were not accessed drug services whereas only 28 (45.2%) of epileptics were accessed drugs from health care services. Medication shortage has far-reaching implications on patients' quality of life because it increases seizure frequency.

A study conducted in Ahvaz city showed 35.2 % of respondents were experienced illness (five years), followed by 34.2 % (eleven years and above) (Momen et al., 2019). With regarding to disease duration, in the study area majority 37 (59.7%) of epileptics were experienced 3-4 years followed by 12 (19.4%) 1-2 years. Duration of the disease determines patients' quality of life because it causes medication effects, depression, stress, fatigue, affects patients' social relationships with others, and their social functions. This can further impair their quality of life. Apart from seizure severity, majority 29 (46.8%) of patients have suffered 3-4 seizures within a day followed by 23 (37.1%) were 1-2 seizure.

In this study, respondents were requested questions on major problems that affected their quality of life. The main problems are stigma and discrimination 52 (86.6%), shortage of food 50 (83.3%), and shortage of drug 48 (80%). This findings has consistency with the study conducted by Doffana and Hawassa (2009) and Murugan and Workineh (2020). According to study conducted by Doffana and Hawassa (2009) and Murugan and Workineh (2020) findings epileptics were suffered food shortage, starvation, stigma and discrimination, poor accessing housing services, and a lack of clean water for drinking and washing at Bachuma and Mizan .

This study also examined epileptics living situations in the camp. Their living conditions are discussed regarding to adequate food access, clean water for drinking and washing access, safe shelter access, treatment and major problems that affect their living situations. In terms of adequate food access; majority 40 (66.6%) are not accessed adequate food. Concerning clean water for drinking and washing the majority 42 (67.6%) of respondents did not access safe water for drinking and washing. About 43 (71.3%) are not accessed suitable housing services from the

governmental organization and the rest 17 (27.4%) were accessed. These findings has consistency with the study conducted Murugan and Workineh (2020) and Doffana and Hawassa (2009). For instance, the study conducted Murugan and Workineh (2020) indicated that epileptics in Mizan Teferi town are faced a lack of basic needs such as food, shelter, and water and a lack of social services such as education and health care services. The same to these, study conducted on epileptics Doffana and Hawassa (2009) also showed that food is not an easy task for epileptic in Mizan and Bachuma. Lack of food and exposure to starvation was thus one of the risks due to the banishment.

The study conducted by Sharon (2011) indicated that epilepsy resulted many social consequences. The study conducted by Doffana and Hawassa (2009) confirmed that epileptics were discriminated against, banished, and stigmatized from his/her families and the communities. In this study, all of the 60 (100.0%) epileptics are discriminated from their family and community's relation. About 51 (85%) of respondents are excluded from social engagement with non-epileptics; about 44 (73.3%) of respondents are excluded from educational opportunities and about 48 (80%) are excluded from physical activities.

The findings of these study go hand in hand with the argument of the stigma theory of Goffman. In this manner, this theory explains how stigmatization and discrimination associated with epilepsy affect the patient's life more than the disease. Because it leads to epileptics' inability to access adequate basic needs like food, shelter, cloth, and water and social services like educational opportunities and health care services. Furthermore, it excluded patients from family and the communities relations, family support and love, ability to access their family resources, in the ability to return, affect their social relationship, caused religious discrimination, and others which has a determinant impact on the overall patients living situations and quality of life.

Chapter Six: Conclusions and Recommendations

This chapter concludes the main objective of the study and gives recommendations depending upon major findings of the study.

6.1. Conclusions

This study investigated the socioeconomic situations of epileptic children in Me'nit Shasha woreda. Various objectives such as variables impacting epileptics' quality of life, epileptics' living situations, government and non-governmental initiatives, and the social implications of epilepsy are investigated in this study.

The quantitative study findings revealed that there are various predictors of patients' quality of life. These are food access, duration of disease, seizure frequency, physical injury, anti-epileptic drug access, stigma from others, and relation with others. Table 4. 2. 1, showed that about 31 (51.6%) epileptics are not accessed food; about 37 (61.6%) of epileptics are experienced long duration of disease (3-4 years); about 29 (48.3%) of respondents have experienced 3-4 seizures within a day; about 39 (65%) of epileptics are suffered physical injure, about 46 (76.6%) of the respondents have encountered stigma from non-epileptics and about 35(58.3%) have poor relation with others. A large number of respondents are exposed to main problems such as stigma and discrimination, a shortage of food, and shortage of drug services 52 (86.6%), 50 (83.3%), and 48 (80%), respectively. Besides, qualitative findings indicate that food scarcity, a shortage of suitable house, seizure frequency, and a shortage of clean water for washing has a major implication on patient's quality of life. There are no separate house for the patients. Additionally, the patients have ware dressed unclean, deteriorated, and low-quality cloth.

This study has showed that epileptics are not accessed adequate food 40 (66.6%) services from the government organizations. In the study area, epileptics are suffered problem in relation to accessing safe and clean water for drinking. The Table above 4.3.1, revealed many 42 (70%) of the respondents did not get clean water for drinking and washings. Standard and suitable house services is significant for good life. But regarding to this, about 43 (71.6%) of epileptics did not access proper and congenial house services. About 53 (58.3%) of patients treat the disease by using anti-epileptic drug, and the remaining 14 (23.3%) treat using traditional drug.

Although qualitative findings revealed that epileptics are suffered from suitable housing issues, drug shortage, safe water for washing, toilet and sanitation materials problems, and food

accessing problems. The main implication of this study is that the need to provide adequate food, a conducive house, safe water for washing, and adequate drugs in health care to improve the overall living situations of epileptics.

The study findings also revealed that epilepsy results in different social problems. As depicted in Table 4. 4. 1, all of the respondents have suffered discriminated from their family's relation 60 (100.0%). A significant number 44 (73.3%) of the respondents were discriminated against from education opportunities. About 51 (85%) of epileptics are excluded from social relation with non-epileptic children, and about 40 (80%) are withdrawal from educational opportunities. The main implication of these findings is the need for policy intervention and overcome the problems of stigmatization, discrimination, and social isolation.

Other findings of this study show that there is some intervention activities carried out by concerned bodies to address the problems of epileptics, but there is a gap in providing basic needs and social services that needs critical interventions from government and non-governmental organizations.

6.2. Recommendations

The study findings on each research objective indicated that addressing the problems would necessitate should need a short term policy intervention, as well as both government and non-governmental efforts. The researcher has recommended possible points based on the research findings, respondents' comments, ideas, and personal opinions raised in the study area.

- ❖ Regular and continuous provision of the adequate drug in health care services is mandatory to improve patients living situations and their quality of life.
- ❖ Governmental organizations such as Labor and Social Affairs Office and Women's, Children and Youth Office should actively involve in awareness creation particularly on perceived stigma, banishment, exclusion, and discrimination associated with epilepsy in the communities that affect patient's life more than the disease.
- ❖ Health care professionals, Psychologists, Social workers and Sociologists should provide the necessary information, counseling, and continuous follow-upping services.

- ❖ Women's, Children and Youth Office should take regulation related to epileptics stigmatization and discrimination because epilepsy victims are isolated from their family care, love, support, and resources access and live in unfavorable conditions. This action is both anti-human beings and immoral. So policy intervention activities should be critical and significant in terms of eliminating patients' survival problems after discrimination.
- ❖ The Woreda and Zonal office should coordinate and assign an adequate budget for building safe shelter and rebuilding those shelter have no doors and windows. Furthermore, they should separate shelters for male and female patients particularly to keep female patients from sexual abuse (rape).
- ❖ Zonal and Woreda government should cooperate with the local communities such as community's elders and religious institutions to raise the attitude of the local communities on epilepsy, negative consequences of epilepsy, and re-integration activities.
- ❖ The Woreda government should cooperate with different sectors like Zonal government, MTU, Community Elders, Women's, Children, and Youth Offices, and Labor and Social Affairs Offices to provide adequate basic needs such as adequate food support, nutritional support, suitable and conducive house support, cloth, and safe water for drinking and washing support, sanitation and hygiene material support.
- ❖ Government and non-governmental organizations should empower and create chances for epileptics to gain social services like educational opportunities that will enhance their situations now and in the future.
- ❖ Some offices holders have suggested that there might be a need for establishing independent offices that exclusively support epileptics through community mobilizing and who work on epilepsy issues in the communities.
- ❖ Finally, higher educational institutions like Mizan-Tepi University and the Mizan-Tepi University Teaching Hospital, as well as interested researchers, should be engaged in research and distribute information to the local communities particularly on epilepsy causes, its treatments, and adverse effects of the disease on the victims.

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Appendix

Appendix I: Action Plan/ Research Plan

The table below showing the time schedule in which this study was complete.

Table 3. Action Plan

No	Activity	Time frame in terms of months		
		September 2020- August2021		
		Sep 18- Nov 04,	Nov5, 2020-	March 15 –

		2020	March 10,2021	August 6, 2021
1.	Topic approval	X		
2	Preparation of thesis proposal		X	
3	Submission of the first draft thesis proposal		X	
4	Summation of second draft thesis proposal		X	
5	Summation of final thesis proposal			X
6	Approval of thesis proposal			X
7	Data collection			X
8	Data analysis and writing report			X
9	Submission of the first draft thesis			X
10	Summation of second draft thesis			X
11	Summation of the final thesis and presentation			X

Appendix II: Budget Plan

Table 4. Budget plan

No	Items	Unit	Amount	Unit cost in birr	Total birr in Ethiopia
1	A 4 paper	Pad	3	120	360
2	Colored paper	Pad	2	140	280
3	Pen	Pad	25	10	250
4	8 GB flash disk	NO	3	250	750
5	Scientific calculator	NO	1	180	180
6	Printing, photocopy and binding	-	-	-	4000
7	Mobile card	NO	50	20	1000
8	Transport fees	NO	80	10	250
9	Breakfast, lunch and dinner	-	-	-	2000
10	Other expenses	-	-	-	2000
	Total	-	-	-	110.70 Birr

Appendix III: Survey Questionnaires for Epileptic Children

Dear respondent, I Genet Damte, MA student in the field of Sociology (Specialization in Social Policy) at Jimma University. Currently, I conducting an MA thesis entitled “*Socioeconomic situations of epileptic children in case of Me’nit Shasha Woreda, West Omo Zone*” for the Partial Fulfillment of MA Degree in Sociology. The purpose of this study was to gathered information on socioeconomic situations of epileptic children in case of Me’nit Shasha Woreda. Your participation in this study is based on your willingness.

Moreover, the information that you provide will be used only for research purposes and you are guaranteed that the researcher has no other hidden agenda. I believe the study findings will serve as a flat-form for policy intervention addressing the socio-economic situations. Therefore, I requested kindly you to answer the questions presented below. Thank you in advance!

Part 1: Survey Socio-demographic Characteristics of Epileptic Children

Direction1: Write the correct answer in the space provided by using this mark (X) (Q. No.1- 5).

1. Sex: A. Male B. Female

2. Age of the respondent

A. 6-9 years B. 9-13 years C.14-17 years D. 18

3. Educational background of the respondents

A. Illiterate B. Can read and write C. primary school completed (1-8)

D. Secondary and Preparatory school completed (9-12) E. Others

4. Religious backgrounds the respondent

A. Orthodox B. Islam C. Protestant D. Traditional religion follower

5. Ethnic backgrounds of the respondent

A. Me ‘nit B. Sheko C. Keffa

D. Bench E. Other

Part 2: Questionnaires Related on Factors Affecting Quality of Life of Epileptics

Hence, under these parts, questions are prepared to elicit necessary information on factors affecting the quality of life of children with epilepsy. Direction 2: Please give an appropriate answer for the following questions (Q.No.1- 11) by using this mark (X).

1. Have you accessed food from governmental organizations? A. Yes B. No

2. For how long since you become an epileptic patient?

A. 1-2 years B. 3-4 years C. 3-4 years

3. How much do you seizures within a day?

A. No seizure C. 3-4 seizure

B. 1 -2 seizure D. >4 seizure

4. Do you have suffered physical injure during seizures?

A. Yes B. No C. If “Yes” what physical? Describe it?

5. Have you accessed anti-epileptic drugs? A. Yes B. No

6. Have you got enough information from health care services? A. Yes B. No

7. Anti-epileptic drugs caused side effect on your health condition?

A. Yes B. No C. If “Yes”, what type?

8. Have you experienced stigma from non-epileptic children? A. Yes B. No

9. Have you worship with non-epileptic children at same churches or mosques?

A. Yes B. No C. If "No", why?

10. What it looks like your relationships with non-epileptic children? A. Mid B. None

11. What problems affecting your happiness in a camp? (More than one answers is possible)

A. Shortage of food B. Shortage of clean water C. Shortage of living shelter
 D. Stigma and discrimination E. If any another list it? _____

Part 3. Questionnaires Related to Living Situations of Epileptics

Direction 3: Under this part questions will be developed to know the living situations of epileptic children in the study area. So, provide your correct answer for the following question (from No 1-10).

1. Have you accessed adequate food from governmental organizations? A. Yes B. No

2. Have you got clean water for drinking in a camp? A. Yes B. No

3. Have you got clean water for washing in a camp? A. Yes B. No

4. Have you access conducive shelter? A. Yes B. No

4. In which methods you treat the disease?

A. Traditional medicine B. Anti-epileptic drugs C. If any other mentioned it?

5. Currently, what major problems are affects your living situations?

- A. A shortage of food B. A shortage of drugs services
- C. Shortage of clean water for washing D. Perceived stigma and discrimination
- E. If another describe?

Part 4: Questionnaires Related to Social Consequences of Epilepsy

Direction 4: Under this section questions which comprised social consequences of epilepsy was developed. Therefore, provides your correct answer (for Q No 1-8).

1. Have you suffered discrimination from family life? A. Yes B. No C. If Yes, why?
2. Have you discriminated from educational access? A. Yes B. No C. If “Yes” why?
4. Due to the seizure what problem do you faced?
- A. Withdrawal from the family and community life B. Excluded from physical activities
- C. Excluded from social engagement D. Excluded from educational opportunity
5. Do you think that epileptic should live with their families after them being epileptic?
- A. Yes B. No C. If “Yes “why?

Appendix IV: In-depth Interview Guidelines for Epileptic Children

Dear respondent, I Genet Damte, MA student in the field of Sociology (Specialization in Social Policy) at Jimma University. Currently, I conducting MA thesis entitled as “*socio economic situations of epileptic’s children in case of Me’nit Shasha Woreda, West Omo Zone*” for the Partial Fulfillment of MA Degree in Sociology. The information that you provide will be used

only for research or academic purpose and I have no other hidden agenda. Accordingly, I requested you to respond the questions developed. Thank you in advance!

Consent Form

I, _____ the above informant, freely agree to participate in this study. I understand that I am free to refuse to answer any question and to withdraw from the study at any time. I understand that my responses will be kept anonymous. If you are willing to communicate with me at any interview time, please provide your contact information below: If you are willing to participate, shall I proceed to the questions? Thank you in Advance!

Date of interview: _____ Time of interview _____ Place of interview: Sex: _____

1. What factors affect your happiness? Please discussed it based the following points:

- Access to food and clean water for washing,
- Access to cloth and conducive shelter
- Physical injury
- Access to medical treatment
- Perceived stigma and discrimination

2. What it looks like your living situations in a camp? In terms of the following points:

- Access to conducive shelter
- Access to clean water for washing
- Access to food including nutrient food
- Access to toilet and sanitation problems

3 Discuss about the basic needs that you have accessed from both governmental and non-governmental organizations? Such as:

- Access to food
- Access to water

- Access to living shelter

1. Discuss about services that you accessed from governmental organizations in a camp?

Such as:

- Access to counseling service
- Access to education
- Access to anti-epileptic medication

Appendix V: Key informant interview for Woreda Administration

Dear respondent, I Genet Damte, MA student in the field of Sociology (Specialization in Social Policy) at Jimma University. Currently, I conducting an MA thesis entitled as “*Socio economic situations of epileptic’s children in case of Me’nit Shasha Woreda, West Omo Zone*” for the Partial Fulfillment of MA Degree in Sociology. This interview guides were designed to collect information on government or non-governmental contribution in addressing the socio-economic situations of epileptics in Me’nit Shasha Woreda. The information that you provide will be used only for academic purpose and you are guaranteed that the researcher has no other hidden agenda.

Consent Form

I, _____ the above informant, freely agree to participate in this study. I understand that I am free to refuse to answer any question and to withdraw from the study at any time. I understand that my responses will be kept anonymous. If you are willing to communicate with me at any interview time, please provide your contact information below: If you are willing to participate, shall I proceed to the questions? Thank you in Advance!

1. Is there any interventions undertaken to improve the situations of epileptic children in a camp? (Like Mizan Tepi University, community elders).

2. If there, what service them providing for epileptic children in a camp? (Food, cloth, awareness creation, health care services and counselling services).

3. Describe the basic needs that the Woreda administration provides for epileptics in a camp? (Such as food, cloth, shelter, water, educational and anti-epileptic drugs access).
3. What challenges have you faced in providing basic services for epileptics in a camp? (Material, non-material constraints, and financial shortage).
4. Generally, what should be done to improve the socio-economic situations of epileptic children in a camp?

Appendix VI: Interview Guide Prepared for Labor and Social Affairs

Dear respondent, I Genet Damte, MA student in the field of Sociology (Specialization in Social Policy) at Jimma University. Currently, I conducting an MA thesis entitled as “*Socio economic situations of epileptic children in case of Me’nit Shasha Woreda, West Omo Zone*” for the Partial Fulfillment of MA Degree in Sociology. This interview guideline was developed to collect data on government and non-government intervention in term of addressing socio-economic situations of epileptic children. The information you provide will be used only for research or academic purpose and you are guaranteed that the researcher has no other hidden agenda. Thank you in advance!

Consent Form

I, _____ the above informant, freely agree to participate in this study. I understand that I am free to refuse to answer any question and to withdraw from the study at any time. I understand that my responses will be kept anonymous. If you are willing to communicate with us at any interview time, please provide your contact information. If you are willing to participate, shall I proceed to the questions? Thank you in Advance!

Name _____ Sex: _____ Age: __ Date of interview _____ Time of interview _____

1. What it seems like the living situations of epileptic children in a camp? In terms of access to food, cloth, shelter and water and sanitation issues).

2. How epileptic children in a camp access anti-epileptic drug?
3. What basic service do you providing for epileptic children in the camp? (Like food, cloth, shelter, and awareness creation services etc. Describe it?
4. What do you recommend to improve the socio-economic situations of epileptic children in a camp?

Appendix VII. Key Informant Interview Guidelines for Community Elders

The researcher conducted this study on socio-economic situations of epileptic children in Me'nit Shasha Woreda. For this purpose, the researcher would like to know some important information on socio-economic situations of epileptics. The researcher would like first to inform your participation in the study must be based on your free will. Second, the researcher is very much grateful for sacrifice that you paid and the information gathered will be highly confidential and will only use for the research purpose. Furthermore, any information that you provide is valuable to this study. I would like to extend my appreciation and thanks for your cooperation and committing your precious time. Thank you in Advance!

Date of interviews: _____ Place of interview: _____ Sex: _____ Age: _____

1. As a community elder what basic needs do you provide for epileptic children in a camp? (Like food, shelter, clothe etc.).
2. Do you think that children with epilepsy should live with their families after them being epileptic? If you said “No “why? If you said “Yes “Provides your reasons?
3. What is done to overcome epilepsy in the community?
4. What do you suggest to improve the socio-economic situations of epileptic children in a camp?

Observation Checklist: This checklist was prepared to observe the situations of epileptic children in a camp Such as:

- Living environment such as sanitation issues,

- Access to food, water, and cloth,
- Access to toilet services,
- Access to comfortable living shelter,
- Access to educational opportunity.