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Knowledge and Beliefs of the General Public towards Epilepsy and the Discriminations of People with Epilepsy in Ethiopia

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Abstract

This study examines knowledge and beliefs of the general public about epilepsy and the discriminations of people with epilepsy. Employing qualitative research methods data were collected from both the general public and people with epilepsy of two purposively selected kebeles in Mizan Teferi town. Twenty four non-epileptic household heads (twelve from each kebele) and ten informants of people with epilepsy were purposively selected in order to gather information on their beliefs and knowledge about epilepsy and the discriminations of people with epilepsy. In addition, key informant interviews were conducted among eligible general public such as religious heads, community elders and government officials in the study areas to gather additional data on the issue under investigation. Study findings indicate that people in the study areas believe epilepsy is caused by evil spirit. It is a transmittable and trans-generational disease that it could be inherited from parents. As a result, the general public in the study areas develop negative attitudes against people with epilepsy. The non-epileptics avoid having marriage relations with the epileptics; they do not allow the children of people with epilepsy to learn along with the children of the general public. People with

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epilepsy are found as incompetent and hence they are denied employment opportunities and are outcast from the community.

Keywords: epilepsy, beliefs, discrimination, transmittable-disease.

1. Introduction

Epilepsy is a chronic brain condition described by recurrent epileptic seizures that are the clinical manifestations (signs and symptoms) of excessive and/or hyper-synchronous, usually self-limited, abnormal activity of neurons in the brain (Mula, Sander, 2016; WHO, 2004). Around the world more than fifty million people have been affected by epilepsy wherein eighty percent of them are living in developing countries (de Boer, Marco, Ley, 2008; de Boer, 2010; Ngugi et al., 2010; Burton et al., 2012); and it is estimated that about one hundred million people will have at least one epileptic seizure at some time in their life (Scott, Lhatoo, Sander, 2001).

Epileptic seizures, if not treated, may lead to physical injury (wounding and bleeding), and frequent seizures have detrimental effects on education, employment and marital life whereby it may result in separation of the spouses, divorce and so forth (Shibru et al., 2002; Sanjeev, Aparna, 2011). Besides, epileptic people experience negative psychosocial consequences of the disorder including social isolation, low self-esteem, and feeling of shame and guilt which resulted from people's assumption that epilepsy is caused by some insane act (being mad as a result of committing an act which is against the will of God) by epileptic individual (Atalay, Cherenet, Waju, 2017). In many parts of the world people with epilepsy were viewed with fear, suspicion and misunderstanding, and were subject to enormous social stigma. As a result, epileptics were treated as outcasts and punished in different forms like social exclusion and denial of job opportunities (Assefa, 2004). Thus, the attitude of the society causes more pain than the seizures to the epileptics (de Boer, 2010).

In most parts of the world, knowledge and beliefs of people towards epilepsy is highly influenced by their perceptions of how epilepsy is caused and how it is transmitted. People believe that epilepsy is a contagious disease (Ghaydaa, 2016) and hence they hesitate to help or touch the person who has fallen during a seizure. Therefore, those suffering from epilepsy are stigmatized and ostracized in the belief that their condition is a demonic possession and believed to be contagious.

Besides, in Ethiopia people with epilepsy have been marginalized within their societies, and have had reduced opportunities for education, employment, marriage and social relationships (Teshome et al., 2006); they were subjected to different forms of stigma and discrimination including banishment, labor

exploitation, identity crises, lack of educational and other basic social services and lack of basic needs (Allotey, Reidpath, 2007; Zarihun, 2009; Statler, 2014). These consequently lead epileptic patients to develop different psycho-social problems such as stigma and discrimination and psychiatric illnesses and these affect epileptic patients more than the seizure itself (Allotey, Reidpath, 2007; Berhanu, Berihun, Bewket, 2015). Patients with epilepsy commonly have multiple psychological, social and health problems which include low self-esteem, fear, and feeling of shame and guilt (Sharon, 2011; Niall, 2013), social isolation, inability to get job, difficulty to find marriage partner and different forms of stigma and discriminations due to their illness (GCAE, 2001; Sanjeev, Aparna, 2011).

Despite its high socio-economic and health burdens, little is studied and known about epilepsy in the developing regions. In developing countries most of the evidence for the impacts of epilepsy has been drawn from studies in the developed countries (WHO, 2004; Baker, 2002). Furthermore, the major constraints which limit efforts aimed at reducing the burden of epilepsy in developing countries are socio-cultural factors that not only maintain the negative attitudes about the cause and treatment of epilepsy, but reinforce negative discriminatory and stigmatization practices (WHO, 2004).

In Africa, people affected with epilepsy have been estimated to be about ten million; this includes people of all ages – children, adolescents and the ageing population (WHO, 2004). In sub-Saharan Africa, active epilepsy was estimated to affect four million people and its prevalence is high among adults and children (Paul et al., 2012). In Ethiopia, it is difficult to know how many people are affected by epilepsy, how many of them have access to modern medicine (antiepileptic drugs) and how many of them have not got any form of treatment or use alternative medicines.

A few studies have so far been conducted on epilepsy in Ethiopia which tried to explain knowledge and beliefs towards epilepsy and access to modern health care services by epileptic people. For instance, Shibru et al., (2002) estimated that in Ethiopia, epilepsy has affected an estimated 5.2 per 1000 of the population, but only 2–3% of people with epilepsy living in rural areas receive medical treatment. Accordingly, most of epileptic people in Ethiopia were not treated in a modern health care center due to various reasons like lack of awareness about modern antiepileptic drugs, inaccessibility of modern health care services, preference of traditional medicine and misconception that epilepsy resulted from some insane activity by epileptic individuals.

In Ethiopia, epilepsy is a major social and health problem; it causes people to face different social, psychological and physical problems as a result of their illness which include stigma and discrimination, inability to find marriage partner, problems with education and employment, serious physical injuries like

bleeding and be wounded during sudden falling as a result of active seizure, and suffered from burns if an open-fire is around during active seizure (Shibru et al., 2002).

With regard to the forms of treatment of epilepsy, in Ethiopia, there is a widespread belief that epilepsy is caused by demon possession, bewitchment by evil spirits/ancestors' spirits or the evil eyes. As a result, affected individuals and/or their families often seek help from religious and traditional healers than modern antiepileptic drugs (Shibru et al., 2002; Gedefa, Wolde, Solomon, 2012; Gizat, Tsegaye, Bogale, 2014).

Even though, the socio-economic and health situation of epileptics and the beliefs and knowledge of the general public towards epilepsy deserves a profound empirical investigation, there are only a few studies on the issue at hand. Studies so far conducted on epilepsy in Ethiopia were mostly institutional (hospital) based survey research in which patients were interviewed about their socio-economic and health situations (Shibru, Prett, 2004; Teshome et al., 2006; Tareke et al., 2015).

Besides, the previous studies on epilepsy have often focused on a separate investigation of attitude and knowledge of both epileptic and non-epileptic people towards epilepsy by targeting epileptics who were attending the medical care services. However, no studies focused on the beliefs of the surrounding (non-epileptic) community towards epilepsy/epileptics and the discriminatory contexts of People with Epilepsy (PWE). Therefore, this study was conducted to fill the identified knowledge gap concerning the issue at hand. In order to specifically address the issue, the study had the following objectives:

- To assess the knowledge and beliefs of the general public towards epilepsy in Mizan Teferi town.
- To study stigma and discriminations of the people with epilepsy.

2. Theoretical framework

The study incorporated Erving Goffman's stigma theory that explains the socio-economic consequences of illness related stigma and the potential influences of stigma on the health care provisions. Since the emergence of stigma's definition proposed by Erving Goffman (1993), widely different models and frameworks for stigma analysis have been extended by a number of authors and have been adapted to fulfill variety of purposes to explain the stigma and discrimination which resulted from illness related problem in general and epilepsy in particular. Stigma as a phenomenon and an analytical framework is relevant to the study of epileptics and their social situations as it indicates that in different ways illness-related stigma had powerful effects on economic status,

psychological wellbeing, social interactions and overall health, even greater than the effects of the illness itself. Stigma is linked to a broad range of psychosocial consequences, including the loss of self-esteem, social withdrawal and isolation, often influencing others within the social network. Further, stigma has the potential to influence the provision of care to people with epilepsy. In order to better understand stigma and discrimination faced by PWE, this paper presents a systematic overview of the theoretical framework of stigma.

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

3. Study area

The study was conducted in two purposively selected *kebeles*¹ (Addis Ketema and Kometa) of Mizan Teferi town in Bench Maji zone, which is one of the twelve zones in the SNNPR (Southern Nations and Nationalities People's Region) of Federal Democratic Republic of Ethiopia. Mizan Teferi town has two sub-cities (Mizan and Aman sub-cities) and a total of five *kebeles* (Addis Ketema, Ibrat, Edget, Kometa and Shesheka). The first three *kebeles* (Addis Ketema, Ibrat and Edget) are found in Mizan sub-city and the other two *kebeles* (Kometa and Shesheka) are found in Aman sub-city. However, a large

¹ *Kebeles* are lower level administrative units (divisions) or farmers or peasant associations in rural Ethiopia.

population of the town is found living in the Mizan sub-city as it is located in the central area of the town. The zone (Bench Maji) is located 562 km away from Addis Ababa to the south west, has a total population of 652,531, of whom 323,348 are men and 329,183 women. As for religious affiliation of the people, 49.27% were Protestants, 18.12% of the populations are followers of Ethiopian Orthodox Christianity, 26.34% practiced traditional beliefs, and 3.47% are Muslims (Zarihun, 2009). Regarding the educational service coverage of the zone, the zonal data for the 2007-2008 Ethiopian calendar shows that, there were two preparatory schools, 176 first and second cycle schools (1 to 8th grade), seven high schools, and one University. Concerning distribution of health care centers in the zone, there were one hospital, sixteen mid-level health centers, and 131 health posts were found in 2006/2007 calendar year (Zarihun, 2009).

On the other hand, it is very difficult to know the exact size of the people with epilepsy in Mizan Teferi town. However, a study by Zarihun (2009) revealed, crude statistical profile of epileptics living in Mizan Teferi town as follows: the total banished population living in the temporary shelter² was 80 (30 males and 50 females). Out of this, the number of epileptics was 54 (17 males and 37 females). However, the number of epileptics living outside the camp was not known. Again most of the outcast epileptics in Mizan Teferi town are also found living in Mizan sub-city as the place has been seen as a main hub for them to beg and to earn by doing menial works.

4. Research and methods

The study employed qualitative research methods to gather data on the issue at hand. Study samples i.e., people with epilepsy (PWE) and non-epileptic household heads (HHs) were selected from two purposively selected *kebeles* namely *Addis Ketema* of Mizan sub-city and *Kometa* of Aman sub-city as a sizable number of people with epilepsy were found in these two *kebeles* of the town. Further, religious leaders, head of zonal social affairs office, and community elders were interviewed from Mizan Teferi town. From the two purposively selected *kebeles*, a total of twenty four HHs (twelve from each *kebele*) were interviewed in order to gather information on their beliefs and knowledge about epilepsy and also their reaction towards people with epilepsy. The household heads were determined on the basis of their age, assuming aged persons may have better understanding about the issue under investigation. In each of the

² Also called communal houses which are built by the local government in order to provide a safe asylum to those outcast epileptics from the surrounding places.

selected households, a senior elderly person was contacted to share his/her views on the issue. In this way, 16 male and 8 female HHs with the age range of 48-60 were interviewed from the study areas. While nine male and four female HHs were studied from *Addis Ketema kebele*, seven male and four female HHs were studied from *Kometa kebele*. On their religious affiliation, among the 16 male study subjects seven respondents are found to be Protestants, while Muslims and Orthodox Christians are found to be five and four respectively. Similarly, among the female study subjects five women HHs are affiliated to Protestantism while three of them are adhering to Orthodox Christianity. Among the 16 male respondents while four of them have completed grade 10, seven respondents have completed grade eight; and five respondents never attended school. On the other hand, among the female HHs all the eight respondents have completed grade ten. Farming is the principal occupation of both men and women respondents as they are residing in the rural *kebeles* of the study areas.

On the other hand, data regarding stigma and discrimination faced by PWE, epileptic respondents were selected based on their availability and the assumption that they can better explain the issue at hand. Ten informants of people with epilepsy living in the two selected *kebeles* (*seven from Addis Ketama and three from Kometa*) of Mizan Teferi town were purposively and conveniently selected. Among the selected PWE respondents eight are men (five from *Addis Ketama* and three from *Kometa*) and two are women (one from each *kebele*) with their age ranging between 24 and 40. None of the selected study subjects i.e., PWE have attended schools as they are discriminated and or outcast by the general public or in other words people without epilepsy. The people with epilepsy were mostly found from the platforms and were standoffish; however, they were catechized with issues on their access to basic need, availability and access to basic social services like education and opportunity to participate in different forms of social gathering, marriage and job opportunities in a detailed way.

Again, in order to gather additional data, key-informant interviews were conducted with some knowledgeable individuals who can best explain the issue under this study. Six key-informants i.e., one community elder (male, 58 years), one Zonal Social Affairs Office Head (male, 33 years), and three religious leaders -Protestantism, Orthodox Christianity and Islam – each one, with the age range of 40 – 51 i.e., 41, 51, and 45 respectively were selected and interviewed on their views about epilepsy, PWE, and generally on how PWE should be treated in the community. On the other hand, two key-informants (males, aged 26 and 37) were selected among the PWE in order to know the miserable conditions experienced by the PWE in the study areas.

All the HHs was interviewed in their respective houses, while PWE were mostly interviewed on the platforms or some under trees in the outskirts of the *kebeles*. Each interview took place about 40 minutes to one hour with both HHs as well as PWE. On the other hand, all the key-informant interviewees were contacted at their respective houses, except the zonal social affairs office head who was interviewed in his office. Each key-informant interview lasted for about 30-40 minutes. Interview guide, tape recording, note taking techniques and partial observation are used to acquire needed information. Based on this, rough notes were prepared in Amharic³ language and then the prepared notes were developed and translated to English. Field notes are used to supplement along with the in-depth interview data in order to give a clear picture about the study matter. The data were first rearranged/organized and finally it was thematically analyzed.

5. Results and discussions

5.1 Knowledge and causes of epilepsy by the general public

Causes of and knowledge about epilepsy are important concerns to make people prejudicial towards people with epilepsy. The sources of information from which people hear about certain disease have profound impact on the way people understand it and it is reflected in their understanding of the cause of the disease. In fact, the cause/s of epilepsy understood by the general public (non-epileptics) across the globe is different from place to place and society to society. Against this backdrop, an attempt was made to know knowledge and causes of epilepsy and its resultant effects by the non-epileptics in the study areas. Consequently, data collected from the study areas show that there is almost a unanimous understanding among the general public/household heads that *'epilepsy is an awkward disease'* and people with epilepsy are *'contemptible persons'*. The household heads in the study areas informed that *'it is a deadly disease that it will put the victim into miserable conditions; if anyone is affected with this [epilepsy] their life will be ruined and they can't live actively'*. In this regard one of the household heads, (a 52 years old male, Orthodox Christian) who is an in-depth interviewee revealed that epilepsy is a *'noxious and abominable condition. It is a disease that can never be cured. Anyone becomes victim of epilepsy should be sent out of the community as it could affect others also'*. Thus, there is a general perception among the general public in the study areas that epilepsy is a loathsome condition that it arouses intense disgust by seeing the seizures.

³ Official working language of Ethiopia.

Regarding source of knowledge about epilepsy, the general public/HHs informed that they have heard about epilepsy from different sources such as their family/friends, religious teaching, media and health workers. However, the general public in the study areas believe that the major cause of epilepsy is *evil spirit* 'Ehe ye keifu menfes sira ne'⁴; they believe that the cause of epilepsy was a fateful decision of the '*supernatural power descendent upon some individuals whom it chooses*'. Besides, epileptic is the one who is punished by the divine being for his/her '*sin*' or '*wrong doing*' and may also be due to God's curse on ancestors which transcends to children (the thought that epilepsy is a trans-generational disease). This is apparent from the following terms of one of the key-informants, a 58 years old community elder, a believer of Orthodox Christianity, that '*you can't question what God has done; look..., we are in his hands, if we do not adhere to his words, such a bad thing [epilepsy] will happen to us. So we have to be careful for ourselves and for our children*'. In the same vein, a 41 years old key-informant who is a Protestant religious leader shared his ideas on the cause of epilepsy in the following terms:

science can say this and that about the causes of epilepsy, I know that...; but as far as I am concerned and also based on the Bible, it is caused by demon possession. I have seen in many occasions practically, those affected people coming to our church and getting free from evil spirits. It was caused to some people when the demon spirit takes over their mind and finally makes them to fall down sometimes.

Nevertheless, people with epilepsy, in this regard, while claiming to refute the non-epileptic's beliefs over the epileptics on the cause of the disease, they could not understand '*as to what they have been suffering from...*'; sometimes, they also believe that it could be because of the '*sinful acts what they have done in the early ages*'.

From the above findings it is obvious that the general public in the study areas have a very strong belief that epilepsy is caused by the possession of '*evil spirit*' and praying is the only healing option. The idea of demon possession regarding the cause of epilepsy was similarly discussed by Reynolds (2012) among ancient Babylonians as they had no concept of pathology; however, they associated each seizure type with invasion of the body by a particular evil spirit, so that treatment was not medical but spiritual. Congruently, the study findings of Fanta et al., (2015) go hand in hand with the findings of the current study that it confirms people believe the cause of epilepsy as evil spirit and supernatural force.

⁴ Amharic – meaning this is the work of evil spirit.

5.2 Knowledge and beliefs of the general public about transmissibility of epilepsy

The views of non-epileptic respondents regarding transmissibility of epilepsy i.e., whether epilepsy is a contagious disease, were further dug out as it is one of the prime concerns of the study. In this regard, the non-epileptic informants revealed that they believe epilepsy is a transmittable/infectious disease except for some who were influenced by modern information which provided them basic facts of epilepsy. Accordingly, the very underlining reason for the stigmatization and discrimination of PWE emanated from such beliefs that epilepsy is transmitted via eating and drinking together with PWE, having any physical contact with the patient, sharing same objects that are used by the person who is suffering from epilepsy, sharing/dwelling with the epileptic patient in the same home, through breathing i.e., inhaling the breathed air from the epileptic and touching the saliva and stepping on the urine of the patients ... to list some. It has been noted that prevailing such beliefs among the non-epileptics have caused a lot of sufferings to the PWE in the study areas as they inflict banishment or eviction from the family and or the community over the people with epilepsy. One of the non-epileptic household heads (female, aged 48, a Protestant believer) this end, informed that *'epilepsy is definitely an infectious disease as it has no age or sex; I know that there are some people in the surrounding areas got infected just because they used to befriend [talking and sitting] with the epileptics'*. Consistently, a male 59 years old non-epileptic household head who is a follower of Orthodox Christianity had to say the contagious nature of the problem epilepsy in the following terms: *'even a speck of his [epileptic's] saliva will be more than enough to infect you [the non-epileptic]. Touching the body parts of the epileptics especially when it sweats will certainly cause to contract the disease'*.

Thus the beliefs about transmissibility of epilepsy has been understood by the non-epileptics in such a way that the disease could be contracted either by touching the body parts of the epileptics or even by 'talking' to them wherein a speck of saliva of the epileptic patient falling on the non-epileptic's body. This was further reinforced by data collected from key-informant interviews that elaborate how the belief by non-epileptic people that epilepsy is a contagious disease make epileptics to face different forms of stigma and discrimination such as social isolation and denial of opportunities. A key-informant, a 58 years old community elder, who is an Orthodox Christian, forwarded his views on the transmissibility of the disease – epilepsy in the following terms:

You know, some years ago, there were only a few epileptics to be seen in this town. But, nowadays, the number of epileptics is highly increasing. Here and there you can find them alongside the street especially around the churches. This disease is highly spreading in our town. You may also be infected with

the disease if you touch them..., if you touch their belongings... Therefore, people should not approach the patients. I advise the people whom I know, not to approach epileptics. They [epileptics] should have to live in a separate village away from this town.

Further, the same key-informant elaborates on how dangerous the disease is and how people have to safeguard themselves:

Let me tell you the truth. Yonder... [indicating to the researchers], see the grave [a dirty – remote place where epileptics are buried] that is where an epileptic was buried sometimes ago; around the grave now trees have grown up. One fine morning a little girl from a non-epileptic family, unknowingly, went around the grave for collecting firewood from those trees. Upon returning home, the girl's mother asked her as to where the firewood came from, the girl responded that was around that grave. Oh, that is the grave of that man with the disease [epilepsy], the mother cried...; and in seconds..., for no reason, the girl fell on the ground and developed seizures. This indicates that it is a contagious disease. So, if the spirit of a dead man from the grave can attack others, you can guess how much we have to fear over those living with the disease [epilepsy].

Thus, it is obvious from the above quotes that people in the study areas strongly believe that epilepsy is a transmittable disease; let alone having a physical contact or any relationship with living epileptics, stepping on the grave of the epileptics was frightening among the study community. As a result, epileptics were not only stigmatized by shameful remarks put on them by the surrounding community; they were even banished by their families and community, so that they would die in alongside street without any help or forced to migrate to unknown places.

The inferiority attitude among the epileptic outcasts is probably a function of this belief that they consider themselves as a '*briyam*'⁵ and this is considered as a lifetime, shameful tag which they cannot avoid. Some even seem to justify the banishers' action by sharing this inimical belief. This has been evidenced from a key-informant, who is a 37 years old married epileptic man, believes in Orthodox Christianity, who has tried to commit suicide three times because of the stigma that he has experienced in the following words:

Look this [showing the scars on his throat]! This is a sign when I tried to strangulate myself; I attempted three times to kill myself; thanks to my wife that she has protected me from this. I was thinking that I am a bad person,

⁵ Amharic word- meaning one who is epileptic.

because I couldn't do what other people do and I couldn't make money. I couldn't, do all sorts of different things; ... I hate myself...

In this manner, people with epilepsy tend to accept and internalize the social stigma they were facing which resulted in devaluation of themselves. In fact, it was observed that most of the people with epilepsy in Mizan Teferi town were spending their time by simply sitting alongside the street in the town. For most of the people with epilepsy, waiting for the day of their death is the only future plan.

5.3 Knowledge and beliefs of the general public about the characteristics of epilepsy and its treatment options

The understanding or the belief that epilepsy is a trans-generational disease by the non-epileptics has its own impact on people with epilepsy, especially on having marriage relationships with non-epileptic people. Concerning this data were collected from both in-depth interviewees and the key-informants. The non-epileptic in-depth interviewees invariably stated that *'since epilepsy is a serious health as well as mental problem, it is not wise to have any social or physical contacts with the epileptics; otherwise, the problem could be transmitted from the epileptics'*. This corroborates with data collected from key-informant interview. In this regard one of the key-informants, a 58 years old community elder, who is an Orthodox Christian, articulated: *'it [epilepsy] is a very dangerous disease; if anyone is affected with this, the person has to suffer throughout his/her life. If any one parent has the problem, definitely that will be inherited to the child so it is better not to have any marital relations with those who are suffering from epilepsy'*. As a result, non-epileptics do not come forward to have marriage relations with epileptics. Conversely, the belief that epilepsy is a trans-generational disease held by non-epileptics has been refuted by the epileptics. In this regard, a 37 years old male epileptic key-informant, believer of Orthodox Christianity, supplements his views in the following terms: *'except amongst ourselves, we cannot marry any non-epileptic woman, because they [non-epileptics] think that the disease will be transmitted to them and in the future, children born from epileptic couples will also be born with the disease. However, since there are many epileptic women who are living with us, we can find a wife among ourselves'*. Further, the same epileptic key-informant stated that irrespective of the belief of those non-epileptics, epilepsy is a transmittable condition, *'the disease [epilepsy] what I have been suffering from is not a trans-generational and it can never be... as I am a married man [married to an epileptic woman] and I have children; so far my children are perfectly fine; they have never experienced seizures. The same you can see among many of the other epileptic people living in this area'*. Nevertheless, the non-epileptics in the study areas believe that epilepsy is a trans-generational disease and hence they determine the epileptics should be

outcast. In fact, this kind of attitude and beliefs are not something peculiar to the people in the study areas in Ethiopia; similar beliefs are there in some other communities that epilepsy is a trans-generational disease (Aydemir, 2011).

Pertaining to the treatability of epilepsy, most non-epileptics in the study areas believed that epilepsy is not a curable disease and people with epilepsy cannot be treated. However, some respondents in the study sites informed that epilepsy can be cured through modern antiepileptic drugs, while many of them believed that the healing option would be through fasting and making prayers, using holy water and going to traditional healers. This finding is congruent with the study findings by Gedefa, Wolde, Solomon, (2012) that states non-western medicine i.e., traditional healing practice is the appropriate treatment option for epilepsy.

Considering treatment options and curability of the disease, non-epileptic respondents were found to be divided in their opinions. The idea that epilepsy is a treatable disease was harbored among some respondents, wherein a few informed that it could be treated by modern antiepileptic drugs, while others believed that it could only be treated by traditional healing practices. Scientifically, there are different causes and treatment options for different diseases, so that knowing the cause of the disease plays great role and helps for seeking a proper care and treatment. The following idea which was forwarded by a 51 years old priest of Orthodox Christianity during key-informant interview can further elaborate the above explanation:

I couldn't imagine epilepsy to be caused by anything else rather; it can be either the will of God or evil spirit. God can do whatever he wants to show his grace in the life of human. Let me ask you one question: do you think the people on the earth can adhere to God's words and believe in his existence if there is always peace? And if there is no disease and death, do you think man will be afraid of his creator God? You see how far God is wise! Therefore, he may sometimes punish people this way (by making them epileptic). The other thing is, what the father of darkness [in Amharic: 'ye cheleme abet'] is doing on some people. You can see many epileptic people who have been healed from their disease in our church by fasting and praying, and drinking holy water.

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

However, according to de Boer (1995), in the ancient Christian world, epilepsy was explained based on the Gospel of Mark (9: 14-29).

Thus, the increasing number of epileptics who were coming to Mizan Teferi town from the nearby towns/areas resulted in the wrong understanding among the community as if others may also be affected by the disease. Such beliefs make those people with epilepsy in the study areas to be isolated from the mainstream society and also at the extreme situation to be outcast by the non-epileptic.

5.4 The general public and their reaction towards people with epilepsy during active seizures

Non-epileptic respondents were asked how they would react when they see somebody who is suffering from active seizures. Consequently, most of the non-epileptics stated that they won't even try to help/treat the epileptic who is suffering from seizures; they may rather develop a kind of awkward feeling and will be afraid of after seeing the action; they further described that they would feel very embarrassing and stop contacting the person with epilepsy. One of the non-epileptic household heads (a female aged 50, she is a follower of Islam), in this regard, aired her views in the following terms:

oh, it will be threatening you to see the action; and you are not supposed to approach the person suffering from...; it is, indeed, the result of the evil spirit. We can do nothing against it; any attempt you make to help the person suffering from seizures, you may also become victim of the disease [epilepsy]. The epileptics are suffering for their own fate.

In the same vein, a key-informant who is a 51years old religious leader of Orthodox Christianity, had to say about helping the epileptic during active seizures in the following terms: *'epilepsy is caused by evil spirit; even if someone is suffering from active seizures the treatment is religious that it could be treated only by way of making prayers, sprinkling holy water, etc. No other means of treatment would help solving the problem'*.

Congruent to the above idea, a key-informant, who is a 58 years community elder, follower of Orthodox Christianity, further shared his views as follows: *'epilepsy is a contagious disease and anyone attempting to help the victim would be contracted with the problem; hence epileptics are to be outcast'*. Thereby, the knowledge gaps about epilepsy among the study community lead them to the mistreatment of epileptics. Thus, epileptics were subjected for banishment and discrimination by both family and the community. On this matter, a 26 years old, Orthodox Christian male with epilepsy who was one of the in-depth interviewees forwarded his experiences in the following terms: *'Biriyo [epilepsy in the local*

language] is a bad disease, it makes you lose everything; your family, friends and property. I have brothers and sisters, but none of them approach me due to this disease. Those people whom I had known earlier are now pretending as if they didn't know me'. In the same vein, another epileptic interviewee, a male 32 years, who is an Orthodox Christian follower, forwarded the bitter experiences that are faced by him from the surrounding community because of his problem- epilepsy in the following terms:

I have been suffering from the problem for the past few years. Before I got developed this problem, people (including family members and relatives) were quite friendly and behaving with me in a normal way; but once when they knew that I have this [epilepsy] problem, people including my own family members started avoiding me for no reason. Everybody looks at me in contempt; and there is a strong disapproval by the community towards me. I have no friends, relatives....; I have no one to talk/ to share my feelings. I am, for no reason, isolated by everybody.

The above explanations by the informants show, once someone is found epileptic, it is not only their old friends or others, even their own family members no longer treat the victim as before and the patients are subjected to disapproval and contempt; they are, indeed, isolated from the mainstream society because of the fear of getting contracted the disease from the epileptic patient and also the fear that by venturing to help the patient those onlookers/bystanders (non-epileptics) may start disliking or rejecting the person attempting to help the patient on the ground that s/he may become vulnerable to the condition- epilepsy.

5.5 The discriminatory attitudes of the general public towards people with epilepsy

People with epilepsy have been facing different forms of discriminations which can affect them than the disease itself. Some of the discriminatory attitudes of the non-epileptic respondents towards people with epilepsy are based on different grounds like getting them engaged in education, employment opportunities, marriage relations, living in the same family/community along with other members and participation in religious gatherings that are also noteworthy to be discussed.

5.6 Educational opportunities

Education plays a pivotal role in determining individuals' socio-economic positions in their society. Lack of educational opportunity of individuals while limiting their skill and knowledge, it transcends to affect individuals'

psychosocial and economic aspects. Against this backdrop, the non-epileptics were interrogated about the chances of epileptic children learning at the same school with non-epileptic children, as educational status of individuals is an important component of human capital. Concerning this, it was observed from the study sites that since epileptics were banished by the community, epileptic children were not having the chances to attend schools along with non-epileptic children. This was due to different reasons among which fear of stigma and economic problems were the major ones. Hereof, the non-epileptics were asked to provide their views on whether epileptic children should learn at the same school together with non-epileptic children. To that effect, almost all of the non-epileptic HHs reported that

children with epilepsy are not active and their learning capacity is very much limited; and hence there is no need to give them education. Even if they could go to school and study that will be futile; in the later stage neither they can perform well in the work place nor will anyone [non-epileptics] accept them [epileptic graduates] to any kind of employment activity.

Further, the household heads reported that the *'epileptic children should not be given opportunities to learn together with non-epileptic children at the same school rather they should be taught in a separate school'*.

Obviously, those respondents who thought of epileptic children to be taught from a separate school reason out their position that the disease will be transmitted to non-epileptic children if they sit and learn together. Therefore, due to this fact it was difficult for epileptic children to continue their education once they face even a single seizure. This was not only because of the disease itself, but also due to the stigma they faced at school because of their epileptic situation.

As a result, it was noted during data collection, the zonal administration in the study areas has taken different measures to intervene this problem by establishing schools outside the town where epileptic people were taken to resettle. In this instance a 33 years old male key-informant who is the head of zonal social affairs office asserted that

there were many epileptic children who were dropped out of school and live on the streets in this town. We have tried to resettle them in an outlying village [Khatin Me'enit] from the town. We have opened one elementary school in the village and currently about 40 epileptic students are on their learning activity. Besides, there are two non-epileptic and three epileptic teachers who are teaching in this school.

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

5.7 Employment opportunities

Epileptics, in general, are considered as mentally retarded in different communities; they can not compete for jobs with non-epileptic people as the non-epileptics are skeptical about the efficiency level of epileptics (Kaleyias et al., 2005; Sanjeev, Aparna, 2011); and the epileptics are viewed with fear, suspicion and misunderstanding, and were subject to enormous social stigma (Assefa, 2004); as a result, epileptics were treated as outcasts and punished in different forms like social exclusion and denial of job opportunities. As is the case with the study respondents' (non-epileptics) views on the employability skills of the epileptics; most of the respondents viewed that *'epileptics are not competent'* and *'they can't be employed'* like non-epileptic people. Some of the reasons forwarded by the respondents on this regard were epileptics are *'mentally weak'* people and hence they can not perform well; they will be hired to certain positions, but they can not effectively perform their duty; in a work place, if epileptics are hired, it will be difficult for coworkers and customers to work together because they will also be infected by the disease.

People with epilepsy not only have to cope with the complex demands of a chronic illness, but also have to deal with social stigma and prejudice in physical activities and job opportunities. One of the grounds on which disadvantaged segment of population discriminated is in their employment opportunity. In this regard, under the current study, respondents were asked if they would hire epileptics in to their business given that the epileptics have the skill or qualification for it. Thus, most non-epileptics/HHs accounted that they will not hire epileptics to their business even if s/he has necessary qualification for it; and some of the reasons mentioned by the respondents were summarized into – *'fear of stigma'* from the surrounding society and the idea that epilepsy is an *'infectious disease'*.

In both study sites, most of the non-epileptic respondents categorically informed that epileptic patients can't be employed for any kind of employment activities: *'as they can't execute the work; they are running with a kind of problem that is caused by evil spirit; by engaging them [epileptics] in to your business you may also be infected with the problem'*. Furthermore, the non-epileptic respondents were agreeing that *'if an epileptic patient is engaged into your business, no body from the community will turn up towards you; rather people [other non-epileptics] will develop a kind of hatred that will eventually lead to exclude or avoid you from the community'*. In the same vein, the following idea forwarded by a 33 years old key-informant, who is the head of

zonal social affairs office, can well supplement the above finding regarding job discrimination against epileptics in the study areas: *'personally, I believe that epilepsy is not a transmittable disease and I have no problem to hire epileptics to my business but you know that you are not in an island, you are living in the community and your customers are people of the town. So, who will come to your business? Who will use your services?'* The above quote well articulates even if some people are willing to accept or to hire epileptics to their business, fear of stigma and discrimination that they may face from the community make them to be unwilling to hire epileptics to their business. The findings of the study go hand in hand with Gedefa, Wolde, Solomon, (2012) and Sanjeev, Aparna (2011) that it reveals epileptics are also discriminated in the job market by the non-epileptics.

5.8 Marriage relations

Additionally, it was observed that one of the other problems epileptics encounter in the study areas is finding marriage partners. Finding a marriage partner among non-epileptics is not an easy task for those epileptics since epilepsy has been considered by the general public as an infectious/transgenerational disease. In this context an attempt was made to know the non-epileptic respondents' views on having marital relations with epileptics in line with their religious affiliation as religion plays a major role among the people in shaping up their attitudes/beliefs. Accordingly, almost all respondents, irrespective of their religious affiliation, reported that they will never make an epileptic their marriage partner.

There were different reasons cited by respondents who were against the idea of marrying epileptics. One of the reasons mentioned by the respondents was their fear that the disease will be transmitted to them. The other reason discussed by the respondents was the assumption that *'epilepsy is a trans-generational disease'* so that their children could inherit the disease from the affected parent. Concerning this one of the in-depth interviewees who is a 38 years old epileptic divorcee, believes in Orthodox Christianity, explained in the following terms: *'Emm, Yeah! Just I have two daughters from my former husband and they have never got married; people in my community knew that my partner banned me out of my home due to my disease – epilepsy. And all people in the community consider that if they marry my daughter they may give birth to infected children'*. Furthermore, the non-epileptic respondents indicated that fear of stigma and discrimination that they may face if married to an epileptic. Even if a non-epileptic personally believes that s/he can marry epileptics, because of the fear that the stigma and discrimination attached to it that they may face by the surrounding community pulls them back from accepting an epileptic as their marriage partner. Not only epileptics, but also people approaching them will also be a subject of different

forms of stigma and discrimination like social isolation. In this regard a male epileptic who is 24 years old, believes in Orthodox Christianity, expressed his views during an in-depth interview in the following terms: *'Look! This man is a non-epileptic but married with epileptic woman; for this reason, he has been banned and isolated from his family; now, he is living with us on the street'*.

5.9 Living with epileptics

Even though epilepsy is a transmittable disease perceived by the study respondents, some non-epileptic respondents in both study sites reported that when someone in the family is found epileptic, s/he can be allowed to live in the same family. It has to be noted that a sense of feeling of immorality behind banishing one's family member really prevents them to send off the affected person out of the home. This idea was further explained by one of the key-informants, a 45 years old Islamic religious leader in the following words: *'Of course, this disease [epilepsy] can be transmitted from one person to the other; but how could you let your beloved ones- son/ daughter to go away from the family? It's not our culture. It is unacceptable. It's better if we die together. Rather you can prepare special room for them in the house'*. The above quote tells us that although the respondents believe that epilepsy is a transmittable disease, due to their cultural/religious values they consider banishing or casting the epileptics out of the house is an unacceptable behavior.

On the other hand, most of the non-epileptic household heads informed that the epileptics must leave the home as soon as possible the moment they are found to be affected by epilepsy in order to *'avoid further transmission of the disease to other family members'*. This has been fortified by data gathered from a 58 years old key-informant, who is a community elder, in the following terms: *'Let me tell you what our father/forefathers used to say, if one of your fingers got sick and you realize that it can't be cured, you should cut it down before the disease affects other fingers'*. Therefore, as it is indicated in the above data from the horse's mouth, for the respondents who were skeptical towards the idea of living with epileptics, fearing of the transmission of the disease was the main reason to abandon the patients.

5.10 Religious participation

The other form of social relationship in which people come together, share their ideas and strengthen their togetherness is in a religious/worshipping place. In this case, regarding epileptics' opportunity of participation at religious place was discussed by non-epileptics. Thus, most of the non-epileptic respondents reported that they would accede the participation of epileptics at the same religious place together with non-epileptic people. This idea, even though,

contradicts with the findings which are revealed under marriage relations and school learning, whereby many respondents took the position of social exclusion of epileptics on different circumstances; but on the ground of religious faith the non-epileptics in the study areas admit epileptics into the holy places. Different reasons were cited by the non-epileptic respondents for accepting the participation of epileptics at religious places together with non-epileptic people. On the one hand, though the non-epileptics believe that epilepsy is a transmittable disease, they trust that God will keep them safe and on the other hand due to the fear of God, they would not prohibit epileptics from coming to churches/mosques. Hence, some of the obvious reasons repeatedly explained by the study respondents were epilepsy as infectious.

6. Conclusions

This study aimed at analyzing knowledge and beliefs of non-epileptics towards epilepsy and the discriminations of the epileptic patients; to this end, a qualitative research approach was employed to gather data on the issue at hand. Study samples include epileptic persons and non-epileptic household-heads who are purposively selected from two *kebeles* (Addis Ketema and Kometa) of Mizan Teferi town of Bench Maji zone.

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

The traditional, deep rooted belief of the people regarding the nature, cause, mode of transmission and curability of the disease has been at dissonance with the scientific facts about the disease and still continue to enjoy widespread acceptance among the people of the study areas, even including the epileptics themselves whereby they internalized the shameful tag attached to them due to their epileptic situation. Such beliefs have put an aura of supernatural uniqueness to the disease locating its origins in the works of evil spirits. The disease has been understood by people of the study areas as one which has less scientific remedy, and thus the only solution to the disease has been to do away with the patient.

The practice of quarantining the epileptic patient has been shrouded in antiquity: it has been in practice for time immemorial. The method of

quarantine has been until recently to put the patient in complete isolation at a faraway location from the home and neighborhood and let him live there until he dies, out of lack of care and support and the workings of nature (cold, rain, heat, wild animals, etc.). There was no preferential treatment offered to the patients irrespective of age, sex, and socio-economic status or otherwise.

To wind up, the findings of this study unveils lack of knowledge and awareness about the nature, cause and modes of treatments of epilepsy were the major reasons for the unfavorable attitude of the non-epileptic surrounding community towards epileptic patients. This in turn result in the stigma and discrimination of epileptics like social exclusion, lack of access to basic social services including educational services, health care services, lack of access to clean and burial sites for died epileptics.

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