PERCEPTIONS OF EPILEPSY AMONG ETHIOPIAN IMMIGRANTS IN THE NETHERLANDS

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THESIS
AMSTERDAM MASTER’S IN MEDICAL ANTHROPOLOGY
UNIVERSITY OF AMSTERDAM
THE NETHERLANDS
2003-2004
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ACKNOWLEDGEMENT

First of all I want to thank Dr Ria Reis for her supervision and critical support during the fieldwork and the writing of the thesis. Dr Reis also kindly arranged relevant literatures related to epilepsy studies conducted here in the Netherlands, in Africa and other third world cultures. I have also made capital out of the comments offered by my fellow students in the Amsterdam Master’s in Medical Anthropology. I am also grateful to Mr. Mulageta Asmelash, manager of ‘Dir net’ who facilitated my research and fieldwork. The aim of Mr. Mulugeta’s organisation is to better integrate Ethiopian immigrants living in the Netherlands with Dutch culture and also to facilitate the return of Ethiopians who wish to go back to their country. He facilitated the selection of the respondents according to the research standard. I am indebted to all my respondents for giving me their time and for their enthusiastic co-operation. They made me enjoy my fieldwork in the Netherlands by sharing their life and experience in Dutch culture. I wish and look forward to continue research on individuals with active epilepsy on socio-cultural dimensions of this illness in rural and urban environments of Ethiopia and if possible among Ethiopian immigrants living with epilepsy in the Netherlands.

I want to thank My Ethiopian government who provided the fund. Through government’s effort it was made possible to attend the Amsterdam Mater’s in Medical Anthropology and to carry out the research on which this thesis is based.

Amsterdam August 2004
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1. Introduction

The term epilepsy is derived from the Greek word “Epilepsia” which means a condition of being overcome, seized or attacked. From the biomedical standpoint epilepsy is not a disease, but rather a symptom of a neurological disorder. From time to time seizures occur and produce sudden and brief loss of consciousness. The pattern of movement during an epileptic seizure catches the attention of other individuals in his surrounding. Loss of self-control is dramatic and leaves its impression at the back of people’s minds, especially when onlookers do not understand the seizures simply as manifestations of a neurological disorder. Having epilepsy, or more accurately, suffering from seizures therefore often negatively influences a person’s social status. This kind of illness if not treated, interferes with one’s own daily activities and makes it difficult to lead a conventional life.

In developing countries having epilepsy is usually more problematic than in the developed world. In the first place appropriate services might be lacking, and in the second place there might be more problems associated with social stigma. In order to reduce these problems, a multi-sectoral collaboration of stakeholders and their joint efforts in the prevention of illness and provision of appropriate health care and rehabilitative care is needed, so that patients may live well with epilepsy in everyday life. With teamwork of stakeholders the quality of life for persons living with epilepsy might be improved and public awareness might be raised to a new level. However, the question is, for perceptions of epilepsy to change, is it enough to live in a technologically and economically advanced society, and to have access to high quality care and information sources? By studying immigrants in western cultures, like Ethiopian immigrants in the Netherlands, we might learn about processes of change in perception of causes of illness, and of appropriate medical and social treatment.
Therefore, the aim of this study was to explore the perceptions of epilepsy among Ethiopian immigrants living in the Netherlands and to examine the effect of epilepsy on social relationships for individuals having the disorder and how these social relationships shape the meaning attached to epilepsy. It was also intended to investigate to what extent perceptions and the social acceptance of epilepsy among Ethiopian immigrants change due to their life in the Netherlands.

1.1 Background information

From different literature reviewed, the magnitude of epilepsy as a public health problem is increasingly identified and it is also considered a more common and prevalent health care problem in developing countries than in developed countries. Although descriptions of epilepsy have reached us from antiquity, it is a relatively new focus for research in different parts of the world in international health. Great attention is nowadays given to those conditions that bring a significant burden to patients and families, and as the most common chronic neurological condition worldwide, epilepsy is now recognised as deserving our co-ordinated efforts (Kleinman, et al. 1995).

A study conducted in Kenya showed a prevalence of epilepsy of 10.2 per thousand in a rural district area and 18.2 per thousands in a semi-urban area. The prevalence of active epilepsy in a rural community in Tanzania ranged from 5.1 to 37 per thousand. The average prevalence of epilepsy in this case, Tanzania, is 10.2 per thousand. On the other hand when we observe the prevalence rate of epilepsy in developed countries like those in Western Europe the prevalence rates ranged between three and eight per thousand (Dekker, 1998). Conditions related to peri-natal problems and high rates of injury and infections are considered among the causes for the higher prevalence of epilepsy in developing countries.

In a community-based study conducted by (Tekle-Haimanot, et al. 1990) in a rural population of 60,000 in central Ethiopia between 1986 and 1988, epilepsy was the most common cause of neurological disability with a prevalence of 5.2 per thousand. Another study conducted in the northwestern part of rural Ethiopia for primary care treatment of epilepsy showed that 87% of the diagnosed patients had not previously been treated with anti epileptic drugs. The majority (86%) had previously
were also discussed in this study. Economic factors accounted for a very little proportion of those who had not been treated with anti epileptic drugs. Inability to pay for medication accounted for only 4% of the total cases seen in the five health centres in the research area. More than 90% of the untreated patients were unaware of existence of medical treatment (Berhanu, et al. 2002). In our country, the treatment gap\(^1\), that is the difference between the number of people with epilepsy and the number of people with epilepsy who receive adequate treatment, sharply contrasts with that of developed world.

From studies conducted and results revealed above in the Ethiopian context, one can assume that a lack of awareness and lack of appropriate health care facilities form the stumbling block for early detection and treatment of the disorder. The study of (Berhanu, et al. 2002) conducted in five clinics was primarily moved by the aim of establishing a treatment program for epilepsy at the primary care level. The study clearly demonstrated how with only a few additional resources the existing health care infrastructure could be strengthened to succeed in giving better care for people living with chronic non-communicable illness. The existing health infrastructures thus form a window of opportunity and hope to alleviate the suffering of people with this kind of illness. However, accessible, affordable and high quality of care is not enough to change the situation of Ethiopian people with epilepsy. People must be made aware of epilepsy as a neurological disorder that can be successfully treated with modern medication. Little is known about present day perceptions of epilepsy in Ethiopia. Studying perceptions of Ethiopian immigrants in the Netherlands might shed some light on the traditional beliefs in shaping the experience of people with epilepsy, as well as on processes of change in these beliefs.

Like any other developed countries the magnitude of epilepsy in the Netherlands remains low with a prevalence rate of five to seven per thousand people at risk for having the disorder (Meinardi et al. 1999). This figure includes all forms of epilepsy. The way to a health care facility for people with this kind of illness is clearly shown as follows.

In The Netherlands a person who experiences a seizure will usually first consult his/her general physician, who will either treat the patient or send him/her to a neurologist, paediatrician, or child neurologist in a general hospital. When the diagnosis is problematic, or when the problems are more complex, general
physicians and medical specialists may refer patients to one of the three specialised
epilepsy centres in the country. These centres, and their network of out patient
clinics, provide patients with both medical and psychosocial care.

(Reis, 2001:357)

In theory these services are also available for Ethiopian immigrants in the
Netherlands, but the question may be raised to what extent immigrants know of these
services? Does the availability of good services indeed lead to greater awareness of
epilepsy as a neurological disorder? And does such awareness indeed lead to a greater
awareness of treatment options? Studies conducted among immigrants living in the
Netherlands might reflect the general trend in health and life situation of Ethiopian
immigrants.

Migration brings changes in lives of the migrants. Passing through a migratory
phase needs enormous psychological and social network adaptation. Some medical
anthropologists even speak of a ‘liminal state’ (Van Bekkum, 1996) in regard to
labour migrants and of ‘exile’ in regard to refugees. A study done by (Limburk
Okken, 1989) among Moroccan and Turkish migrants in the Netherlands reveals that
lack of housing, labour, juridical insecurity, role change, being homesick, racism and
disillusions, sexual and affective isolation have negative effects on the health of the
migrant. A study conducted by (Balla, 1995) on refugees, shows an accumulation of
stressful changes: traumatic experiences and often irreparable loss of basic securities,
loss of social network and familiar environment, adaptation to a new set up,
existential insecurity due to long asylum procedures and the threat of deportation.

On the other hand migration offers opportunities for personal lives and the
advantage of life in two different cultures. (Boedjarath & Van Bekkum, 1997)
emphasise the importance of having a delicate balance between loss and enrichment
for migrants.

Like any country in the world The Netherlands is composed of different
cultures and ethnic groups. In addition to these variations, The Netherlands
accommodates migrants from different parts of the world. “The four main groups are
Moroccan, Turkish, Surinamese and Antillean migrants and including 950,000
persons” (1 January1999, RVZ 2000, p.102)². The number of Ethiopian immigrants
living in The Netherlands is about ten thousand (Central Bureau voor de Statistiek,
2004). Out of this figure, one thousand individuals live in the capital city of The Netherlands, namely Amsterdam.

Differences in culture will be expressed when members of a particular culture start to interact with health professionals for seeking health services and treatment of their illness. From the point of view of the Dutch it is generally believed that migrants have unique ways of dealing with health and illness. Since migrants have another culture than that of their host country, it is sound to expect this kind of public response. In addition to this kind of belief, "migrants are often defined either as risk groups or problem groups or are considered as problem patients." (Van Dijk & Van Dongen, 200:47).

In medical anthropological studies, a lot of attention is paid to traditional illness explanations. These kinds of studies in the Netherlands have resulted in the description of *winti* in the case of Surinam people, *brua* in Antillean people, the evil eye, magic and *jinns* in the case of Moroccan, Turkish and Somali immigrants, and *yin* and *yan* in Chinese and Vietnamese populations. These studies reached the conclusion that:

Migrants in the Netherlands generally have three explanations for illness: natural causes of illness can be found in the disturbance of the balance in the body, the warm-cold distinction being the best known. Another explanation is that of human agency: the evil eye, black magic or curses. A third explanation is that there are supernatural causes of the illness: demons, *jinns*, ancestor spirits or punishment from the Gods. (van Dijk & van Dongen, 2000:59)

Ethiopian immigrants in the Netherlands are also not unique to the rest of immigrants. It is expected that they will share some of the above three explanations of illness. A study conducted by (Rob van Dijk, 2000) showed the most important problems that occur in the Dutch health care service for migrants. Ethiopian immigrants are also part of the migrant situation and it would be wise to expect and face these problems. He showed that strangeness of immigrants’ behaviour, the existing language barriers and cultural difference was misinterpreted in terms of western culture and the service delivered to them insufficient. He also demonstrated that cultural differences have not reached to last end of cause and effect chain to make sound interpretation. It is just at its beginning (Rob van Dijk, 1998).
1.2 Problem statement

This research aims to explore and describe perceptions of epilepsy among Ethiopian immigrants living in The Netherlands. To my knowledge, until now no research had been done among Ethiopian immigrants on this particular issue. On the other hand, some studies have been done on the perceptions of and attitudes to epilepsy in Ethiopia itself. These Ethiopian immigrants are now encountered with a new culture, western culture, which is significantly different from their original culture in their homeland.

Studies conducted in two different parts of Ethiopia showed that the psychological and social trauma of having epilepsy is enormous and impose hardship. For example the study conducted in the north-western part of the country showed that twenty four percent of the cases with the condition reported stigmatisation, thirty one percent of those eligible for marriage attributed their failure to arrange for a partner to their epilepsy. Problems with education, for example a parent’s unwillingness to send the child to school, were reported in seventeen percent of the cases. Problems with employment were reported by nine percent of the cases in adults. Nine percent of the cases had suffered serious physical injuries as a result of seizures and ten percent had suffered from burns. The study also showed that eighty six percent of those attending modern health care had previously received traditional treatment. Traditional treatment usually consists of treatment with Holy water and amulets. Only thirteen percent of the cases found in this study were treated with anti epileptic drugs (Berhanu, et al. 2002). The situation concerning epilepsy in Ethiopia is not unique; other reports from Africa show similar tendencies. For instance, a similar study was conducted in Tanzania showing the knowledge attitudes and practices among rural Tanzanian residents (Jilek-Aall, 1970). The study showed that negative sociocultural situations like ostracization, rejection, and isolation from the community result from beliefs such as witchcraft, possession by the devil, and contagiousness as causes of epilepsy.

Ethiopian immigrants living in the Netherlands have full access to health care and sources of information as long as they fulfil the rules and regulations of the health care system. It can be assumed that they will have some language and cultural barriers. My study starts from the assumption that there is a probability of change in
hypothesised that a fusion of ideas and culture may take place and that the awareness of and ideas about epilepsy may be changed. With my study I hope to shed some light on this process.

**Problem analysis diagram for immigrant’s perceptions on epilepsy**
1.3 Literature review

1.3.1 Epilepsy from the medical perspective

The medical domain is the dominant authority on epilepsy. It is also the
mainstay about what illness is and what the important questions are to ask about it.
When we compare medical science with the sociological perspective biomedicine is a
practical enterprise. In other words knowledge is gathered to be able to intervene. The
word epilepsy in medical science is not often used. Rather the word seizure disorder
or convulsive disorder is popular in the medical discourse. “An epileptic seizure is the
product of an abnormal paroxysmal discharge of cerebral neurons, and epilepsy itself
is sometimes defined as a continuing tendency to epileptic seizures” (Scambler
1989:1). A standard medical textbook defines epilepsy in the following terms: “A
convulsive disorder is the expression of a sudden, excessive, disorderly discharge of
neurons in either a structurally normal or diseased cortex. The discharge results in an
almost instantaneous disturbance of sensation, loose of consciousness, convulsive
movement, or some combination thereof” (Harrison, 1980:131). (Schneider and
Conrad, 1983) describe the existence of two related medical categorizations available
for epilepsy with some difference in terminology. The previously official and well-
known categorization discerns grand mal epilepsy, petit mal epilepsy, focal seizure
patterns (i.e. psychomotor seizures), and localized motor seizures, Jacksonian
epilepsy, focal motor epilepsy, and controversive. Both standard medical textbooks
and people with epilepsy utilize this kind of classification. In recent decades a new
classification is gaining popularity including and exceeding the older classification.
(Gastaut, 1970) and (Merlis, 1970) have proposed a differentiation between a
classification of “epileptic seizures” and of “epilepsies,” respectively, which has
received widespread attention and official endorsement. The major classifications can
be mentioned as follows. “Generalized seizures or epilepsies”, “partial seizures or
epilepsies” and “unclassifiable.”

These complex categories are based, among others, upon criteria related to the
internal processes that give rise to seizures and the phenomenology of these seizures.
The partial epilepsies include all those conditions that involve only one segment of
the brain and the corresponding overt movements. Typical movements in the partial
epilepsies are localized muscle contractions, problems in speaking, tactile stimulation in different parts of the body, distorted sight and impaired consciousness, auditory hallucinations, and sometimes repetitious movement of the mouth, arms, hands, and legs. In generalized epilepsy on the other hand the entire body is affected. Its two major types according to the older classifications are grand mal and petit mal – translated as “little” and “great” sickness.

However, there is a growing dissatisfaction with the classic grand mal and petit mal labels in the medical context, since they are increasingly considered as misleading and stigmatizing. For this reason the new classification places these terms in parenthesis after the preferred “Absence” and “tonic-clonic.” The term absence reveals the physical and intellectual absence of someone from the immediate social environment. It is the affective appearance of someone who is temporarily away. The person remains in a dreamy state. Such behaviors are usually brief in duration lasting a few seconds to a minute. Absence seizures involve symptoms such as a stare, preoccupied glance, rhythmic blinking, muscle jerking, and sometimes automatic movements such as lip smacking, chewing and picking at clothes or body. On the other side tonic-clonic seizures are considerably more dramatic and visible. The person looses consciousness and falls to the floor in sometimes-violent convulsive movements that involve involuntary salivation, gnashing of teeth, and incontinence. These kinds of seizures last longer than absence seizures and usually followed by a period of deep sleep.

Of those diagnosed by doctors, tonic-clonic seizures account for about 50% of the cases. It is the single most common type followed by psychomotor seizure that accounts for 25% of the cases and other forms of minor epilepsy only including psychomotor, 20% (Commission Report, 1978, Vol.I: 21-22). Another 3-8% of adults with epilepsy suffer an event called “status epilepticus” (The Commission Report, 1978, Vol. II. Pt I: 163). In this event the person with epilepsy develops one seizure after another in rapid succession. It is presently considered to be a medical emergency, which can lead to disability and even to death.

The causes of epilepsy are often not fully understood. The causes of epilepsy are as complex as their manifestations. Genetic factors are nowadays considered important even though it was less than assumed a generation ago.
Depending on the etiology for epilepsy we can label it as idiopathic or acquired. When it is not possible to identify a cause we call it idiopathic. When we are in a position to attribute the cause then we call it acquired or symptomatic. (Schneider and Conrad, 1983) mentioned that the major known causes of epilepsy are peri-natal factors, infection (especially in early childhood), and trauma (head injury, especially from automobile accidents). There is some evidence that laws mandating seat belts, safety helmets for motorcyclists, and enforcement of 55mph speed limits have measurably reduced the incidence of epilepsy (Commission Report, 1978, vol. IV: 170-175). One study only could identify epilepsy's cause in 23.6 percent of the cases, leaving the majority with unknown origins (Hauser and Kurland, 1975).

Depending on the site of abnormal neuronal discharge in the brain epilepsy takes different forms. If the abnormal discharge remains in one part of the brain it is called partial seizure or petit mal. But if the abnormal discharge starts from one part of the brain and subsequently spreads to involve all parts of the brain through the involvement of mesodiencephalic system the seizure is said to be a partial seizure with secondary generalization. The abnormal discharge originating from the mesodiencephalic system and spreading to all parts of the brain simultaneously or generalized from the start it is described as a primary generalized seizure or grand mal. Epilepsy recurs and produces a sudden and brief disturbance in electrical function of the brain. The usual and most common course of grand mal and petit mal epilepsy is clearly described by an inspiring author as follows:

As the discharge is generalized the person is struck unconscious and falls rigidly to the ground. This is the tonic phase, characterized by powerful muscular contraction; air is forced from the chest through the larynx, sometimes resulting in a 'cry', and the teeth are clenched. No respiratory movements occur and the person rapidly becomes cyanosed. The tonic phase lasts for about half a minute and is followed by the clonic phase, consisting of violent convulsive movements of the limbs, which gradually occur, in decreasing frequency. The lips and tongue may be bitten. The combination of relaxed sphincter and the contraction of abdominal musculature may cause incontinence of urine and, less often, faeces. The tonic phase lasts for, on the average, 2-3 minutes, and is followed by a complete relaxation of the muscles; the person lies still, normal ventilation returning. The period of unconsciousness generally lasts for a few minutes. On recovering consciousness the person is likely to be confused, usually for 20 minutes to an hour, and may complain of headaches, nausea or drowsiness.
With petit mal seizures, which are largely seizures of childhood, all the cortical neurons are affected more or less simultaneously. Petit mal consists of brief interruption of consciousness: sudden arrest of movement and speech occurs and the person may appear pale her or his eyelids may flutter. The person doesn’t fall down and is frequently unaware that any thing has happened; to an observer he or she may seem dazed or to be daydreaming. The seizures are short lived, lasting only a few seconds, and recovery is immediate; there are no sequelae. Whereas a person would be unfortunate to have more than one grand mal seizure in a day, petit mal seizures may occur much more frequently, ten to fifty times a day being encountered. (Scambler, G 1989:3)

Some people with epilepsy experience a sensation called an aura or warning before a seizure starts. The warning may occur far in advance to give time to lie down and prevent injury from falling. The type of aura experience differs from person to person. Some people feel a change in body temperature. Others feel a sense of anxiety or tension. Still in some cases aura manifests itself as a musical sound, a strange taste or a marked odor. The precise description of an aura assists the doctor in localizing the region of the brain where the initial electrical discharge originates.

From the medical perspective the epidemiology of epilepsy is an important area that deserves mentioning. Epidemiology in general can be defined as the study of frequency, distribution and determinants of disease in human population. It is an important method to identify potential causal factors and to measure the burden of the disease. However, since epilepsy is often stigmatized and kept hidden it is very difficult to collect accurate data. All available figures are estimates. “The Epilepsy Commission Report used the following figures as minimums. The estimated incidence of epilepsy in the United States is 46.7% per thousand or 100,000 new cases each year” (Schneider and Conrad, 1983:50). The above-mentioned authors also showed that epilepsy can occur at any age but it is most common below the age of twenty.

Most adults who develop epilepsy will remain with it through out their life. On the other hand children with epilepsy show different patterns of remission. Some study showed that about 40% of children studied experienced remission for about four years (Sofijanov, 1982). Another inspiring study showed even higher significant remission rate by concluding that children who are free from additional risk factors, “have an excellent chance of remaining seizure-free after the withdrawal of convulsant drugs” (Thurston, et al. 1982).
In the medical treatment of epilepsy, control is usually common while cure is a very rare situation. The Commission Report (1978, Vol. II, Pt. 1:491) concludes: “About half of the epileptic population will achieve complete seizure control, and an additional 35% can achieve good seizure control (three or four seizures a year).” Generally speaking 85% of people living with epilepsy show a significant reduction in the number of seizures experienced by using anti convulsant medications. More than forty years ago (Lennox and Lennox, 1960:34) already claimed, “The emancipation of epileptics by the physician began some three hundred years ago and has proceeded with progressively increasing success.” But this “emancipation” of people with epilepsy is far from complete.
1.3.2 Epilepsy from the historical perspective

Epilepsy is a chronic illness that affects the everyday life of those suffering from it. The historical dimension of this chronic illness is rather unique. Throughout history epilepsy was and is plagued by misinformation and misconception. During antiquity the person with epilepsy himself was seen as unclean. If some one touched a person with this kind of illness common belief assumed that you might catch the disease.

Among the Romans, to escape this kind of unclean infection people devised a strategy. To avoid such an infection, he or she would spit. The idea behind it was that spitting would throw the contagion back. However, if a person with epilepsy was suspected to have contaminated his family it could happen that he might be isolated and sent away. If individuals were suspected to contaminate others, nobody would be willing to eat from the same dish or drink from the same cup, as such epilepsy was considered a kind of contagious disease. This by itself made the life of those people with epilepsy miserable and the disease disgraceful. Another interpretation also caused stigmatization, by its interpretation of epilepsy as a sign of sin. It was believed as an infliction on the person who has sinned against the moon. The repulsive sight of the attack also contributed to the feeling of isolation.

Epilepsy was one of the conditions treated as a sacred disease, as can be seen from the prominent work of one of the earliest authors on epilepsy as a medical as well as social problem.

Diseases can be considered as acts or invasion by gods, demons, or evil spirits, and treated by invocation by supposedly supernatural powers. Or they are considered the effects of natural causes and treated by natural means. The struggle between magic and the scientific conception, the latter has gradually emerged victorious in the western world. The fight has been long and eventful, and in it epilepsy held one of the key positions. Showing both physical and psychic symptoms, epilepsy more than any other diseases was open to interpretation both as physiological process and the effects of spiritual influences. And where as purely mental afflictions such as neuroses and certain maniac and melancholic reactions, often were, and even are, not recognized as pathological, epilepsy, on the other hand, was always considered a disease. (Temkin, 1971:3)
(Temkin, 1971) also described an important monograph written about 400 years B.C by an unknown physician which directed an attack against popular superstitions and magicians who termed the disease “sacred.” This writer considered the alleged divine character of the disorder a shelter for ignorance and fraudulent practices. He opposed the irrational assumption of these fundamentally irreligious people who claimed that God would cause epilepsy.

Physicians of that time argued that epilepsy is not more divine than other diseases were, and like all diseases it was hereditary; its cause lies in the brain, a brain overflowing with superfluous phlegm. When the phlegm rushed into the blood vessels of the body it caused all symptoms of the attack. The releasing factors of the attack were thought of as cold, sun and winds, which changed the consistency of the brain. The author said that diet and drugs could treat epilepsy as long as it had not yet become chronic and firmly resisted treatment of epilepsy through magic. Finally, the author reaches the fundamental conclusion that the seat of the disease was in the brain. We may assume that this kind of revolutionary approach about root causes of the epileptic attack had a positive consequence for the better acceptance of the illness.

As mentioned before, during antiquity, a person with epilepsy was considered rather an object of horror and disgust than a saint or prophet. With time, the pattern started to change the other way round. The debate on possession also had a great impact on the way people look upon a person with seizures. In Christianity, epilepsy has always had strong connotations because of their discourse on the avoidance and combat of evil powers. Discourses such as the following can reinforce this kind of magicoreligious context.

Few people in the time of the renaissance doubted the existence of a personal power of evil. Catholics, Protestants, and Jews alike dreaded it and tried to evade and to combat it. Physicians and laymen recognized it as the opponent of God, yet driving its power from God and exercising it by its permission to fulfill His ends. This power of darkness is Satan, the Devil and usually has believed to be helped in his sinister purpose by the whole host of Devils or evil demons. Very conflicting views are held, however, regarding the sphere of influence granted to the Devil, to the ways in which he might attack mankind, and the means by which he might be defeated. Thus, a discussion arose whether Devil and Demons could really act as a physical force or whether there influence was restricted to the mind of man, whether they could act through the medium of sorcerers and witches, whether they were able to reveal the future, and whether they should be repelled by exorcisms and charms or by the strength of the pure faith. (Temkin, 1971:139)
Again Temkin mentions that epilepsy is so unique and strange a phenomenon that some super human agency was frequently assumed. Among this witchcraft is one of them. Even some theologians and physicians, also believed that epilepsy might be caused by witchcraft. One physician of the time said that demons caused epilepsy, paralysis and other maladies by a stoppage of the heavier physical fluids, obstructing and blocking the ventricle of the brain and the nerve roots. Since some convulsive movements are counted as the characteristic symptoms of sickness brought on by witchcraft, and because possession resembled epilepsy for them it is necessary to acknowledge the differences between natural disease and supernatural afflictions.
1.3.3 Epilepsy from the sociological perspective

Like the medical perspective, the sociological perspective is also an outsider’s perspective. For both perspectives, important questions include those of etiology and effective treatment. But from a social science perspective, answers to such questions are not sufficient to tell the whole illness story. As already mentioned above medicine is a practical enterprise while sociology focuses on the description and analysis of patterned aspects of social life and illness experience. On this aspect the two outsiders’ perspectives differ significantly. In this sense sociology is closer to “basic” science while medicine is more “applied.”

Epilepsy is a chronic illness. When we talk about illness first of all it is good to make clear distinctions between the illness and the disease. ‘While illness and disease are related they are not the same. Disease is best understood as an undesirable physiological process or state. Illness, in contrast, has less to do with problems of body per se than with the social and psychological phenomena that accompany these putative physiological problems (Feinstein, 1967; Freidson, 1970).

Illness can be understood as a social phenomenon that may or may not rest on disease as foundation. Illness is seen as a social phenomenon that emphasizes the common experiences, activities, feelings, insights, relationships and problems that surrounded sickness in social life (Schneider and Conrad, 1983).

The “sociological perspective” on illness includes four main areas of study. The first examines different “social factors” like occupation, gender and life stress assumed to be causally related to disease. The second concentrates on the definition of illness as a “sick role” or on patient behavior. The third focuses on a detailed study of how conceptions of illness vary across different cultures. The fourth part of the sociology of illness examines how and under what circumstances people perceive symptoms and seek medical care (Estes and Gerard, 1979; Litman, 1976; Kendall and Reader, 1979). Studies of epilepsy have been clearly focused on the third and fourth sociological perspective of illness. For this study of epilepsy among Ethiopian immigrants the third sociological perspective on how illness is perceived and conceptions vary cross-culturally might have important implication on the study of epilepsy among Ethiopian immigrants. The other remaining sociological perspectives have no immediate and direct relationship to this particular study.
Schneider and Conrad were the first sociologists to focus upon epilepsy as an illness rather than a disease. They started their monographs by challenging some of the popular myths and misconceptions about epilepsy. First of all they reiterated that epilepsy is not a disease, but it is rather a symptom of brain disorder. It is a chronic illness affecting the full range of activities of the individual. It affects different ages, races, both sexes and social classes. In general it transcends all the demographic variables.

Schneider and Conrad challenged three popular myths. The first myth they challenged was the idea that epilepsy is an inherited disease. Even though epilepsy has a long history for being hereditary we now know that heredity plays a much lesser role. “The statistics of the time suggested inheritance in about 30%” (Temkin, 1971:348) a high figure for any disorder. Nowadays it is generally agreed that “inheritance plays a very minor role in epilepsy despite the widely held misconception that epilepsy is inherited.” (The Commission Report on epilepsy in Schneider and Conrad, 1983:32).

The myth that epilepsy is hereditary has contributed to a number of social policies resulting in restrictive laws and regulations. These laws are applied in different parts of the world like the United States of America and Sweden. In Sweden the law has prohibited people with epilepsy from marrying for about one hundred and fifty years. Different American states passed a law, which prohibits marriage i.e. “eugenic marriage” and “eugenic sterilization”. The other form of restricting marriage was to institutionalize people with epilepsy and thereby preventing reproducing. Before 1965, Immigration laws in the United States of America restricted people with epilepsy. This kind of law has distorted the public image of epilepsy and advanced negative social responses. They showed people with epilepsy as biologically incapable and thus as not to be relied upon for relationships, bearing offspring and earning a living. In relation to this kind of thought it is good to mention the following assumption.

The assumption that epilepsy is a hereditary illness, particularly when the evidence was inconclusive or limited—which is to say most of the time-led to a variety of official discriminatory policies. More over it took an uncountable toll on the everyday relationship and self-concepts of people with epilepsy. (Schneider & Conrad, 1983:33)
The second myth, which is described by (Schneider and Conrad, 1983), is the idea that epilepsy creates psychopathology and leads to mental illness, since there is an intimate relation between brain and personality, self and intelligence. The myth has led to the belief that people with the condition are subnormal and that they would have a peculiar and unpleasant epileptic personality. In the late nineteen century mental deterioration in people with epilepsy was widely accepted as an outcome of repeated seizure attacks. In mild degrees it resulted in deterioration or defective memory while in sever degrees it resulted in greater imperfection of intellectual power and marked decrease in for attention and defective moral control.

All studies before the 1950’s tried to put epilepsy as coinciding with subnormal intelligence but after that, studies were published that refuted these earlier research results and argued that people with epilepsy have never differed significantly from the general population. Generally speaking the assumption that epilepsy itself causes psychopathology remains widespread and in itself yields negative consequences. It stigmatizes people with epilepsy by linking them to mental illness, and it becomes especially damaging when such association is institutionalized in official documents.

The third myth in relation to epilepsy is its association to cause aggression and crime. This kind of idea has been dominant especially in criminological circles and popular literature for a long period of time (Schneider and Conrad, 1983). One possible source for this causal association is the unpredictable and violent movements and loss of control exhibited during seizures. Especially those who exhibit automatism, which is common in temporal lobe seizures, “they strike mechanically, without motivation, without interest, without knowing what they do or, at least, with a very vague consciousness of their actions” (Temkin, 1971:321).

From different research conducted there is no evidence for the allegation that epilepsy causes crime, and there is little support for the idea that seizures are related with aggressive behavior. According to Schneider and Conrad arguments that try to associate epilepsy with aggressive behavior, is a sort of inclination to medicalize deviant behavior. Such myths are not only inaccurate and burdensome for people with epilepsy but also they legitimize and perpetuate stigmatization and are also part of the social problem with which people with epilepsy must live.
According to the Epilepsy Canada website, other myths and fears have distorted the true nature of epilepsy. Thus people continue to hold mistaken notions about the disorder. Some of the myths can be found as follows: people hold the notion that individuals with epilepsy can swallow their tongue during a seizure, but the fact is that it is physically or anatomically impossible to swallow one’s tongue. Again people think that you should force something into the mouth of someone having a seizure. This is absolutely a bad idea since it might even chip teeth, puncture gums, or even break someone’s jaws. The correct first aid is never put something in his or her mouth and put him or her on either sides or safe place where there is no hard and sharp materials to avoid physical injury. Some people say you should restrain someone having a seizure but the truth is that you should never use restraint! The seizure will run its course and you cannot stop it.

Some still hold the idea that epilepsy is contagious but the fact is that you simply cannot catch epilepsy from another person. Some people say that only kids get epilepsy but the fact is that epilepsy can happen in old age as often as it does in children aged ten and under. Some still hold the misconception that people with epilepsy are disabled and cannot work although the facts show that they have the same range of abilities and intelligence as the rest of us. Others say that people with epilepsy should not be employed in jobs with responsibilities over other people with stress but they are found in all walks of life and at all levels in business, government, arts and science. Some people say that you cannot die from epilepsy but the fact is that you can die from prolonged or repetitive seizures. Finally some say that people with epilepsy are physically limited in what they can do. In most cases it is not a barrier to physical achievement although some individuals are more severely affected and may be limited in what they can do.

Throughout history people with epilepsy were viewed with fear, suspicion and misunderstanding, and were subject to enormous social stigma. They were treated as outcasts and punished. Sociologists started the fight against popular myths and misconceptions by revealing by the role of social meanings and reactions. For individuals living with epilepsy this kind of study was a major starting point to examine the way they perceive themselves and start the fight against popular myths and misconceptions.
1.3.4 Epilepsy from the public perspective

Throughout the course of human history, both inside and outside medicine epilepsy was subjected to demonological interpretation and sufferers to ritualistic and institutional abuse (Temkin, 1945). In contemporary third world cultures, epilepsy often still remains defined in terms of supernatural power. A study conducted in Nigeria reached to a conclusion that after heredity, witchcraft was the cause most commonly associated with epilepsy among the general public (Awaritefe, et al. 1985).

The Central Health Service Council (CHSC) of United Kingdom showed the viewpoint of the general public as follows:

Through ignorance and prejudice about the nature of the disease, there is a reluctance to give them a home, a job, or to accept them as relations by marriage or as fit to become natural or adoptive parents (CHSC, 1969: 16).

When we explore the orthodox viewpoint of the general public it can be characterized by four main themes. The first theme is the claim that the public does not know what epilepsy is. The second theme consists of the notion that the public is intolerant in its attitude towards people with epilepsy. The third theme says that the public is predisposed to discriminatory practices against people with epilepsy. Last but not least, the public is responsible for most of the problems associated with an epileptic identity (Scambler, 1989).

According to (Scambler, 1989) there are three wrong beliefs that summarize public ignorance. These can be described as follows: the first wrong belief is the definition of epilepsy only in terms of grand-mal seizures and the second false belief is the classification of epilepsy as a type of mental disorder. The third erroneous belief includes the association of epilepsy with the possession of an anti-social trait.

A community-based survey (Scambler, 1983) conducted among adults using semi-structured interview revealed that fifty four percent of the respondents exclusively defined epilepsy in terms of grand mal seizures, which is the most conspicuous and dramatic manifestation. Another similar study was conducted in London Street. The survey employed highly structured interviews. The respondents were people aged between 14-45 years. When they were asked to describe 'epileptic
attack' sixty seven percent gave descriptions consistent with grand-mal seizure. But when asked subsequently if there was more than one epileptic seizure, seventy one percent answered in the affirmative (Jordan, et al. 1986). This survey showed that people’s initial response to epilepsy is in terms of grand mal seizure, despite the fact that many of them are aware of the existence of alternative forms of seizure. (Scambler, 1989) clearly presented epilepsy and its relation to insanity from different researches conducted as follows:

The belief that epilepsy is a form of mental disorder has been researched widely throughout Europe and US. The Windsor study found sixteen percent categorizing epilepsy as a mental disorder. Twenty five percent in London street survey saw epilepsy as a mental as opposed to a physical disorder, although some clearly dead so only because the brain was the part of the body affected. In Harrison and West’s street survey in Bristol and Oxford, relying on semi structured interviews, eleven percent apparently regarded people with epilepsy as ‘mental types’ (i.e. disturbed, ‘mental’ or having a psychiatric problem). (Scambler, 1989:41)

The two London street surveys as mentioned above also included a question on employment and six percent felt that people with epilepsy should not be employed in jobs like others, compared with the contemporary nine percent of the American figure. In order to check participants’ agreement or disagreement scaling was used for the statement ‘some jobs are unsuitable for people with epilepsy’ twenty nine percent ‘strongly agreed’, sixty two percent ‘agreed’, and nine percent ‘didn’t know’; the surprising thing is that not a single participant disagreed with the statement. In this condition it is clear that laypersons’ strong acceptance of the right of epileptic person to work was strictly conditional on the nature of the work.

On the other hand, some studies produced results that seem to contradict the trend to greater enlightenment and toleration. (Bagley, 1972) found that there is still considerable public antagonism towards people with epilepsy. One of his findings was that people with epilepsy are more often rejected as compared to cerebral palsy or mental illness. A study in US employed a similar method and found that people with epilepsy are less often neglected than those with cerebral palsy or mental illness (Albercht, et al. 1982).

Deviance is usually seen as a threat to the social order. This kind of view can be explained by the existence of ‘innate prejudice against epilepsy’, which is
grounded in a fear that person with epilepsy is always prone to sudden, unpredictable and dramatic loss of self-control. This is something which normal people fear in this kind of situation. (Scott, 1972:13) put the question “why individuals should be labeled deviant and excluded from full participation when there is nothing in their behavior to warrant this kind of treatment?” The main theme of this question is that blind people and others like them create a sort of threat to the social order (Scambler, 1984). This kind of view is elaborated as follows:

The prejudiced observer of epilepsy may ask himself the implicit question: ‘If he can maintain control of himself for days, weeks, or months, why can’t he control himself now?’ The victim of cerebral palsy cannot be blamed in this way, for he has never gained control of himself, and so he cannot lose it. He is not ‘morally’ responsible. (Bagley, 1971:113)

The reason for not accepting epilepsy as a normal kind of illness and for negative social attitudes can be explained by the values of maintenance of the social order. This kind of idea is clearly described as follows:

The social structure survives through its experience of value of control, order and reason. Circumstances which threaten loss of control provoke a strong social reaction, be they in the crowd behavior or in the deviant group, or in alcohol excess, or drug intoxication” (Taylor, 1969:107).

The way in which person with epilepsy would threaten the social order is twofold. First they fail to conform to cultural norms. This idea is illustrated below.

Failure or success at maintaining such norms has a very direct effect on the psychological integrity of the individual. At the same time, mere desire to abide by the norm—mere good will—is not enough, for in many cases the individual has no immediate control over his level of sustaining the norm. It is a question of the individual’s condition, not his will; it is a question of performance, not compliance. (Goffman, 1968:152-3)

The second threat to the social order includes ambiguity in social interaction. In a study conducted to assess the attitudes of normal people ambiguity in social interaction is the most common frequent reason given for distancing from the
stigmatized (Albrecht, et al. 1982). The three principal dimensions that provoke ambiguity in social interaction with person having epilepsy are concerns of unpredictability, the dramatic loss of control and fear of coping.

1.3.5 Epilepsy from the social response perspective

Before going into the details of the social response to stigma it is worth to mention the origin of the word stigma and its most insightful analysis.

The Greeks ... originated the term stigma to refer to bodily signs designed to expose something unusual or bad about the moral status of the ... [individual]. The signs were cut or burnt into the body and advertised that the bearer was ... a blemished person ritually polluted, to be avoided especially in public places. Later in Christian times, two layers of metaphor were added to the term: the first referred to bodily signs of holy grace... [stigma]; the second a medical allusion, referred to bodily signs of physical disorder. Today the term is widely used in something like the original literal sense, but is applied more to the disgrace itself than to the bodily evidence of it. (Goffman, 1963:1-2)

At this point it is helpful to show the difference between enacted stigma and felt stigma. Enacted stigma refers to episodes of discrimination against people with epilepsy solely on the grounds of their social and cultural unacceptability. On the other hand felt stigma refers to two things. The first part is associated with shame of having epilepsy and its second part refers to simply the fear of meeting with enacted stigma (Scambler, 1989:56). Based on this distinction a model has been constructed by (Scambler and Hopkin, 1986) known as the hidden distress model. This model shows how people with epilepsy learn the label of medical diagnosis and its status as social liability or social disadvantage. The second and most important element in this understanding of stigma is the 'special view of the world'. This special view of the world predisposes people to hide their condition from others. The third important element is the policy of concealment. This policy of concealment has the intention to reduce the opportunities of enacted stigma common in the context of personal relationships and work.

People's life with epilepsy is usually marked periodically by discreditable public seizures. When we say discreditable attribute it is that aspect of devaluing
quality of the evidence according to Goffman. If people with epilepsy manage to keep the information hidden, they can manage to be the virtual self like any other normal individual with out the condition. But if the information is not kept secret because of occurrence in public places it needs redefinition of the self for the individual himself and even the general public tries to readjust their perception towards the affected individual. Therefore, although a person with epilepsy might not actually be discredited through his epilepsy, his disorder might still be considered a discreditable condition: if it is discovered it might discredit the person.

What the individual thinks about himself and what others think of him is very crucial in the genesis and construction of stigma. If the individual thinks and perceives the attributes as discreditable then it becomes relevant. In addition to his own perception other people in his surrounding react to him with disapproval of the attribute and further rejection which teaches him further the negative image of the devaluing attribute he possesses. So both the individual who possesses the attribute and the people in his surrounding are the prime producer of the meaning attached to it.

According to (Scambler and Hopkins, 1988) parents frequently functioned as stigma coaches: through advice and example they prompted ‘naïve’ offspring to define and react to epilepsy as a stigma. Most of the time parents are trying to overprotect their children by making the discrediting attribute secret and concealed. Probably this may be due to the feeling that epilepsy brings a sense of shame to the family but also a sense of blame to the parents. Keeping the truth as secret as possible has its own negative consequence in the future adult life of the affected individual. The relationship can be seen as follows.

Parents generally react to the diagnosis of epilepsy with a mixture of apprehension, shame, anxiety, frustration, and helplessness. This leads to ‘an oppressive atmosphere of secrecy and despair’, which has an adverse effect on the child. The child is unable to discuss his or her condition openly and soon comes to see it as something undesirable. Stigmatization may be experienced at the hands of schoolmate, friends, and neighbors who are in- the- known. The child usually remains confined to the home and socially isolated. The intricate social relationships are never learned and he or she remains insecure, overdependent, emotionally immature and inept’ when adulthood is reached. (Scambler, 1989:81)
Even if he or she remains seizure-free for a long time, two years without
seizures and treatment a person formally no longer has epilepsy, the stigma label has
the habit of outliving the attribute or condition, which it denotes initially. This idea is
described as follows:

Unlike other imputed qualities, stigma is by definition ineradicable and irreversible:
it is so closely connected with identity that even after the cause of the imputation of
the stigma has been removed and the social reaction has been ostensibly redirected,
identity is formed by the fact of having been in a stigmatized role; the cured mental
patient is not just another person, but an ex-mental patient; the rehabilitated criminal
gone straight is an ex-convict. One’s identity is permanently spoiled. (Freidson
1970:236)

The prejudicial ideas and discriminatory behaviors are powerful tools, which
could affect the conventional life of people with epilepsy. Prejudicial ideas are
directed towards what people say and also what they believe and think towards people
with epilepsy. On the other hand discriminatory behavior has more to do with what
others do towards people with epilepsy. When we say prejudice we mean the
preconceived judgment, which has great potential to affect quality of social life. The
American public health attitude was surveyed for about thirty years starting from
1949 up to 1979 and the results of the survey showed that there is a reduction in
prejudice towards people with epilepsy. For example the study showed that fewer
people object to their children playing with people with epilepsy and fewer people
think of epilepsy as a form of insanity. While about twenty percent of the respondents
don’t agree with the idea that people with epilepsy “should be employed in jobs like
other people.” in this study also more educated and young urban dweller received less
prejudice as compared to their counter parts (Schneider and Conrad 1983:44).

There was also another important small study, which tries to make sense about
the social acceptance of epilepsy by comparing them with alcoholics and blind men.
The study showed that people with epilepsy were more accepted than alcoholics but
less accepted than the blind. This study also asked people’s willingness to participate
in a variety of hypothetical situations to see the relation with social distance and social
acceptance. The result revealed that social acceptance was inversely related to social
distance (Ries, 1977). The parameters that were taken into consideration include
marriage, renting a room, working together, participation in clubs with epileptics and allowing people with epilepsy in their neighborhood.

The emergence of discriminatory behavior may present itself informally overtime or formally produced by official policies. These two factors finally resulted in markedly reduced opportunities for people with epilepsy. The most important challenge and discrimination for people living with epilepsy take place during employment. Present day employers are market oriented and profit aimed. In this kind of intense competition people with epilepsy, at least in employer’s eyes, are less fit and desirable for the competitive market economy. For this reason employers are hesitant to employ people with epilepsy. The chance of employing them in factories and allowing them to operate potentially hazardous machine and drive vehicles is reduced while having uncomplicated epilepsy has little effect on employer’s productivity and safety as quoted by (Schneider and Conrad, 1983:45).

Generally speaking, this section tried to show the slow and gradual defeat of magical conceptions of epilepsy and the triumph of scientific conceptions throughout human history. The section on historical perspective has a strong relevance in relation to people whose culture is still greatly influenced by supernatural powers. Ethiopian immigrants, while living in the Netherlands, are still parts of the culture of their homeland and might be expected to have encountered ideas and worldviews shaped and influenced by the belief in supernatural powers. Therefore, it may be hypothesized that causal concepts such as spiritual possession and the possibility of epilepsy as contaminating other healthy individuals might be mentioned during fieldwork.

Throughout history people with epilepsy were viewed with fear, suspicion and misunderstanding, and were subject to enormous social stigma. They were treated as outcasts and punished. Sociologists started the fight against popular myths and misconceptions by revealing the role of social meanings and reactions. For individuals living with epilepsy this kind of study was a major starting point to examine the way they perceive themselves and start the fight against popular myths and misconceptions.

Different authors explored the viewpoints of the general public. Studies showed that the public is ignorant about the true nature of epilepsy and they are intolerant in their attitude towards people living with epilepsy. Also they are prone to discriminatory behavior and thus the public is responsible for problems associated
with identity of people living with epilepsy. Studies also showed that the values of
control, order, reason and the value of norms direct the maintenance of social
structure of the society. Any act that threatens the maintenance of social structure is
seen as an antisocial trait.

Also, this section tried to gain insight into the most important theoretical
concepts related to the social response to epilepsy. The concepts mentioned in this
section include enacted and felt stigma, discredited and discreditable attributes, and
finally prejudice and discriminatory behavior. With the help of these concepts we may
better understand attitudes and perceptions of people about individual with epilepsy as
well as the decision-making to accept people with epilepsy.

Finally, I think it is very important to discover the psychological attitudes of
the immigrant community towards people with epilepsy. Exploring the perception and
psychological make up of Ethiopian immigrants is the first step to understand their
thoughts and beliefs. Their thoughts and beliefs might serve as a base line to devise a
strategy and launch a campaign against misconceptions of epilepsy. However, in
large-scale campaign immigrants might be often forgotten. In a nationwide campaign
these group might not be addressed properly. Their cultural values and expressions of
illness might not be properly understood. If we try to better understand and integrate
the views of minority groups we are in better position to combat stigma. We might be
successful in our campaign against myths and misconceptions and thus raise the level
of awareness, reduce negative attitudes and bring enhanced level of understanding
with the majority of the population. The objective of my research is to address these
issues, as can be seen in the following chapter.
CHAPTER-2

2 General Objectives

Before I elaborate on the methodology of the research, I think it is good to proceed a little bit into details of the objectives of the research. Attention is given to recognizing the sources of information about causes of epilepsy. Significant observation was given to the different kinds of treatment choices offered to a person with epilepsy. Sharing social life with a person with epilepsy and taking full responsibility is seen from different walks of life. The beliefs and practices of immigrants will be explored. Generally speaking the general objective of the study is to explore and gain insight into the perceptions of epilepsy among Ethiopian immigrants living in the Netherlands.

2.1 Specific objectives

Φ To know and assess sources of information about epilepsy.
Φ To know the way Ethiopian immigrants perceive and interpret epilepsy.
Φ To know how Ethiopian immigrants react upon and deal with epilepsy.

2.2 Research questions

Φ How do Ethiopian immigrants perceive epilepsy?
Φ What is the meaning attached to epilepsy according to Ethiopian immigrants?
Φ To what extent is epilepsy accepted socially according to Ethiopian immigrants?
Φ To what extent do people know about epilepsy?
Φ What role can the general public play in epilepsy care?
CHAPTER-3

3 Research Methodology

3.1 Research design

This research consists of a qualitative study of epilepsy among Ethiopian immigrants. The broad aim of the research is to explore and describe the general perceptions of epilepsy among Ethiopian immigrants in the Netherlands. The study has the intention to gain insight into the perception of Ethiopian immigrants of epilepsy and of individuals living with epilepsy. Gathering data about epilepsy was done with the hope that knowledge about these matters would increase insights into Ethiopian migrants' behavior, so that if deemed necessary findings may be applied or appropriate policies may be implemented to improve the situation concerning knowledge of epilepsy among Ethiopian migrants in the Netherlands. In this sense this research is aiming for action. On the other hand due to its explorative and small-scale character the research does not try to create or prove hypotheses.

The framework of my research is based on the traditional image and its traditional explanatory model, the biomedical model, own experience and influence of media on the perception of epilepsy in the aforementioned immigrants and how they deal with it.

In order to include participants in the study, preparations started before the beginning of the fieldwork. The duration of fieldwork was from the end of May to the end of June for a period of six weeks and thesis writing for another six weeks. During the preparatory phase arrangement were made to have a research facilitator. The research facilitator arranged suitable places of interview. He also selected a potential site where most Ethiopian immigrants come together.

From my own experience and from literature that I came across during my study, it is clear that epilepsy is still socially stigmatised in many respects and that people hesitate to express their feelings about it in public space. In other words, it is a sensitive issue to discuss in-groups. As a suitable data collection technique I have chosen to conduct individual, in-depth interviews, and interview key informants in the community. Key informants were chosen according to certain criteria. The criteria
included frequent exposure to people with epilepsy, individuals with better awareness about epilepsy and individuals that are more aware about their previous culture for example religious people like priests. All interviews except one were tape-recorded and were transcribed into English word for word.

3.2 Study Sample

The respondents of this study are legal immigrants living in Amsterdam freely like any ordinary citizen of The Netherlands. Only participants, who have stayed in the Netherlands for a long time, for example ten years or more, were selected for participation in the study. Because of time constraints, ten interviews were arranged. Five respondents were males and the other five were female. Since I am interested on the investigation of public perceptions of epilepsy appropriate research respondents were nominated by snowball method. In order to gain maximum cultural information the older age group was preferred. Individuals between the age of 25 and 55 years were included in the study.

The research that I conducted with Ethiopian immigrants was made clear to participants in the interview. The research objective was discussed in detail in order to make it more understandable. All the information collected from respondents during fieldwork was kept confidential and remain anonymous. Even if in written documents it was not made known without the permission of the respondent. The address and their real names were kept confidential. Any kind of harm to the privacy of the respondent was eliminated.

Any kind of hierarchical relationship between researcher and respondent was eliminated in order to gain confidence and trust and create a conducive and friendly atmosphere, thereby generating as much information as possible. The respondent’s willingness to participate was welcomed and also their right to leave in the middle of the interview session was respected if something went wrong. I adhered to and followed the code of ethics of the American Anthropological Association and the Dutch Anthropological Association. I respected my respondent’s privacy and culture. I provided information to research respondents to allow them to make an informed decision whether they wanted to remain anonymous or receive recognition. I have already made every effort to comply with their wishes.
Informed consent of my research respondents was obtained just before the beginning of our interview. The right and dignity of participants was respected and I took responsibility for that. Participation in the sample was entirely voluntary and optional. Potential participants in the research project were provided with all information that might influence their decision of whether to participate or not. Research participants were informed about the purposes of the study, the duration of interview, the risks and benefits of participation, and their rights to refuse participation or terminate interview session. Generally speaking the condition was made in such a way that participants accept or refuse participation in the research.

3.3 Data collection techniques

The technique of in-depth semi-structured interview was used to generate ‘rich’ descriptions of Ethiopian immigrants’ perception in relation to exposure to people living with epilepsy. This kind of semi-structured interview allowed the respondents to establish their own agenda for discussion, within broadly defined research themes. This method also ensured that the data were reflexively generated and grounded in the experience of epilepsy in the general public. First open questions were used to reach all themes. These questions were followed by participant’s own words as a means of eliciting further elaboration and questions.

All interviews were tape-recorded except for an interview with one respondent. Tape-recording was done after each individual signed the informed consent form. Afterwards the interview was transcribed verbatim. The interview data were analysed using a system of open coding, which involved sorting the data into analytical categories by breaking down, examining, comparing, conceptualising and categorising data. These categories of data were compared and contrasted to generate themes; these themes form the basis for analysis and discussion.
3.4 Limitations of the study

Qualitative research is often criticised and perceived as somewhat limited due to its small scale, but this is because the underlying principle of such research is misunderstood. The study sample seeks to encompass a broad diversity of participants particularly in relation to age, occupation and level of education. This research does not seek to be representative of all Ethiopian immigrants' experience in the Netherlands. This research does not seek to be statistically generalisable. Rather my study seeks to explore the ways in which we might understand immigrants' experiences and perceptions using the process of logical inference. It is possible to use logical inference to generate theoretical generalisations from the analysis of the sample that is not statistically representative. In short this study does not claim to represent the experience of all Ethiopian immigrants living in the Netherlands, but claims to identify themes and variables that are of importance to understand Ethiopian migrants' perceptions of epilepsy.
CHAPTER-4

4 Findings and discussion

4.1 Introduction and Presentation of respondents’ profile

In relation to the respondents’ profile it is essential to describe the context and site of fieldwork. The site of fieldwork as mentioned before is in the city of Amsterdam, near the Wibautstraat. Near to this street the ‘Dir net’, a private organisation for helping Ethiopians to integrate in Dutch culture was located in the basement of a large building. This building also houses similar organisations for Somali people and other immigrants located near to ‘Dir net’. ‘Dir net’ has its own manager and other supporting staff.

‘Dir net’ has a radio program every Sunday morning for about one to two hours transmitted through our national language, Amharic. In this radio program general information transmitted includes a message for all Ethiopians living in the Netherlands to come together and discuss their social problems and try to find a solution. For example, obtaining a job may be one of such problems. Another issue might be to facilitate their return if they wish to return or to facilitate investment in their homeland. The radio program also sends health education messages on hot issues like HIV/AIDS and tuberculosis.

‘Dir net’ has six computers with free access to Internet. It also provides training for those who are not knowledgeable about computers. ‘Dir net’ has six offices for running its daily activities. Last but not least, it is also the meeting place for many Ethiopian immigrants when they feel homesick.

After describing the context of interview set up, now I come back to how the interview session was done. The managing director of ‘Dir net’ arranged for participants using the snowball method. I used to go frequently to the computer and Internet room where I could establish personal relationships with Ethiopian immigrants. There was also a separate room for coffee and tea. All these facilitated my integration with research participants. I gained their confidence to talk freely as if I had stayed long time with them.

Appointments were made with each research respondents on the day that suits them. Their choice was given priority. On the other hand, some research participants gave their time without making appointments beforehand. All the interviews were
conducted inside the office of managing director of ‘Dir net’ and inside the room for radio transmission. The ‘Dir net’ staffs have co-operated fully to conduct my interview.

To better understand and have clear picture about the research respondents, their profiles were presented in the following table.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Respondents pseudonym</th>
<th>Age of respondents in years &amp; duration of stay in the Netherlands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>First respondent</td>
<td>35 &amp; stayed for eleven years</td>
</tr>
<tr>
<td>Male</td>
<td>Second respondent</td>
<td>37 &amp; stayed for ten years</td>
</tr>
<tr>
<td>Female</td>
<td>Third respondent</td>
<td>30 &amp; stayed for thirteen years</td>
</tr>
<tr>
<td>Female</td>
<td>Fourth respondent</td>
<td>30 &amp; stayed for twelve years</td>
</tr>
<tr>
<td>Female</td>
<td>Fifth respondent</td>
<td>28 &amp; stayed for eleven years</td>
</tr>
<tr>
<td>Male</td>
<td>Sixth respondent</td>
<td>42 &amp; stayed for twenty two years</td>
</tr>
<tr>
<td>Male</td>
<td>Seventh respondent</td>
<td>49 &amp; stayed for twenty five years</td>
</tr>
<tr>
<td>Male</td>
<td>Eighth respondent</td>
<td>36 &amp; stayed for ten years</td>
</tr>
<tr>
<td>Female</td>
<td>Ninth respondent</td>
<td>26 &amp; stayed for twelve years</td>
</tr>
<tr>
<td>Female</td>
<td>Tenth respondent</td>
<td>27 &amp; stayed for eleven years</td>
</tr>
</tbody>
</table>

Table 3 showing marital status, family size and religion

<table>
<thead>
<tr>
<th>Religion</th>
<th>Pseudonym</th>
<th>Marital status &amp; number of child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orthodox Christian</td>
<td>First</td>
<td>Married and has two children</td>
</tr>
<tr>
<td>Orthodox Christian</td>
<td>Second</td>
<td>Married &amp; has two children</td>
</tr>
<tr>
<td>Orthodox Christian</td>
<td>Third</td>
<td>Married &amp; has three children</td>
</tr>
<tr>
<td>Orthodox Christian</td>
<td>Fourth</td>
<td>Divorced &amp; has two children</td>
</tr>
<tr>
<td>Orthodox Christian</td>
<td>Fifth</td>
<td>Single &amp; has no child</td>
</tr>
<tr>
<td>Orthodox Christian</td>
<td>Sixth</td>
<td>Single &amp; has no child</td>
</tr>
<tr>
<td>Orthodox Christian</td>
<td>Seventh</td>
<td>Married &amp; has five children</td>
</tr>
<tr>
<td>Orthodox Christian</td>
<td>Eighth</td>
<td>Not willing to tell</td>
</tr>
<tr>
<td>Protestant Christian</td>
<td>Ninth</td>
<td>Married &amp; is pregnant currently</td>
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<tr>
<td>Orthodox Christian</td>
<td>Tenth</td>
<td>Married &amp; has two children</td>
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Among my respondents there were five males and five females. Viewpoints of both genders were entertained in gathering field data. The age of the participants ranges from twenty-six years to forty-nine years. Most of my respondents adhered to the major religion of their homeland namely Orthodox Christianity. Only one respondent is a protestant Christian. Because of time constraint it was not possible to search for a respondent having Islamic religion. Concerning marital status six respondents were married, two were single, one divorced and the other one did not want to disclose his marital status and other private data.

Concerning their duration of stay in the Netherlands the range was very wide. The minimum duration of stay in the Netherlands was ten years and the maximum duration of stay was twenty-five years. On the average the duration of stay in the Netherlands among my informants was about fourteen years.

Concerning their family size, four of the research respondents have two children each. One respondent has three children and another respondent five children. Two of my respondents were single and do not have child. One respondent was not willing to tell. This same informant was the one who doesn’t want to tell all private data in this research. Finally one respondent was pregnant at the time of interview and she was near to term. In relation to the respondents’ level of education, four of them have completed grade twelve. Two of the respondents hold a diploma and three of the respondents are degree holders. One respondent is not willing to tell but he has received an education from the Orthodox Church.

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<th>Table five showing level of education</th>
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4.2 Presentation of study results

All respondents were asked about their knowledge of epilepsy and they replied in different ways. All of the research respondents referred to epilepsy as a disease, but none of them regarded epilepsy as a mental disease. I asked most respondents about their perceptions of abnormal movement of the limbs and its association with violent behaviour. None of the research respondents gave affirmative answer for this particular question. All research respondents identified the brain as the location or place of the disease. When I asked them if the muscles could be the sites of convulsions none of the respondents agreed. They mentioned the brain as the site of epilepsy. They gave this idea by giving the following explanation. Most of them mentioned that unless the brain is affected you would not lose self-control. For them losing self-control was the marker for localisation of the disease.

Most research respondents gave significant attention to the notion that it threatens self-control and consciousness. For them, keeping self-control comes first before everything else. If one loses self-control and consciousness, the result would negatively reflect on the life of the individual affected. Most research respondents said that losing self-control does a lot of damage to the psychological and social well being of the individual. Losing self-control is not oriented to time, place and person. It can happen at any time and this will affect peace of mind and bring shame to one’s own sense of identity.

Almost all research respondents mentioned the most commonly found signs and symptoms of epilepsy. They mentioned headache, excessive salivation, gnashing of teeth, protruding of eyes, falling down to the ground spontaneously through losing consciousness and self-control and abnormal movement of the upper and lower limbs. Most research respondents also mentioned a sleep-like state just after the abnormal movement of the upper and lower limbs. They also stated the average duration of the attack to be between one and two hours including the sleep-like state. On the other hand, only one respondent mentioned the presence of abnormal sound as a symptom of epilepsy during the attack. Also another respondent mentioned the presence of incontinence of urine. Incontinence of faeces was not mentioned as a symptom of epileptic seizure.
Some respondents also know that epilepsy has warning signs and symptoms. They said that these warning signs might help to avoid injury resulting from falling down accident. They came to understand this through intimate contact with individuals with epilepsy, discussion with other close friends and also by reading brochures and books. Only two research respondents mentioned that during epileptic seizure the body becomes rigid and the mouth becomes tightly closed. Only two respondents mentioned that it was not possible to control abnormal movement of limbs during epileptic seizure. Others assumed that it was possible to control limb movement just by pressing down through your hands.

All research respondents were asked to give their views if they knew more about the classification and types of epilepsy. This question was intended to discover to what extent respondents really knew about the nature of epilepsy. Only one research respondent gave what he calls ‘light form’ and ‘severe form’ of epilepsy. According to his description, the ‘light form’ of epilepsy comes and goes without being noticed by people around him. He also mentioned that this kind of epilepsy has a brief duration and it is subtle. On the other hand he also mentioned that the ‘severe form’ of epilepsy comes with full-blown manifestations that are visible to everybody in the surroundings. This particular research respondent has a friend living with epilepsy and has a degree in psychology. As he mentioned, he wanted to know more about his friend’s epilepsy by reading books and looking on the Internet.

Most research respondents said similar things about the nature of epilepsy. They said that epilepsy is a strange kind of illness. The way things happen during attacks were unusual. Normal kinds of illness affect the person with slow progress by making the person feel uncomfortable and making the individual decrease his routine activity and finally confine him in bed. His energy will decrease slowly. During this slow process he can look for help for himself either medical or social.

On the other hand, they said that, an epileptic seizure does not give time to search for help. It is an emergency situation and it also goes fast by its own will. Four research respondents agreed with the idea that it is as if you are under the control and will of some kind of strange power. These research respondents try to associate it with possession by the devil through their previous cultural interpretation. Abrupt loss of self-control makes epilepsy strange and unacceptable. It throws you in unexpected place and time. You don’t know what is happening in your body. They said that the funny thing about epilepsy is that you will be completely ok after three or four hours
and continue your previous activity. This kind of nature of epilepsy makes it unique from what we call normal kind of illness.

The idea about contagiousness of a person with epilepsy was raised during the interview sessions, and a majority of the research respondents gave their view as follows: Nine out of ten research respondents don’t believe that epilepsy is contagious. They said that it couldn’t be transmitted from person to person through direct contact. On the other hand, one individual believes that epilepsy is contagious. This research respondent stressed that a long period of exposure was necessary for transmission of epilepsy from one individual to another. This respondent said that he had seen people in the church acquire epilepsy while giving service for a long time to individuals with epilepsy.

All research respondents’ exposure to a person with epilepsy was asked after in order to understand and share their own experience. Almost all of the research respondents mentioned schools and universities as their initial place of exposure to a person with epilepsy and the first exposure to epileptic seizure. Few research respondents mentioned that their first place of exposure to epileptic seizure was in their village and along the roadside. They described the epileptic seizure as a terrifying event. They expressed their feelings by saying that it is dreadful. Research respondents also said that the epileptic seizure catches your attention because of its special nature. It provokes a strong social reaction.

In addition to educational level respondents were also asked about their exposure to mass media and change of attitude in order to appreciate the diffusion of biomedical model to its maximum extent possible. Knowing about their activities in this aspect gives me some clue about cultural diffusion, culture increment through new contact and degradation of their previous culture through loss of contact and isolation. Most research respondents claimed that they have access to mass media like Dutch television channels, radio programs and access to the Internet. They told me that Dutch television channels have enormous educational value. My research respondents mentioned that all kinds of health issues are presented in the programs. Issues related to high blood pressure, high sugar level in the blood, asthma, heart disease, lung disease and liver diseases are also commonly presented. They said that epilepsy is included in this kind of program. Most respondents described that they do not strictly follow this program and consequently only few told me that they actually attended epilepsy education program. They told me that since it is not highly relevant
for them they choose to do other activities. But they told me that they know something that is not good enough.

The research respondents also mentioned that they all have access to the Internet. If they experience any kind of health problem they are able to help themselves in finding the appropriate information. One respondent said, “if you give me some kind of health problem to search on the Internet, I could show you right now through a Yahoo and Google search.” They said that they knew the manifestations of epilepsy.

Research respondents were also asked about gender preference for epileptic seizure. Most said that they do not have any information either cultural or scientific. But they shared their experience and exposure to individuals with epilepsy. Only one research respondent described exposure to women with epilepsy. The other nine research respondents mentioned exposure to men with epilepsy. Even one respondent said that it is a disease of men. He came to say this because he has never seen or heard of females with epilepsy in his life.

Research respondents were also asked to give their views about the age distribution of epilepsy from what they know and from their exposure to people with epilepsy. Almost all research respondents do not have scientific information but they shared their experience as follows. Most research respondents who witnessed epileptic seizure at schools and universities intended to describe high epilepsy prevalence during young age. They also admitted the presence of epilepsy in latter adult life.

Research respondents were also asked about exposure to Ethiopian individuals with epilepsy here in the Netherlands. This kind of interview has the intention to know the presence of epilepsy cases and to better understand the attitudes of research respondents. They mentioned that they know three individuals with epilepsy. Out of these three individuals two are male and one female. Research respondents were asked to tell the story about what they know about these individuals with epilepsy. Most of the research respondents know that one Ethiopian man with epilepsy has died recently. They said that this individual was living alone and he was found dead in his room. They mentioned that he was not fully co-operative about taking the prescribed medications. For this problem, he was admitted to hospital and later discharged with medical advice. “We Ethiopians who approached him very closely advised him to take the tablets as directed by his physician but he was not fully co-operative to take
the medication. I think he had behavioural problems. He drank alcohol too much. We advised him to stop taking alcohol but it was not possible. He was also living alone. Finally he was found dead in his room. The police called us and we went to look at him and I saw excessive salivation in his mouth area. The police also took pictures of the dead body.” One research respondent said that he had a problem accepting his illness. “He said, ‘I am ok and I am fine’. In actual fact he was not acting in proper way.” The respondent who knows a woman with epilepsy has lost contact recently and she does not know where she is right now. The research respondent said that she came across this Ethiopian woman when she was looking for a room from the municipality. Since they are from same country they agreed to live together, and during that time her roommate told her that she had epilepsy. She reassured her colleague not to be frightened if she develops the attack. The woman with epilepsy told her that she developed malaria because of malaria infection. This research respondent became aware that attacks of malaria could bring about epileptic seizures. The woman with epilepsy had graduated from university with bachelor’s degree from Addis Ababa University.

One voluntary participant attempted arrangement of interview with another male living with epilepsy. This research respondent said that in no way this individual is different from me. He is a professional and leading his life like any healthy individual. This research respondent also has witnessed the stable life of the individual with epilepsy. He told me that he is married and leading a healthy family life. He also knew that he had children. This research respondent also knew that his colleague takes his medication properly. My research respondent was aware that this individual with epilepsy had stopped alcohol intake. I asked my research respondent to arrange a meeting with me for this individual with epilepsy to share his feelings. This research respondent tried to make it happen for two to three weeks and finally it was not possible to convince this individual. This individual with epilepsy was found to be unwilling to participate in the study.
Access to health care was also asked after in order to detect the weakest link on the way to seek treatment. They said that access to Dutch health care is no problem except in our cultural difference and language competence to fully understand doctors and express our internal feelings. There is an open and transparent system of reception. The more you stay in the Netherlands, the more you will better adapt. They will direct you to the appropriate section. You take your number and then you wait for your turn. All research respondents appreciated the handling of hospital staffs.

Interviews related to recurrent epileptic seizures were also conducted during the interview period, and epilepsy’s association with the moon was also explored. All respondents agreed on cyclical pattern of the seizure. They said that it might come every month, every three months, or every year. They gave this idea from their experience. They said that epileptic seizures do not come every month with the moon. They said that the way the moon comes and goes might have a similarity to the attack of epilepsy; otherwise they do not think the seizures are strictly related with the moon.

Based on the above mentioned facts, from their own personal experience, access and exposure to mass media, most respondents seem to have a good understanding about the manifestations of epilepsy.
4.3 Perceived causes and treatment of epilepsy in the eyes of Ethiopian immigrants in the Netherlands

In this particular section I am going to describe some of the perceived causes and treatment of epilepsy among Ethiopian immigrants living in the Netherlands. Starting with the perceived causes of epilepsy, the main categories mentioned were magico-religious, naturalistic and medical causes.

The magico-religious causes were those associated with spirits, possession, witchcraft, sitting on goats skin, the evil eye, punishment or curses from ancestors. From the interviews conducted the majority of the respondents came across these causes from within their original culture but most of them didn’t believe them to be the causes of epilepsy. On the other hand two of the respondents talked about epilepsy as being caused by evil spirits as follows:

Epilepsy is purely spiritual possession from the kingdom of evil. It has nothing to do with God. It is purely the act of evil spirit. It is caused by satanic possession. (Respondent eight)

This is the work of spirits, satanic spirits, which makes a person lose control. The spirits govern him or possess him. (Respondent nine)

Looking at the other respondents, I found them mentioning some of the culturally accepted magico-religious causes of epilepsy but they don’t believe them to be the causes. Some of them say that as educated people they do not believe in such causes.

Usually in our culture it is viewed as possession by the Devil. That is why they put the cross around him and that is why the person is made to worship the cross. Epilepsy is also viewed as a curse from God or sin committed by his father and mother whereas in the circle of educated people like me it is not viewed like that. (Respondent seven)

Probably these things like sitting on goat’s skin, evil eye, witchcraft and the moon may be common in our society where ignorance and illiteracy is prevalent. As an educated person you know these things have nothing to do with epilepsy except the moon where you can make some kind of association for the periodic seizure and as a light source that will have a relation with your sight. (Respondent ten)
The issue of sitting on goat's skin has long been regarded as something undesirable and related to something negative. Goats generally do not represent a good symbol in our culture as compared to sheep. (Temkin, 1971) also mentioned the association of epilepsy to sitting on goat's skin.

According to (Foster, 1998:148), "In the naturalistic system a personal health strategy seems to consist of avoiding those situations or not engaging in behaviour, known to produce illness". There were some things that my informants believed to bring some sort of balance in their lives and if this balance is lost, it can lead to the development of epilepsy. The respondents talked of the coffee ceremony, smoking of incense and hashish as important rituals.

The coffee ceremony is a cultural ceremony that includes different steps involved in the preparation to drink it. In the first step a certain amount of coffee estimated to serve the invited villagers would be roasted. The special smell and smoke of roasted coffee would be made to move towards coffee drinkers. After smelling the roasted coffee, it would be grinded into powder by a culturally prepared instrument. While serving the prepared coffee, smoke of incense is made to fill the room. The usual round for serving coffee is three times. The duration of the ceremony might be for three to four hours. During this time invited villagers talk and talk and chat about their feelings. The owner of the house is in charge of preparation. If the coffee was nice everybody will bless the owner and finally they depart to their daily activity. This ritual is done turn-by-turn among villagers. If someone did not observe these rituals or has missed them for a long time it was believed to result in epilepsy. According to (Helman, 2000) ritual is seen as any form of repetitive behaviour that doesn't have any overt technical effect. Helman also pointed out that this ritual has important psychological, social and symbolic function to those who participate in it. This kind of notion was also reflected among research participants and can be seen as follows:

In our culture there are conditions or rituals that are done frequently. If they miss that it is seen as a cause of epilepsy. Some people who have addiction to coffee ceremony and smoking of incense may develop epilepsy if they miss these rituals. It is like an obsession to some kind of procedures. (Respondent one)

The sixth respondent also suggested that epilepsy might be initiated through absence of performing something you have been adapted to or used to doing.
There was also a belief that epilepsy is caused by something gone wrong in the head that will be discussed later but here they also mentioned the association with severe forms of light affecting the head. The television, sunlight and the moon were said to be sources of extreme forms of light striking on the head and leading to epilepsy. Talking about extreme exposure to the television and sunlight, the first respondent said:

Staring at the television, definitely. Definitely, all those things that affect sight are related to the brain and I think it will have strong relation. Most of the time people say exposure to sunlight will be taken as a reason for the 'falling illness'. (Respondent one)

There may be some relation with the moon because the moon emits light and it affects your brain and heart. The heart is the organ responsible for redistribution of blood to every part of the body including the brain. (Respondent six)

Medical and biological causes were also mentioned by some of the respondents. These causes were mostly related to problems with the nervous system and the brain. They believed the brain to be the centre where people's actions are controlled and hence when the brain is affected it can lead to epilepsy, which was seen as a condition leading to loss of bodily control.

Since trauma to the head is related to the central nervous system I think it will have influence in the development of epilepsy. The control system may be disturbed. I think it has a strong association. (Respondent one)

I heard our neighbours talking about one baby getting epilepsy through fall down accident from his bed. I think it is possible to have a relation to the development of epilepsy whether the head injury is happening in early or late life. (Respondent three)

In addition to the causes mentioned above, the respondents also talked about possible modes of transmission and some factors, which may aggravate the epilepsy. Person to person transmission was mentioned possible by one unique respondent, while three respondents not commenting about it and six of them saying it is not possible. As for the idea a hereditary disease, only two respondents thought of
epilepsy being hereditary while the remaining respondents thought it was not or did not know any thing about such an association.

Following all the causes mentioned above, the respondents also talked about some factors, which can aggravate the already existing condition. Such factors included lack of enough sleep, lack of enough food and excessive intake of alcohol.

I don’t have much information in relation to alcohol but I can imagine that a person with epilepsy should be careful not take alcohol and should have a proper sleep habit. These things can exacerbate the illness. (Respondent one)

Yes, now I remember our neighbour having epilepsy was prohibited from taking alcohol. When he takes alcohol he will develop epileptic seizures. Both alcohol and lack of sleep have connection to the function of the brain and I think there may be a strong relation even though I am not sure how it works. (Respondent two)

Yes I think excessive alcohol intake and lack of sleep has strong relation with the brain and they can contribute to the development of epilepsy. Even missing meals can be a problem, not only for a person living with epilepsy but also for normal healthy individuals. (Respondent six)

In the reflection given above by research participants, it is clear that disturbance of balance is seen as cause of illness. This kind of thinking is deeply embedded in the naturalistic system, which explains illness in impersonal terms. This can be seen from works of Foster.

Disease is thought to stem, not from the machinations of an angry being, but rather from such natural forces and conditions as cold heat, winds, dampness, and, above all, by upset in the balance of basic body elements. In naturalistic systems, health conforms to an equilibrium model. (Foster, 1998:143)

Categorisation of the causes of epilepsy was mentioned above; accordingly the respondents suggested different means of treatment. When asked about the treatment of epilepsy their responses can be broadly categorised into first aid given to a person experiencing the convulsion, daily treatment for a person with epilepsy and preventive measures to be taken against epilepsy.

When a person was experiencing epileptic convulsions, the respondents talked about some safety measures to be taken. These were measures to be taken to avoid the
person hurting himself with sharp objects, restraining him and the appropriate way to position a person having the convulsions.

I will remove hard and sharp materials from his surrounding to protect him from physical injuries. If he is not in good and comfortable position, I will try to put him in a natural lying position. (Respondent three)

I think holding arms and legs during seizure may help to avoid injury. This is to help him not to have physical damage. I will remove harmful things from his surrounding and then I will call an ambulance. (Respondent four)

In our culture from what I remember, making the victim hold a piece of metal is seen as a first aid measure. Also making the sign of a cross or putting the cross over him is also seen as a first aid measure. There is a belief that this kind of illness is possession by the Devil. As you know the power of Jesus casts out this kind of illness in the New Testament. Holding any type of metal is believed to help this kind of illness. From what I know in scientific study, metal as conductor of electricity may help as grounding to remove excessive electrical discharge from our body. After I came to the Netherlands I learnt to put the victim in a flat and comfortable position. Here in Holland everybody knows how to give first aid. (Respondent seven)

Following the first aid measures, the respondents talked about reviving the patient who has lost consciousness. They talked of what should be done to wake up the patient who has lost consciousness. They described inhalation of smoke and directing light towards the patient as means of waking the patient up.

Lighter and igniting match have a value in making him free from the seizure. Fire and lighter are required to make smoke for waking her up. (Respondent one)

I don't know whether it is traditional or medical treatment, people around a person experiencing an epileptic seizure always request for matchsticks. They request this help to wake up the victim of seizure. Once they have the matches they will ignite it near his nose in order to give special smell of ignition smoke. I have seen through my naked eyes unconscious victims of epilepsy waking up through this kind of help. They show marked gain of consciousness. (Respondent two)
What I know is how to treat recent seizure, just after they have happened through smelling of herbal medication. For example smelling smoke resulting from bones regurgitated from hyena or fox. There is a belief that the hyena eats Satan. (Respondent eight)

After discussing some of the first aid and emergency measures to take, they also talked about day-to-day treatment for people with epilepsy. They generally believed that there is no cure for epilepsy, but things can be done to reduce the frequency of attacks. Modern medication was seen to reduce the frequency of attacks and the majority who believed in the medical causes of epilepsy would advise the person to see a doctor.

She told me that she takes medication for her illness and it is possible to prevent seizures by taking medication. It can be treated with medication even though it is difficult to eliminate. (Respondent four)

Yes, I think much can be done through modern treatment. I know there is medication to reduce the frequency of seizures. I have seen people taking tablets to reduce seizures of epilepsy. (Respondent four)

Yes I have heard there is medical treatment to avoid epileptic seizures. I do not think there is cure through medical treatment. I have never seen or heard cure of epilepsy up to now. As long as there is no cure the treatment is life long. (Respondent ten)

Those respondents who believed in religious treatment talked about prayer and administering holy water as means of treatment and prevention of further seizures. In religious treatment, the respondents believed the disease could be cured as opposed to medical treatment that reduced frequency of seizures. Respondent nine talks about curing through the will of God as opposed to life long dependency on tablets, which don't eliminate the disease.

I believe he will be cured only by means of prayer. As long as I am a believer, then through God's spirit and through Jesus Christ, epilepsy will be cured. They can give tablets and they can decrease the frequency of seizures, I have seen the side effects of tablets like harming their bodies, excessive weight gain and obesity. People with epilepsy are adapted, addicted or governed by tablets and they walk or move with these tablets. The tablet may help them and may reduce the appearance of seizure
for a short period of time but the illness is still living with them. Therefore it is not possible to cure it medically. (Respondent nine)

Since I am an Orthodox believer, I believe Holy water can help to prevent seizures. Also people in our country use Holy water as treatment and prevention of further seizures. Otherwise I do not accept those rituals done out of the will of God. I have never seen cure by modern ways of treatment. (Respondent two)

Treatment through serial Holy Water and putting the cross on his face will help to clean the evil spirit. But you see it will be possible to cure through the will of God. No, I do not think it is possible to cure through modern treatment. It is through the will of God that cure is possible. (Respondent eight)

In the medical treatment of epilepsy, control is usually common while cure is a very rare situation. This kind of study is quite interesting in sharing some truth about the success rate of anticonvulsant. The Commission Report (1978, vol. II, Pt. 1:491) concludes: “About half of the epileptic population will achieve complete seizure control, and an additional 35% can achieve good seizure control (three or four seizures a year).” Generally speaking 85% of people living with epilepsy show a significant reduction in the number of seizures experienced by using anti convulsant medications.

Finally, this section tried to show the most important issues related to the causes and treatments of epilepsy among Ethiopian immigrants living in the Netherlands. According to the three assumed causes of epilepsy, namely the magico-religious, naturalistic and medical causes, treatment strategy was directed to avoid getting epileptic seizures. In the magico-religious context most research participants mentioned the cause and treatment of epilepsy from their original culture but they don’t believe anymore in it. On the other hand most research participants also mentioned naturalistic causes and treatments even though their knowledge is superficial. The treatment strategies of these participants seem to maintain rituals or to avoid those situations known to produce illness. The medical causes and treatments are not well known by most participants. Medical treatment was seen only as something supportive in reducing frequency of seizures. These research participants don’t give room for cure through medical treatment although the first aid offered seems quite good.
4.4 Psychological and social aspects of epilepsy in the eyes of Ethiopian immigrants

In this section of the paper I present and discuss the most important categories generated from the analysis of field data. The important categories that came into the picture include adequacy to take responsibility or reliability, suffering, sharing social life with a person with epilepsy, right and dignity, and contagiousness.

The concept of adequacy to take responsibility was raised in relation to giving them jobs, approving driving license and in relation to issues of marriage. In relation to giving them jobs, all research participants mentioned that the decision to accept them depends on the type of job and the place of work. All research participants refused to offer jobs in areas of factory work, heavy machinery and construction works. All research participants suggested the following jobs as dangerous or risky. These include working near open fire, enjoying near water bodies, riding a bicycle and driving motor vehicle. Half of the research respondents would decline to give them jobs. They do not want to take responsibility for anything that affects the performance of their staff. They feel and anticipate that individuals with epilepsy may have frequent absences from their job due to seizures. As employers, all research participants would refuse to accept someone with epilepsy as a member of health insurance. Participants were not willing to give service at the same level of payment, which was designed for any healthy individual.

Research was conducted in a London street survey concerning the statement; ‘some jobs are unsuitable for people with epilepsy’. This study found that twenty nine percent ‘strongly agreed’, sixty two percent ‘agreed’, and nine percent ‘didn’t know’; the surprising thing is that not a single person disagreed with the statement (Jordan, et al. 1986). In relation to this, it is clear that laypersons’ strong acceptance of the right of epileptic person to work was strictly conditional on the nature of the work. Ethiopian immigrants living in the Netherlands also reflected this kind of attitude.

In relation to approving a driving license, all research respondents strongly disagreed with issuing driving licenses to people living with epilepsy. All respondents do not even consider individuals with epilepsy fit to fly aircraft or drive cars. They claimed that these individuals were not reliable to maintain self-control.
According to respondents, “if they develop an epileptic seizure in high traffic areas, there is a huge catastrophe to human life and property of the nation.”

The concept of suffering was generated during the analysis of field data. This issue was particularly mentioned in relation to the decision to marry someone with epilepsy. All research respondents refused to accept being married to someone with epilepsy. One of the male respondents described his feelings of having marriage partner as follows:

Oh! This kind of thing is very hard and difficult to decide in our culture. Since it is a life long illness we should think twice before we decide. For me I do not want to have a wife with epilepsy and from the start I will defer not to marry. The reason is that I do not want to suffer life long and I do not want to have my wife having accidents of burn and other body injuries and it is also difficult to raise our child. Also to my relative I do not want her life to be miserable throughout and I will keep her decision with strong advice not to marry him. (Respondent two)

I would not do that. You see, life by itself is a suffering. If you add another big and obvious suffering it will be difficult to bear. Sorry for this kind of response (Respondent four)

The concept of sharing social life was also raised during the interview session and generated during analysis of fieldwork. This concept was considerably mentioned in relation to parties, wedding ceremony and funerals. The concept of sharing social life with peer groups was also explored from different participants. All research participants completely agreed on the full interaction of their child with another child having epilepsy. For example, to play together and also eat and drink even share utensils. Renting them a room in one compound and even sharing room together was also explored and the majority of the respondents seem to accept renting room rather than living in the same room. From the literature reviewed above (Ries, 1977) it was clear that social acceptance is inversely related to social distance. It is evident that the reflections of the participants in my research support this fact concerning marriage and sharing rooms. Willingness to marry someone was expressed by a research participant as follows.
I am sure that nobody is willing to give his child to a person with this problem. He cannot work properly and more over he cannot control him self. It is a burden for his marriage partner and parents. Already there is negative moral meaning attached to this kind of illness. (Respondent eight)

During analysis of fieldwork, the concepts of rights and dignity were also generated. These concepts were raised in relation to approval of marriage for individuals living with epilepsy, the question of having children and sending them to school. All research participants accepted approval of marriage for all people with epilepsy. They also said that we have to respect their reproductive rights and everybody in this world has problems. Concerning the issue of people with epilepsy having children, all participants of the research said that they deserve to have children and this is their reproductive right. The question of sending children with epilepsy to school was also another area where issues of human rights came up in our discussion. All research participants approved allowing education for someone having epilepsy.

During analysis of fieldwork the concept of contagiousness was also generated. This issue was raised in the interviews related to intimate contact with individuals having the disorder. Only one research participant mentioned and believed transmission through frequent direct contact.

It is difficult to live with this kind of individuals. Usually they live near church for support and help. Through long period of contact there is risk of acquiring epilepsy. It would be transmitted from person with epilepsy to priest. It will be wise not to have close contact for long time. It is good to safeguard myself without damaging his moral and psychological wellbeing. (Respondent eight)

The difference between epilepsy and other chronic illnesses was also discovered through interview. They said that epilepsy is a strange kind of illness. It is related to evil spirit, curse and punishment for sin. On the other hand other chronic illnesses are free from this kind of notion. Epilepsy is also unpredictable in its signs and symptoms provoke a strong social reaction. On the other hand, other chronic illnesses are predictable. Their signs and symptoms do not affect public attention. Epilepsy was considered to be like possession by the devil. This was not the case in other chronic illness.

These ideas can be seen from research participants as follows:
This is work of spirit, Satan spirit, which makes a person out of self-control, which governs him or possesses him. In Holland people consider this problem as a disease. I feel sad for the victim because he has illness inside him that took control of himself. All things happening to him were so frightening. Like shaking on the ground, protruding eyes, frothing of saliva and rigidity of body. One may think that he may die on the way and even the attack may come to your dreams. (Respondent nine)

Diabetes is easy to live with as compared to epilepsy. In case of diabetes someone has self-control and able to ask help. Unless the individual tells it is not possible to know his or her problem. On the other hand attacks of epilepsy will be known out of his will. It may throw him in front of many people and provokes strong social reaction and surprise. (Respondent five)

Of course it is dreadful. All things that were happening were strange and not seen in normal individuals. It threw the individual to the ground and you do not have the power of self-control something took that self control. You see losing self-control means a lot of damage to the social and psychological wellbeing. (Respondent four)

From literature reviewed, the value of control was given significant attention in the society.

The social structure survives through its experience of value of control, order and reason. Circumstances which threaten loss of control provoke a strong social reaction, be they in the crowd behaviour or in the deviant group, or in alcohol excess, or drug intoxication (Taylor, 1969:107).

(Goffman, 1968) also described that the psychological integrity of the individual depends on his ability to maintain the above-mentioned norms of the society.

All in all the social treatment of participants towards person with epilepsy depends on the situation in which these individuals present themselves. Situations that require reliability to maintain self-control and establish intimate relationship are mistreated in most cases. As reviewed from literature above, (Ries, 1977) found it to be true that the further the social distance from a person with epilepsy the greater the social treatment offered and rights respected. Contagionness was mentioned and believed by one unique respondent. All participants described the major difference of epilepsy from other chronic illness through its spectacular manifestation, contamination with demons and negative historical record.
CHAPTER-5

Conclusion and recommendations

This chapter consists of conclusions and recommendations. The conclusions and recommendations deal with the perceptions of Ethiopian immigrants living in the Netherlands. The study sample is not representative of all Ethiopian immigrants, but through in-depth interviewing, the data gathered was rich in content and can therefore give important insights. The perceptions of Ethiopian immigrants were explored through different kinds of questions. These research questions consisted of three elements namely: exploring awareness, attitudes and the way research participants deal with individuals living with epilepsy.

The perceived causes of epilepsy were medical, magico-religious, and naturalistic. From the analysis of field data it seems that most immigrants have little awareness about epilepsy as a neurological illness although injury to the head and brain infection were mentioned. In the literature biomedical knowledge about epilepsy was often contrasted with personalistic misconception such as witchcraft and spirit possession. However, most research participants perceived causes of epilepsy to be naturalistic but their knowledge about it was also superficial. They associated epilepsy with not performing specific rituals, exposure to strong light signals such as, the sun and the moon. The magico-religious causes were possession by the Devil, punishment for evil deeds from the ancestors and curses. Some research participants still hold misconceptions from their original culture. In the literature of epilepsy from a historical perspective I expected to come across misconceptions and my data conforms this. For example, although naturalistic explanations were dominant, possession by the devil was also still seen as a cause of epilepsy by some.

Treatment for epilepsy was associated with the perceived causes above. Medical treatment was thought not to produce cure but to reduce the frequency of seizures. Maintaining rituals like the coffee ceremony and smoking incense was seen as prevention against getting epilepsy. In terms of exposure to light signals, they recommended to avoid strong sources of light rays. In the magico-religious context Prayer and serial Holy Water treatment was seen as a mode of treatment. In terms of first aid for a person experiencing seizures, they seemed to know the common sense precautions like removing harmful materials from the surrounding environment. To
wake up a person with epilepsy from unconsciousness, they suggested that making the victim hold piece of metal, exposure to light from matchsticks and creating smoke near the nose was believed to revive him.

From the analysis of my data, it seems that most migrants were fearful about epileptic seizures and thus hold a negative attitude towards individuals living with epilepsy. Marriage, employment and issuing driving license were the three most important areas where most participants discriminated people with epilepsy.

Comparing epilepsy to other chronic illness, the participants viewed epilepsy as a unique form of illness with spectacular manifestation. The major differences of epilepsy as a chronic illness from others was particularly it’s strange symptoms. These strange symptoms include loss of self-control, loss of consciousness, convulsions, frothing of saliva, widely open and protruding eyes. These symptoms are not seen in other chronic illnesses. Another major difference of epilepsy from other chronic illness was its relation to possession by the Devil. Other chronic illnesses are clean from this kind of misconception. The third major difference of epilepsy from other chronic illness was the attachment of negative meanings that came from historical records. From historical point of view epilepsy was related to sin, punishment and curses. On the other hand majority of other chronic illnesses have clean historical record.

Generally speaking, six weeks of data gathering is not enough to fully understand the perceptions of Ethiopian immigrants in the Netherlands. Also, as mentioned in the introduction, this research concerned a relatively older group who have come to the Netherlands at least more than ten years ago. As such the data, the analysis and conclusions cannot be considered representative for the Ethiopian community in the Netherlands. Therefore my first recommendation is that more research should be done into conceptions of and attitudes against epilepsy and people with epilepsy among immigrant Ethiopian in the Netherlands. Such a research should also address the experiences of Ethiopian immigrants with epilepsy themselves.

However, on the basis of my data it has become clear that the awareness of Ethiopian immigrants is indeed problematic. Therefore my second recommendation is that a health education campaign is urgently needed to increase awareness about epilepsy and its management.
Abstract

The aim of this study was to explore the perceptions of epilepsy among Ethiopian immigrants living in the Netherlands. This study examines the effect of epilepsy on social relationships and how these social relationships also shape the meanings attached to epilepsy. It was also intended to investigate to what extent perceptions and the social acceptance of epilepsy change due to long periods of stay in a technologically advanced and economically developed society like the Netherlands. The study utilised qualitative methods for gathering data through fieldwork. The research was based on in-depth interviews with seven interviewees and three key informants. In connection to this research a number of secondary data was utilised. The findings of this study revealed that most Ethiopian immigrants living in the Netherlands have little awareness and progress in handling epilepsy. The level of social acceptance of epilepsy in areas of responsibility, establishing intimate relationships and their opinion on how people with epilepsy should be dealt with was found far behind western culture. The belief in contagiousness of a person with epilepsy was another important finding of the study and it still exists. This study also found that inappropriate treatment practice like creating smoke was used in the treatment of epileptic seizures. Based on the findings specific recommendations are suggested.
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1 The official definition of the seizure treatment gap (Meinardi et al 2001:137) is: the difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point of time, expressed as a percentage. This definition includes diagnostic and therapeutic deficits. Active epilepsy is defined as: Two or more unprovoked epileptic seizures on different days in the prior year that are disabling to the individual. And appropriate treatment is defined as: Diagnosis and treatment of underlying causes; treatment of recurrent seizures according to international standards.

2 The Antillean migrants descend from the former Netherlands Antilles. Other ethnic minorities of substantial size are the Muluccan, Chinese, and Cape-verdian migrants. Among the refugees and asylum seekers the Somali, Iraqi and Iranian, and refugees from the former Yugoslavia constitute the largest groups, approximately 30,000 persons each.
Annex

Research tool

Socio-demographic questions
  Identification of key informants or
  Name
  Age
  Sex
  Number of children
  Occupation
  Religion
  Income per month
  Language (mother tongue)
  Marital status
  Level of education

Awareness related questions
  1. Do you know the existence of falling disease?
  2. Have you read or heard something about epilepsy?
  3. From where did you get epilepsy information for the first time?
  4. Do you know a person with epilepsy?
  5. Have you seen someone having a seizure with you necked eyes?
  6. Do you know the manifestations of falling disease?
  7. Do you think epilepsy has other forms of expression?
  8. Do you think alcohol will have influence on epilepsy? If yes how?
  9. Do you think lack of sleep will have influence on epilepsy?
 10. Do you think epilepsy is a form of insanity?
 11. Do you think epilepsy is a punishment from God?
 12. Do you think epilepsy is hereditary disease?
 13. Do you think epilepsy is misfortune?
 14. Do you think epileptic attack can be prevented?
 15. What do you think the circumstance would be for convulsion to begin?
 16. Do you know about the things that provoke seizures?
 17. Do you think high-grade fever will bring an epileptic seizure?
18. Do you think and believe that this kind of illness has periodicity?
19. Do you think that epilepsy has something to do with sitting on goat’s skin, the moon, witchcraft, evil eyes
20. What do you think and know about the causes of this illness? Punishment from God, sin, possession, infections, trauma, contagious.
21. Do you think that epilepsy will be cured once and for all?
22. Do you know the ways of transmission of epilepsy? Can you tell me all the ways you think?
23. Is epilepsy a contagious disease?
24. Is it dangerous to help someone having convulsions?
25. Do you have information about local healers in relation to epilepsy?
26. Do all epileptic patients have the same symptoms?
27. Is epilepsy a disease that can be treated?
28. Do you the existence of other types of epilepsy?
29. May some seizures end in few seconds without anybody recognizing them?
30. Do you think that cure from cure from epileptic seizure is possible through modern medicine?
31. Have you seen that people with epilepsy taking their medications? If so are they complaining side effects like skin discoloration, rash or weight gain because of the prescribed medications?

Attitude and practice related questions

1. Do you think it is appropriate for a person with epilepsy to get married?
2. Do you think it is appropriate for a person with epilepsy to have a child?
3. If a person with epilepsy plans to marry your relative how do you this?
4. If a person with epilepsy plans to marry your daughter will you approve?
5. Would you marry a person with epilepsy?
6. Do you think that epilepsy is dreadful? If so why?
7. Can epilepsy bring psychological and emotional disturbance?
8. Would you approve of your child’s sharing activities and full interaction with a friend with epilepsy?
9. Would you approve if your son or daughter married a person with epilepsy?

10. Do you think that a person with epilepsy can leave alone?

11. What do you advice someone who has epilepsy?

12. If you have a work colleague with epilepsy how do you handle him?

13. If you are the manager of an organization and if one of the top candidates is having epilepsy, how do you react towards him?

14. Do you think that people with epilepsy can have driving license?

15. How do you react if a person with epilepsy utilizes public transport?

16. Do you find it acceptable to work with a person with epilepsy (colleague) at work?

17. If you compare epilepsy with asthma, diabetes and cancer which kind of illness will be easy to live with in your opinion?

18. If you are given the chance to compare and chose one out of the two conditions which one will you prefer to live with? Epilepsy with blind, epilepsy with deafness, epilepsy with alcoholic, epilepsy with poliomyelitis, epilepsy with mental illness, epilepsy with HIV/AIDS.

19. Can a person with epilepsy be successful in some specific professions like physician, scientist and engineers as any ordinary people?

20. Do you allow a child with epilepsy to attend school?

21. Can a child with epilepsy be successful in a normal class?

22. Do you think that people with epilepsy should not often participate in social activities because of having frequent seizures?

23. Is it necessary for a person to be prevented from participating in sports activities?

24. If someone has epilepsy for many years is it possible to help him through modern health care?

25. Do you think that person with epilepsy needs life long medication?

26. Do you believe that every body with epileptic seizure has to use drug treatment?

27. Do you think that Smelling traditional herbs and ignited matchsticks or ginger and onion help to stop seizures?

28. Do you think that holding the arms and legs is sensible during convulsions?
29. Do you know how to help a patient with epilepsy during convulsion?
30. Do you think that person with epilepsy die of convulsions?
31. Do you think and know that the presence of moments of separation from parents for individuals with epilepsy?
32. Do you feel shame for this kind of illness? If yes explain
33. Do you rent room for person with epilepsy?
34. Do you share room together with a person having an epileptic seizure?
35. Do you think cooking, fetching water, getting firewood, and riding a bike would be good jobs for person with epilepsy?
36. Do you recommend special kind of meal or fasting or prayer for people with epilepsy?