

Awareness and Knowledge of Epilepsy among the Population of Rohingya Refugee Camp in Cox's Bazar, Bangladesh".

Mohammad Musahidur Rahman Khan

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ABSTRACT

Introduction: Epilepsy is a neurological disorder characterized by recurrent unprovoked seizures which is transient with abnormal, excessive and synchronous neuronal activity in the brain. It is a common and chronic neurologic disorder worldwide. Aim of the Study: To find out awareness and knowledge about epilepsy among the population of Rohingya refugee camp in Cox's-Bazar. Materials & Methods: It was a descriptive type of cross-sectional study. Kutupalong Rohingya refugee camp (Cox'sBazar) had been covered as study population. Semi-structured and modified interview administrated questionnaire had been followed to collect data properly. Results: Out of 205 respondents there were 68% (140) were Illiterate and only less then 01% (1)respondents found Graduate. 32% respondents were jobless and 33% respondents of them were self-employed. 77% of respondents were earning <5000 BDT which was really very low amount to survive. Around 50% respondents had good knowledge of Epilepsy symptoms, but they didn't know the first aid of epilepsy. Only 15% respondents know that it's medically treatable. A total of 76% respondents of them did not know that it is a neurodevelopmental disorder. 42% respondents didn't know the causes of epilepsy and 20% believed that It's an evil spirit.Discussion: Though 11% respondents had experience as they had family members diagnosed with Epilepsy and 78% had witness of sudden Seizure attack, still now 24% respondentsdid not know, 12% to 15% respondents had know (because their family members also suffering), 61% to 64% respondents had both correct and incorrect Knowledge about first aid of epilepsy. The community people must be counselled with training about Epilepsy, its diagnosis, first aid and treatment procedure. Conclusion: They were living in poor socio-demographiccondition. Awareness and consciousness very much depend on proper

knowledge on particular issues. **Recommendation:** It is advisable for an education program aimed at improving knowledge and attitude towards epilepsy held in the study area.

I. INTRODUCTION

1.1 Background:

Epilepsy is a neurological disorder characterized by recurrent unprovoked seizures which is transient with abnormal, excessive and synchronous neuronal activity in the brain ^[1]. It is a common and chronic neurologic disorder worldwide. The prevalence of epilepsy varies among countries which may be 1.5 in developed countries to 18 per 1000 in Latin America^[2]. It has been estimated that 80.0% of 50 million people with epilepsy reside in developing countries ^[3]. The risk of having epilepsy at some point in average life span of any individual varies between 2.0% to 5.0%². Some hospital and community-based studies from South East Asian countries (SEAR) have reported the incidence of epilepsy from 2 to 10 per thousand population ^[4]. WHO estimates that there are at least 1.5 to 2.0 million people with epilepsy in Bangladesh ^[2]. The incidence and prevalence of epilepsy being higher in poor areas which maybe 49 to 225 per 100,000 people per year which poses a huge social and economic burden to the poor 5. It is very interesting that about half of the total epilepsy population lives in Asia [3]. The annual mortality rate per 100,000 people from epilepsy in Bangladesh has decreased by 52.4% since 1990, an average of 2.3% a year ⁵. Though this has been the trend overall, adjust the filters at the top of the visualization to see how the mortality rate for epilepsy has changed over time for men and women of specific age groups in Bangladesh; for men, the deadliness of epilepsy in Bangladesh peaks at age 80+. It kills men at the lowest rate at age 5 to 9 years. At 11.5 deaths per 100,000 men in 2013, the peak mortality rate for men was higher



than that of women, which was 8.1 per 100,000 women. Women are killed at the highest rate from epilepsy in Bangladesh at age 75 to 79. It was least deadly to women at age 65-69 years.

Childhood epilepsy is a great concern to Neurologist. The incidence of epilepsy is high in childhood which decreases in adulthood and can rise again in older age. The first peak occurs in the childhood as well as the young adults; however, another peak age is in old age ^[6]. Epilepsy cases are reported higher in rural area than in urban area especially in developing countries ^[7]. Epilepsy is a common health problem in Bangladesh and 30.0 to 40.0% of patients are still treated by traditional healer ^[8]. Superstitious belief is a stigmata in the community. There are several causes of treatment failure include improper compliance, incorrect diagnosis, inappropriate drug, dose & duration, and lastly refractory epilepsy ^[8]. The most common cause of non-compliance is cost of drug; however, other causes for noncompliance include nonaffordability of drugs, unavailability of drugs, inadequate knowledge and attitude, lack of counseling, adverse effects of drug, social factors 8-11; however, 50 to 60.0% patients remain symptoms free with 4 common $drugs^{-1}$. Though most of the anti-epileptic drugs (AEDs) are cheap, the volume of prescription and duration of treatment often makes the expenditure high enough for the poor. As the definition implies, epilepsy is a disorder of uncertainty and unpredictability. A seizure event can occur anytime, anywhere without warning; causing embarrassment, injury or even death of the person. This may have a disastrous effect on employment and independence. About 50% of the patients become seizure free with the first drug tried and can lead a normal life. Seizure can be controlled with mono-therapy in majority of them. This usually requires careful and rigid adherence to drug regimens, which involve taking tablets regularly, two or three times each day for many years, sometimes for a lifetime. Physicians often judge the effectiveness of treatment by gross clinical response. There are wide variations in each person's response to treatment, and the plasma concentration of AEDs provides little information about a person's likelihood of reduction of seizures or side-effects. The available data on effectiveness of drugs are mostly from the western studies [8]. But the drug response and effectiveness may vary depending on the genetic. environmental, pharmaco-dynamic and pharmacokinetic interaction in different racial groups. Moreover, the cost of AEDs often poses a treatment gap in management of epilepsy, especially in least developed country like Bangladesh^[8].

Bangladesh is one of the densely populated countries in the world where infectious malnutrition diseases, and many chronic neurological disorders are quite common. Although there is no national statistics yet in our country but there are some hospital-based studies that reflect to some extent the situation of epilepsy in Bangladesh. Studies in developed countries shows prevalence rate of about 5 per 1,000 populations whereas in developing countries it is higher. Men are more often affected than female and rural populations are affected more than the urban populations. Based on the prevalence rate of 10 per 1,000 populations, the number of epilepsy patients in Bangladesh is about 1.3 million. The common ages of epileptic patients in Bangladesh are between 16 to 31 years. The etiology varies with age. Birth trauma, birth asphyxia, central nervous system infections are common in neonate and infancy whereas head trauma, brain tumor, stroke, infections are common causes in middle aged and elderly. Vast majority of the people in Bangladesh does have superstitious belief about Epilepsy. This belief usually is a strong barrier for total care of patients with epilepsy. Misunderstanding and negative attitude of the parents, family members and society towards epilepsy are still prevalent. Thus, many patients with epilepsy are still neglected in diagnosis, treatment, education, rehabilitation and other social needs. The epilepsy patients are often reluctant to seek advice from physicians. Rather they believe epilepsy has no cure and they seek advice from indigenous medicine practitioner 'Kabiraj', snake charmer 'Ojha' and spiritual healers. A report of 130 patients from the epilepsy clinic of BSMMU (a government post-graduate medical center) showed that close to 70% of patients visited indigenous medicine practitioners, exorcists, spiritualists prior to consulting the clinic, only 29% perceived epilepsy as a disease, 50% dropped out from school (58% of whom due to epilepsy), and 52% of patients had to change job because of epilepsy ^[9]. Appropriate antiepileptic drugs are sometime unavailable in Bangladesh. The BSMMU study showed 23% of patients found it difficult to continue treatment due to financial problem [9]. Financial factor is likely to partly account for the treatment gap.

Community awareness is needed to reduce the burden of the disease. Training of doctors is necessary for appropriate approach. National guideline for treatment of epilepsy is needed. Community based clinic needed to treat the epileptic patient in rural areas. International Epilepsy Day is a special event which promotes



awareness of epilepsy in more than 120 countries each year. Every year on the second Monday of February people join together to celebrate and highlight the problems faced by people with epilepsy, their families and careers. This is a day for everyone, focus on the medical or the social aspects of the disease. Celebrate International Epilepsy Day. Let's speak with one global voice. The Day is a joint initiative by the International Bureau for Epilepsy (IBE) and the International League against Epilepsy (ILAE).

1.2 Epilepsy and some Information:

Epilepsy is a group of neurological disorders characterized by recurrent epileptic seizures. Epileptic seizures are episodes that can vary from brief and nearly undetectable periods to long periods of vigorous shaking.^[1] These episodes can result in physical injuries, including occasionally broken bones.^[1] In epilepsy, seizures have a tendency to recur and, as a rule, have no immediate underlying cause. Isolated seizures that are provoked by a specific cause such as poisoning are not deemed to represent epilepsy.^[12] People with epilepsy may be treated differently in various areas of the world and experience varying degrees of social stigma due to their condition.^[1]

The underlying mechanism of epileptic seizures is excessive and abnormal neuronal activity in the cortex of the brain. The reason this occurs in most cases of epilepsy is unknown.^[1] Some cases occur as the result of brain injury, stroke, brain tumors, infections of the brain, or birth defects through a process known as epileptogenesis.^{[1] [2] [3]} Known genetic mutationsare directly linked to a small proportion of cases.^{[4][10]} The diagnosis involves ruling out other conditions that might cause similar symptoms, such as fainting, and determining if another cause of seizures is present, such as alcohol withdrawal or electrolyte problems.^[4] This may be partly done by imaging the brain and performing blood tests.^[4] Epilepsy can often be confirmed with an electroencephalogram (EEG), but a normal test does not rule out the condition.^[4]

Epilepsy that occurs as a resultof other issues may be preventable.^[1] Seizures are controllable with medication in about 70% of cases;^[7] inexpensive anti-seizure medications are often available.^[1] In those whose seizures do not respond to medication, surgery, neurostimulation or dietary changes may then be considered.^{[5] [6]}Not all cases of epilepsy are lifelong, and many people improve to the point that treatment is no longer needed.^[1] As of 2015, about 39 million people have epilepsy.^[8] Nearly 80% of cases occur in the developing world.^[1] In 2015, it resulted in 125,000 deaths, an increase from 112,000 in 1990.^[9] Epilepsy is more common in older people. In the developed world, onset of new cases occurs most frequently in babies and the elderly. In the developing world, onset is more common in older children and young adults due to differences in the frequency of the underlying causes.^[11]

1.3 Definition:

- 1. At least two unprovoked (or reflex) seizures occurring more than 24 hours apart.
- 2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years.
- 3. Diagnosis of an epilepsy syndrome.

Epilepsy is a disorder of the brain defined by any of the following conditions:

1.4 Epidemiology:

Epilepsy is one of the most common serious neurological disorders affecting about 39 million people as of 2015.^[8] It affects 1% of the population by age 20 and 3% of the population by age 75. It is more common in males than females with the overall difference being small.^[11]

The estimated prevalence of active epilepsy (as of 2012) is in the range 3–10 per 1,000, with active epilepsy defined as someone with epilepsy who has had a least one unprovoked seizure in the last five years. Epilepsy begins each year in 40–70 per 100,000 in developed countries and 80–140 per 100,000 in developing countries. Poverty is a risk and includes both being from a poor country and being poor relative to others within one's country.^[11] In the developed world epilepsy most commonly starts either in the young or in the old.^[11] In the developing world its onset is more common in older children and young adults due to the higher rates of trauma and infectious diseases.^[11]

1.5 Prognosis:

Epilepsy cannot usually be cured, but medication can control seizures effectively in about 70% of cases.^[7] Of those with generalized seizures, more than 80% can be well controlled with medications while this is true in only 50% of people with focal seizures.^[5] One predictor of long-term outcome is the number of seizures that occur in the first six months.^[13] Other factors increasing



the risk of a poor outcome include little response to the initial treatment, generalized seizures, a family history of epilepsy, psychiatric problems, and waves on the EEG representing generalized epilepsy. In the developing world, 75% of people are either untreated or not appropriately treated.^[14] In Africa, 90% do not get treatment.^[14] This is partly related to appropriate medications not being available or being too expensive.^[14]

1.6 Mortality:

People with epilepsy are at an increased risk of death. This increase is between 1.6 and 4.1 fold greater than that of the general population.^[21] The greatest increase in mortality from epilepsy is among the elderly.^[21] Those with epilepsy due to an unknown cause have little increased risk.^[21]

In the United Kingdom, it is estimated that 40–60% of deaths are possibly preventable.^[13] In the developing world, many deaths are due to untreated epilepsy leading to falls or status epilepticus.^[11]

1.7 Causes:

Epilepsy can have both genetic and acquired causes, with interaction of these factors in many cases. Established acquired causes include serious brain trauma, stroke, tumors and problems in the brain as a result of a previous infection. In about 60% of cases the cause is unknown.^{[13][14]} Epilepsies caused by genetic, congenital, or developmental conditions are more common among younger people, while brain tumors and strokes are more likely in older people.^[13]

Seizures may also occur as a consequence of other health problems; if they occur right around a specific cause, such as a stroke, head injury, toxic ingestion or metabolic problem, they are known as acute symptomatic seizures and are in the broader classification of seizure-related disorders rather than epilepsy itself.

1.8 Genetics:

Genetics is believed to be involved in the majority of cases, either directly or indirectly.^[10] Some epilepsies are due to a single gene defect (1–2%); most are due to the interaction of multiple genes and environmental factors.^[10] Each of the single gene defects is rare, with more than 200 in all described. Most genes involved affect ion channels, either directly or indirectly. These include genes for ion channels themselves, enzymes, GABA, and G protein-coupled receptors.

In identical twins, if one is affected there is a 50–60% chance that the other will also be affected.^[10] In non-identical twins the risk is 15%.^[10] These risks are greater in those with generalized rather than focal seizures.^[10] If both twins are affected, most of the time they have the same epileptic syndrome (70-90%).^[10]

1.9 Acquired:

Epilepsy may occur as a result of a number of other conditions including tumors, strokes, head trauma, previous infections of the central nervous system, genetic abnormalities, and as a result of brain damage around the time of birth.^[14] Of those with brain tumors, almost 30% have epilepsy, making them the cause of about 4% of cases.^[15] The risk is greatest for tumors in the temporal lobe and those that grow slowly.^[15] Other mass lesions such as cerebral cavernous malformations and arteriovenous malformations have risks as high as 40-60%.^[15] Of those who have had a stroke, 2–4% develop epilepsy.^[15] In the United Kingdom strokes account for 15% of cases and it is believed to be the cause in 30% of the elderly.^{[13][15]} Between 6 and 20% of epilepsy is believed to be due to head trauma. Mild brain injury increases the risk about two-fold while severe brain injury increases the risk seven-fold. In those who have experienced a high-powered gunshot wound to the head, the risk is about 50%.^[15]

1.10 Signs and symptoms:

Epilepsy is characterized by a long-term risk of recurrent seizures. These seizures may present in several ways depending on the part of the brain involved and the person's age.^[13]

1.10.1 Seizures:

The most common type (60%) of seizures are convulsive.^[13] Of these, one-third begin as generalized seizures from the start, affecting both hemispheres of the brain. Two-thirds begin as focal seizures (which affect one hemisphere of the brain) which may then progress to generalized seizures.^[13] The remaining 40% of seizures are non-convulsive. An example of this type is the absence seizure, which presents as a decreased level of consciousness and usually lasts about 10 seconds.^[2]

Focal seizuresare often preceded by certain experiences, known as auras. They include sensory (visual, hearing, or smell), psychic, autonomic, and motor phenomena.^[2] There are six main types of generalized seizures: tonic-clonic, tonic, clonic, myoclonic, absence and atonic seizures. They all involve loss of consciousness and typically happen without warning.

Tonic-clonic seizures occur with a contraction of the limbs followed by their extension along with arching of the back which lasts 10–30 seconds (the tonic phase). A cry may be heard



due to contraction of the chest muscles, followed by a shaking of the limbs in unison (clonic phase). Tonic seizures produce constant contractions of the muscles. A person often turns blue as breathing is stopped. In clonic seizures there is shaking of the limbs in unison. After the shaking has stopped it may take 10–30 minutes for the person to return to normal; this period is called the "postictal state" or "postictal phase." Loss of bowel or bladder control may occur during a seizure.^[14]

Myoclonic seizures involve spasms of muscles in either a few areas or all over. Absence seizures can be subtle with only a slight turn of the head or eye blinking.^[2] The person does not fall over and returns to normal right after it ends.^[2] Atonic seizures involve the loss of muscle activity for greater than one second.

About 6% of those with epilepsy have seizures that are often triggered by specific events and are known as reflex seizures. Those with reflex epilepsy have seizures that are only triggered by specific stimuli.^[33] Common triggers include flashing lights and sudden noises. In certain types of epilepsy, seizures happen more often during sleep and in other types they occur almost only when sleeping.^[35]

1.10.2 Post-ictal:

After the active portion of a seizure (the ictal state) there is typically a period of recovery during which there is confusion, referred to as the postictal period before a normal level of consciousness returns. It usually lasts 3 to 15 minutes but may last for hours. Other common symptoms include feeling tired, headache, difficulty speaking, and abnormal behavior. Psychosis after a seizure is relatively common, occurring in 6–10% of people. Often people do not remember what happened during this time. Localized weakness, known as Todd's paralysis, may also occur after a focal seizure. When it occurs it typically lasts for seconds to minutes but may rarely last for a day or two.

1.10.3 Psychosocial:

Epilepsy can have adverse effects on social and psychological well-being. These effects may include social isolation, stigmatization, or disability.^[13] They may result in lower educational achievement and worse employment outcomes. Learning disabilities are common in those with the condition, and especially among children with epilepsy.^[13] The stigma of epilepsy can also affect the families of those with the disorder.^[14]

Normally brain electrical activity is nonsynchronous, as neurons do not normally fire in sync with each other, but rather fire in order as signals travel throughout the brain.^[2] Its activity is regulated by various factors both within the neuron and the cellular environment. Factors within the neuron include the type, number and distribution of ion channels, changes to receptors and changes of gene expression.

1.11.1 Epilepsy:

The exact mechanism of epilepsy is unknown, but a little is known about its cellular and network mechanisms. However, it is unknown under which circumstances the brain shifts into the activity of a seizure with its excessive synchronization.

In epilepsy, the resistance of excitatory neurons to fire during this period is decreased.^[2] This may occur due to changes in ion channels or inhibitory neurons not functioning properly.^[2] This then results in a specific area from which seizures may develop, known as a "seizure focus".^[2] Another mechanism of epilepsy may be the upregulation of excitatory circuits or down-regulation of inhibitory circuits following an injury to the brain.^{[2][3]} These secondary epilepsies occur through processes known as epileptogenesis.^{[2][3]} Failure of the blood–brain barrier may also be a causal mechanism as it would allow substances in the blood to enter the brain.

1.11.2 Seizures:

There is evidence that epileptic seizures are usually not a random event. Seizures are often brought on by factors such as stress, alcohol abuse, flickering light, or a lack of sleep, among others. The term seizure thresholdis used to indicate the amount of stimulus necessary to bring about a seizure. Seizure threshold is lowered in epilepsy.

In epileptic seizures a group of neurons begin firing in an abnormal, excessive,^[13] and synchronized manner.^[2] This results in a wave of depolarization known as a paroxysmal depolarizing shift. Normally, after an excitatory neuron fires it becomes more resistant to firing for a period of time.^[2] This is due in part to the effect of inhibitory neurons, electrical changes within the excitatory neuron, and the negative effects of adenosine.^[2]

Focal seizures begin in one hemisphere of the brain while generalized seizures begin in both hemispheres. Some types of seizures may change brain structure, while others appear to have little effect. Gliosis, neuronal loss, and atrophy of specific areas of the brain are linked to epilepsy but it is unclear if epilepsy causes these changes or if these changes result in epilepsy.



1.12 Diagnosis:

The diagnosis of epilepsy is typically made based on observation of the seizure onset and the underlying cause.^[24] An electroencephalogram (EEG) to look for abnormal patterns of brain waves and neuroimaging (CT scan or MRI) to look at the structure of the brain are also usually part of the workup.^[24] While figuring out a specific epileptic syndrome is often attempted, it is not always possible.^[24]Video and EEG monitoring may be useful in difficult cases.^[16]

1.13 Classification:

In contrast to the classification of seizures which focuses on what happens during a seizure, the classification of epilepsies focuses on the underlying causes. When a person is admitted to hospital after an epileptic seizure the diagnostic workup results preferably in the seizure itself being classified (e.g. tonic-clonic) and in the underlying disease being identified (e.g. hippocampal sclerosis).^[16] The name of the diagnostic results and the applied definitions and classifications (of seizures and epilepsies) and its respective terminology.

The International League Against Epilepsy (ILAE) provided a classification of the epilepsies and epileptic syndromes in 1989 as follows:^[17]

- 1. Localization-related epilepsies and syndromes
- 1. Unknown cause (e.g. benign childhood epilepsy with centrotemporal spikes)
- 2. Symptomatic/cryptogenic (e.g. temporal lobe epilepsy)
- 2. Generalized
- 1. Unknown cause (e.g. childhood absence epilepsy)
- 2. Cryptogenic or symptomatic (e.g. Lennox-Gastaut syndrome)
- 3. Symptomatic (e.g. early infantile epileptic encephalopathy with burst suppression)
- 3. Epilepsies and syndromes undetermined whether focal or generalized
- 1. With both generalized and focal seizures (e.g. epilepsy with continuous spike-waves during slow wave sleep)

Special syndromes (with situation-related seizures)

This classification was widely accepted but has also been criticized mainly because the underlying causes of epilepsy (which are a major determinant of clinical course and prognosis) were not covered in detail. In 2010 the ILAE Commission for Classification of the Epilepsies addressed this issue and divided epilepsies into three categories (genetic, structural/metabolic, unknown cause) that were refined in their 2011 recommendation into four categories and a number of subcategories reflecting recent technologic and scientific advances.^[18]

- 1. Unknown cause (mostly genetic or presumed genetic origin)
- 1. Pure epilepsies due to single gene disorders
- 2. Pure epilepsies with complex inheritance
- 2. Symptomatic (associated with gross anatomic or pathologic abnormalities)
- 1. Mostly genetic or developmental causation
- 1. Childhood epilepsy syndromes
- 2. Progressive myoclonic epilepsies
- 3. Neurocutaneous syndromes
- 4. Other neurologic single gene disorders
- 5. Disorders of chromosome function
- 6. Developmental anomalies of cerebral structure
- 2. Mostly acquired causes
- 1. Hippocampal sclerosis
- 2. Perinatal and infantile causes
- 3. Cerebral trauma, tumor or infection
- 4. Cerebrovascular disorders
- 5. Cerebral immunologic disorders
- 6. Degenerative and other neurologic conditions
- 3. Provoked (a specific systemic or environmental factor is the predominant cause of the seizures)
- 1. Provoking factors
- 2. Reflex epilepsies
- Cryptogenic (presumed symptomatic nature in which the cause has not been identified)^[18]

1.14 Management:

Epilepsy is usually treated with daily medication once a second seizure has occurred,^{[13][16]} while medication may be started after the first seizure in those at high risk for subsequent seizures.^[16] Supporting people's selfmanagement of their condition may be useful. In drug-resistant cases different management options may be looked at including a special diet, the implantation of a neurostimulator, or neurosurgery.

1.14.1 First Aid:

Rolling a person with an active tonicclonic seizure onto their side and into the recovery position helps prevent fluids from getting into the lungs. Putting fingers, a bite block or tongue depressor in the mouth is not recommended as it



might make the person vomit or result in the rescuer being bitten. Efforts should be taken to prevent further self-injury. Spinal precautionsare generally not needed.

If a seizure lasts longer than 5 minutes or if there are more than two seizures in an hour without a return to a normal level of consciousness between them, it is considered a medical emergency known as status epilepticus.^[16] This may require medical help to keep the airway open and protected;^[16] a nasopharyngeal airway may be useful for this. At home the recommended initial medication for seizure of a long duration is midazolam placed in the mouth. Diazepammay also be usedrectally. In hospital, intravenous lorazepam is preferred.^[16] If two doses of benzodiazepines are not effective, other medications such as phenytoinare recommended.^[16] Convulsive status epilepticus that does not respond to initial treatment typically requires admission to the intensive care unit and treatment with stronger agents such as thiopentone or propofol.^[16]

1.14.2 Anticonvulsants:

The mainstay treatment of epilepsy is anticonvulsant medications, possibly for the person's entire life.^[13] The choice of anticonvulsant is based on seizure type, epilepsy syndrome, other medications used, other health problems, and the person's age and lifestyle. A single medication is recommended initially; if this is not effective, switching to a single other medication is recommended.^[16] Two medications at once is recommended only if a single medication does not work.^[16] In about half, the first agent is effective; a second single agent helps in about 13% and a third or two agents at the same time may help an additional 4%. About 30% of people continue to have seizures despite anticonvulsant treatment.^[7]

There are a number of medications available including phenytoin, carbamazepine and valproate. Evidence suggests that phenytoin, carbamazepine, and valproate may be equally effective in both focal and generalized seizures. Controlled release carbamazepine appears to work as well as immediate release carbamazepine, and may have fewer side effects. In the United Kingdom. carbamazepine or lamotrigineare recommended as first-line treatment for focal seizures, with levetiracetam and valproate as second-line due to issues of cost and side effects.^[16] Valproate is recommended first-line for generalized seizures with lamotrigine being second-line.^[16] In those with absence seizures, ethosuximide or valproate are recommended; valproate is particularly effective in myoclonic seizures and

tonic or atonic seizures. If seizures are wellcontrolled on a particular treatment, it is not usually necessary to routinely check the medication levels in the blood.^[16]

The least expensive anticonvulsant is phenobarbital at around US\$5 a year.^[11] The World Health Organization gives it a first-line recommendation in the developing world and it is commonly used there. Access however may be difficult as some countries label it as a controlled drug.^[11]

Slowly stopping medications may be reasonable in some people who do not have a seizure for two to four years; however, around a third of people have a recurrence, most often during the first six months.^[16] Stopping is possible in about 70% of children and 60% of adults.^[14] Measuring medication levels is not generally needed in those whose seizures are well controlled.

1.14.3 Surgery:

Neurostimulation may be another option in those who are not candidates for surgery.^[16] Three types have been used in those who do not respond to medications: vagus nerve stimulation, anterior thalamic stimulation, and closed-loop responsive stimulation.^[5]

1.14.4 Diet:

There is promising evidence that a ketogenic diet (high-fat, low-carbohydrate, adequate-protein) decreases the number of seizures and eliminate seizures in some; however, further research is necessary.^[6] It is a reasonable option in those who have epilepsy that is not improved with medications and for whom surgery is not an option.^[6] About 10% stay on the diet for a few years due to issues of effectiveness and tolerability.^[6] Side effects include stomach and intestinal problems in 30%, and there are long-term concerns about heart disease.^[6]

1.14.5 Other:

Avoidance therapy consists of minimizing or eliminating triggers. For example, those who are sensitive to light may have success with using a small television, avoiding video games, or wearing dark glasses. Operant-based biofeedback based on the EEG waves has some support in those who do not respond to medications. Psychological methods should not, however, be used to replace medications.^[16]

Exercise has been proposed as possibly useful for preventing seizures, with some data to support this claim. Some dogs, commonly referred to as seizure dogs, may help during or after a seizure. It is not clear if dogs have the ability to predict seizures before they occur.



1.14.6 Alternative medicine:

Alternative medicine, including acupuncture, routine vitamins, and yoga, have no reliable evidence to support their use in epilepsy. Melatonin, as of 2016, is insufficiently supported by evidence. The trials were of poor methodological quality and it was not possible to draw any definitive conclusions.

1.15 Prevention:

While many cases are not preventable, efforts to reduce head injuries, provide good care around the time of birth, and reduce environmental parasites such as the pork tapeworm may be effective.^[14] Efforts in one part of Central America to decrease rates of pork tapeworm resulted in a 50% decrease in new cases of epilepsy.^[11]

1.16 Problems Statement: Society and culture:

Epilepsy can have both genetic and acquired causes, with interaction of these factors in many cases. Established acquired causes include serious brain trauma, stroke, tumors and problems in the brain as a result of a previous infection. In about 60% of cases the cause is unknown. Epilepsies caused by genetic, congenital, or developmental conditions are more common among younger people, while brain tumors&strokes are more likely in older people.

Seizures may also occur as a consequence of other health problems; if they occur right around a specific cause, such as a stroke, head injury, toxic ingestion or metabolic problem, they are known as acute symptomatic seizures and are in the broader classification of seizure-related disorders rather than epilepsy itself.

For every 1000 people in Bangladesh aged 1 month and older, there are almost 9 cases of epilepsy. Bangladesh is one of the densely populated countries in the world where infectious diseases, malnutrition and many chronic neurological disorders are quite common. Although there is no national statistics yet in our country but there are some hospital based studies that reflect to some extent the situation of epilepsy in Bangladesh. Studies in developed countries shows prevalence rate of about 5 per 1,000 populations whereas in developing countries it is higher. Men are more often affected than female and rural populations are affected more than the urban populations.

Based on the prevalence rate of 10 per 1,000 populations, the number of epilepsy patients in Bangladesh is about 1.3 million. The common ages of epileptic patients in Bangladesh are between 16 to 31 years. The etiology varies with

age. Birth trauma, birth asphyxia, central nervous system infections are common in neonate and infancy whereas head trauma, brain tumor, stroke, infections are common causes in middle aged and elderly. Vast majority of the people in Bangladesh does have superstitious belief about Epilepsy. This belief usually is a strong barrier for total care of patients with epilepsy.

Misunderstanding & negative attitude of parents, family members and society towards epilepsy are still prevalent. Thus, many patients with epilepsy are still neglected in diagnosis, treatment, education, rehabilitation and other social needs.Epilepsy patients are often reluctant to seek advice from physicians. Rather they believe epilepsy has no cure and they seek advice from indigenous medicine practitioner 'Kabiraj', snake charmer 'Ojha' and spiritual healers.

A report of 130 patients from the epilepsy clinic of BSMMU (a government post-graduate medical center) showed that close to 70% of patients visited indigenous medicine practitioners, exorcists, spiritualists prior to consulting the clinic, only 29% perceived epilepsy as a disease, 50% dropped out from school (58% of whom due to epilepsy), and 52% of patients had to change job because of epilepsy. Appropriate antiepileptic drugs are sometime unavailable in Bangladesh. The BSMMU study showed 23% of patients found it difficult to continue treatment due to financial problem. Financial factor is likely to partly account for the treatment gap. The most common type of epilepsy is primary generalized tonic clonic seizure, followed by partial epilepsy. The survey revealed a concerning treatment gap – nine out of every ten persons with active epilepsy were not receiving appropriate treatment. Until now, there has been a lack of national data on epilepsy in Bangladesh.

Stigma:

Stigma is commonly experienced, around the world, by those with epilepsy. It can affect people economically, socially and culturally. In India and China, epilepsy may be used as justification to deny marriage.^[14] People in some areas still believe those with epilepsy to be cursed.^[111] In parts of Africa, such as Tanzania and Uganda, epilepsy is incorrectly claimed to be associated with possession by evil spirits, witchcraft, or poisoning and is believed by many to be contagious.^[11] Before 1971 in the United Kingdom, epilepsy was considered grounds for the annulment of marriage.^[14] The stigma may result in some people with epilepsy denying that they have ever had seizures.



Economics:

Seizures result in direct economic costs of about one billion dollars in the United States. Epilepsy resulted in economic costs in Europe of around 15.5 billion Euros in 2004.^[13] In India epilepsy is estimated to result in costs of US\$1.7 billion or 0.5% of the GDP.^[14] It is the cause of about 1% of emergency department visits (2% for emergency departments for children) in the United States.

Vehicles:

Those with epilepsy are at about twice the risk of being involved in a motor vehicular collision and thus in many areas of the world are not allowed to drive or only able to drive if certain conditions are met.^[12] In some places physicians are required by law to report if a person has had a seizure to the licensing body while in others the requirement is only that they encourage the person in question to report it themselves.^[12] Countries that require physician reporting include Sweden, Austria, Denmark and Spain.^[12] Countries that require the individual to report include the UK and New Zealand and the physician may report if they believe the individual has not already.^[12] In Canada, the United States and Australia the requirements around reporting vary by province or state.^[12] If seizures are well controlled most feel allowing driving is reasonable.^[22] The amount of time a person must be free from seizures before they can drive varies by country.^[22] Many countries require one to three years without seizures.^[147] In the United States the time needed without a seizure is determined by each state and is between three months and one year.^[22]

1.17 Objective of the Study: A. General Objective:

01. To find out awareness and knowledge of epilepsy among the Population of Rohingya refugee camp in Cox's-Bazar Area.

B. Specific Objectives:

01. To determine awareness about epilepsy among the respondents (Rohingya Population).

02. To determine knowledge about epilepsy among the respondents (Rohingya Population).

03. To identify socio-demography characteristics of the respondents (Rohingya Population).

C. Research Question:

01. How people are aware about Epilepsy Diseases in studied area?

II. LITERATURE REVIEW:

Bangladesh is one of the densely populated countries in the world where infectious diseases, malnutrition and many chronic neurological disorders are quite common. Although there is no national statistics vet in our country but there are some hospital based studies that reflect to some extent the situation of epilepsy in Bangladesh. Studies in developed countries shows prevalence rate of about 5 per 1,000 populations whereas in developing countries it is higher. Men are more often affected than female and rural populations are affected more than the urban populations. Based on the prevalence rate of 10 per 1,000 populations, the number of epilepsy patients in Bangladesh is about 1.3 million.

The epilepsy patients are often reluctant to seek advice from physicians. Rather they believe epilepsy has no cure and they seek advice from indigenous medicine practitioner 'Kabiraj', snake charmer 'Ojha' and spiritual healers. A report of 130 patients from the epilepsy clinic of BSMMU (a government post-graduate medical center) showed that close to 70% of patients visited indigenous medicine practitioners, exorcists, spiritualists prior to consulting the clinic, only 29% perceived epilepsy as a disease, 50% dropped out from school (58% of whom due to epilepsy), and 52% of patients had to change job because of epilepsy. The BSMMU study showed 23% of patients found it difficult to continue treatment due to financial problem. Although epilepsy is a global disease, it has an unequal distribution, and about 80% of the affected individuals reside in low and middle income countries (LMIC)^[23].

Epilepsy is considered a treatable condition with high rates of therapeutic response. About 70% of patients with epilepsy are controlled with antiepileptic drugs (AED)^[24].

However, despite this apparently "benign" prognosis, 73.3% of patients with active epilepsy in rural areas of LMIC do not receive treatment or receive it inappropriately. This concept is known as epilepsy treatment gap (TG), and is associated with several psychosocial complications such as impaired quality of life (QoL), social stigma and labor discrimination The TG seems to depend on the per capita income, with a significant trend towards larger epilepsy treatment gaps in countries with lower incomes ^[25].

The TG is also associated with higher rates of mortality, and in some LMIC of Africa, the standardized mortality ratio can be up to six times higher than in developed countries ^[26].

According to the global burden of disease study (GBD) published in 2010, which intended to



describe the collective disease burden produced by all diseases around the world, epilepsy represents around 0.7% of the overall global burden of diseases measured in disability adjusted life years (DALYs). Epilepsy ranks as the 36th leading cause of DALYs globally, and in some LMIC of Latin-America and western Sub-Saharan Africa, ranks as the 21th and 14th leading cause of DALYs respectively^[27].

Among neurological disorders, epilepsy represents the second most disabling disease as measured in YLD only surpassed by migraine, and in some LMIC of Latin America, ranks as the 9th leading cause of YLD^[28].

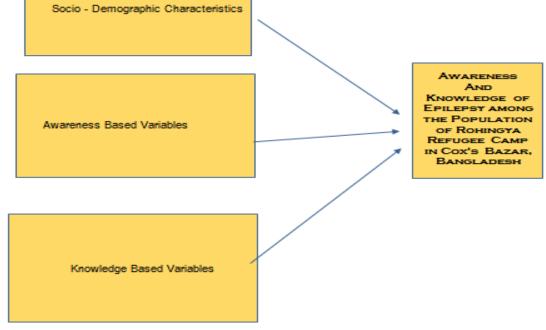
The World Bank ranks epilepsy in the top five of all non-communicable diseases for costeffective-ness in treatment. One study found that in some regions of sub-Saharan Africa and South East Asia, the availability in primary care of older AED (phenytoin and phenobarbital) with a coverage of50%, could save 1360 annual DALYs per each million population^[29].

A narrative review regarding the epidemiology of epilepsy in low income populations by searching PubMed, EMBASE, Google Scholar and thoroughly examining relevant bibliographies. This review aims to summarize the main epidemiological aspects of epilepsy in LMIC, emphasizing on incidence, prevalence, sociodemographic profile, TG, social stigma and QoL. Incidence, prevalence and socio-demographic profile of epilepsy in LMIC. The incidence and prevalence of epilepsy in LMIC is higher than in the rest of the world. The median lifetime epilepsy prevalence for developed countries is 5.8 per 1.000, whereas in rural areas of developing countries is 15.4 per 1.000. The incidence of epilepsy is 45/100.000/year in high income countries, compared to 81.7/100.000/year in LMIC ^[30].

The difference of prevalence and incidence among high income countries and LMIC is partly explained by some risk factors such as head trauma, CNS infections and perinatal injuries, which are more common in poor regions, particularly in rural areas^[31].

Traumatic brain injury (TBI) is a common cause of epilepsy. Some studies have shown an incidence of 180–250/100.000/year with higher values in individuals living in poor regions and in some LMIC such as South Africa ^[32].

III. MATERIALS AND METHODS 3.1 Conceptual Framework Independent Variables Dependent Variable



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3.2 Study Design: It is a descriptive type of cross sectional study.

3.3 Study Population: Kutupalong Rohingya Refugee Camp of Cox's Bazar, have been covered as study population.

3.4 Study Period: This study have been started from August, 2020 and continued till December, 2020.

3.5 Study Area: Kutupalong Rohingya Refugee Camp of Cox's Bazar have been covered as study area.

3.6 Inclusion & Exclusion Criteria:

3.6.1 Inclusion Criteria: Populations with given consent who willingly joined or participate in the study living in the area.

3.6.2 Exclusion Criteria: Populations who felt unwilling to participate and who is unable to provide information due to physical and mental illness or handicapped and not permanently living in the area. Age less then 18 years.

3.7 Data Collection Tools: Semi-structured and modified interview administrated questionnaire have been followed to collect data properly.

3.7 Sampling Technique: Non probability purposive sampling.

3.7.1 Data Collection Technique: By following face to face interview of the participants.

3.8 Data Analysis & Management Plan: All interviewquestionnaire were checked for its completeness, accuracy and consistency to exclude missing or incomplete data. Then data was checked, cleaned and edited again before analysis. The data will be analyzed by using Microsoft Excle. Descriptive statistics was used for the interpretation of the findings.

3.9 Sample Size Calculation: The sample size will be determined by using the following formula,



Due to COVID-19 pendemic situation and time limitation the researchers took 205 samples according to guide's decision.

3.10 Limitations of the study:

The following were the limitations of the study:

- The time frame was not enough to complete the study properly to cope up the real pictures.
- Due to inclusion and exclusion criteria the findings might be associated with biases a little bit.

3.11 Quality Control & Quality Assurance:

Following measures have been taken for quality control & quality assurance:

- 1. Regular assistance and guidance from the supervisor taken for conducting interview.
- 2. Data collection and analysis performed by the researcher himself.
- 3. Report made with the respondents before data collection
- 4. Data were collected by trained data collectors having exclusive experience in this area techniques of face to face interview.
- 5. Data checked and rechecked for reliability.
- 6. A semi-structured questionnaire used.
- 7. Questionnaire described in both English and Bengali languages for better understanding of respondents.

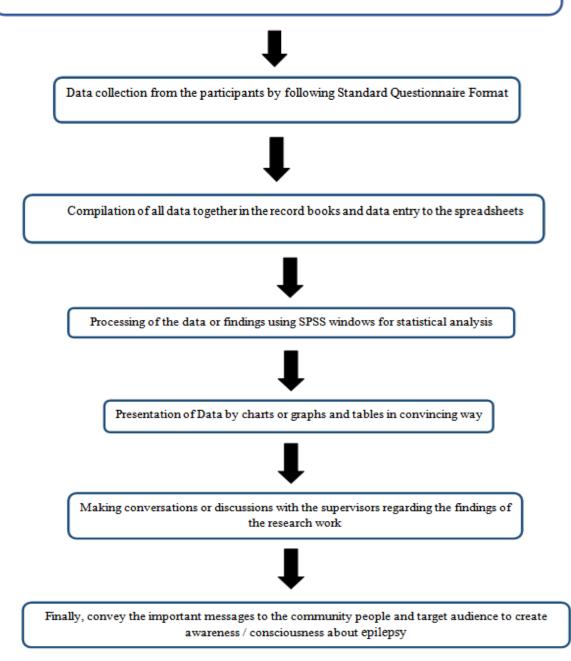
3.12 Ethical Consideration:

For conducting the study, Ethical approval was obtained from ethical board of University of Creative Technology Chittagong (UCTC). An informed consent was obtained from the participants before being enrolled in the study. In addition, participants were assured about the aim, possible risk if any, and confidentiality of the study using their own local language. The personal identification, information of the subjects involved in the research was replaced by codes in the protected archived computer data files. The paper forms with the personal identification information was stored in a high security procedures. Data files for statistical analysis was prepared to ensure the confidentiality of any information about the study participants and was not include any personal identification.

3.13 Flowchart of cross sectional study: (questionnaire based)



Selection and designing physical map of different areas of Rohingya Refugee Camp patients of Cox's Bazar district where the data collection for the research work will be conducted along with full preparation with the requirements that are essential for the research



IV. RESULTS

Epilepsy is a neurological disorder characterized by recurrent unprovoked seizures which is transient with abnormal, excessive and synchronous neuronal activity in the brain. It is a common and chronic neurologic disorder worldwide. It has been estimated that 80.0% of 50 million people with epilepsy reside in developing countries. The risk of having epilepsy at some point in average life span of any individual varies between 2.0% to 5.0%. Some hospital and community based studies from South East Asian countries (SEAR) have reported the incidence of epilepsy from 2 to 10 per thousand population. WHO estimates that there are at least 1.5 to 2.0 million people with epilepsy in Bangladesh.



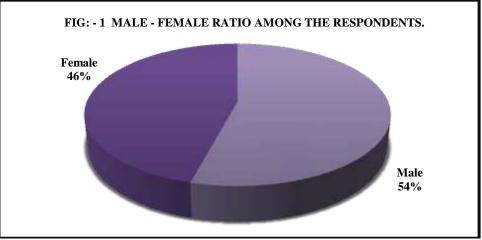


Fig 1:- Distribution of respondents by gender

This pia diagram showed that, there was 54% (111) male and 46% (96) female among the respondents (fig:1).

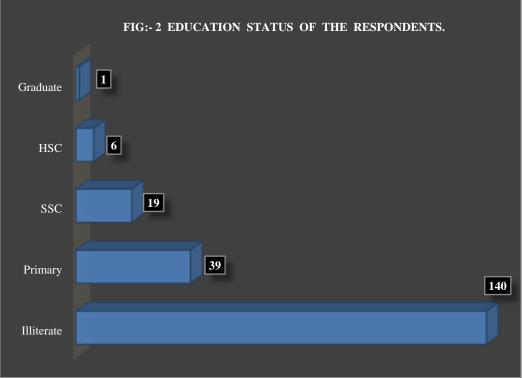
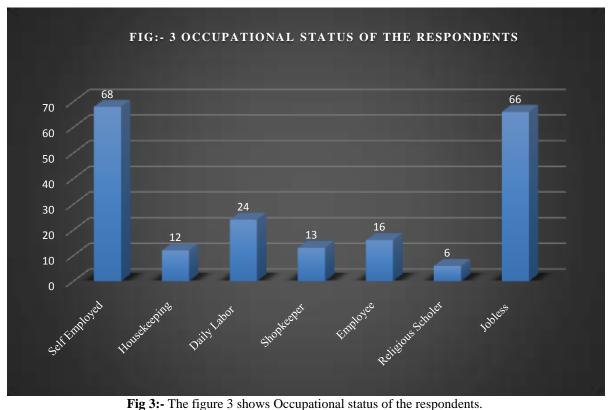


Fig 2:- Education level of the respondents.

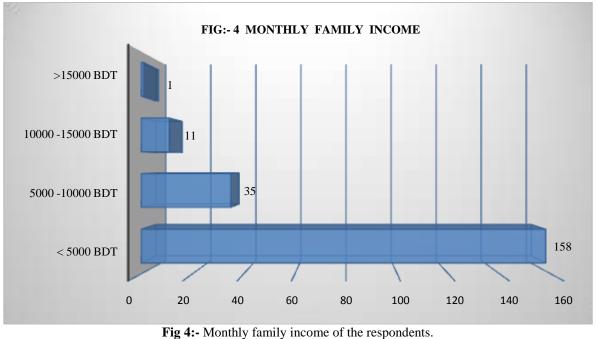
Out of 205 respondents there were 68% (140) were Illiterate, 19% (39) completed Primary Education, 09% (19) completed SSC, 03% (06) completed HSC and less then 01% (01) found completed Graduation (fig:2).





The above bar diagram we observed the occupational status of the respondents we found 33% (68) were Self-Employed, 06% (12) were Housekeeper, 12% (24) were Daily Labor, 06%

(13) were Shopkeeper, 08% (16) were Office Employee, 03% (06) were Religious Worker and 32% (66) were Jobless (fig:3).



We observed that out of 205 respondents, 77% (158) were earning < 5000 BDT, 17% (35) (11) were earning in between 10000 – 15000 BDT



and less then 01% (01) were earning > 15000 BDT (fig:4).

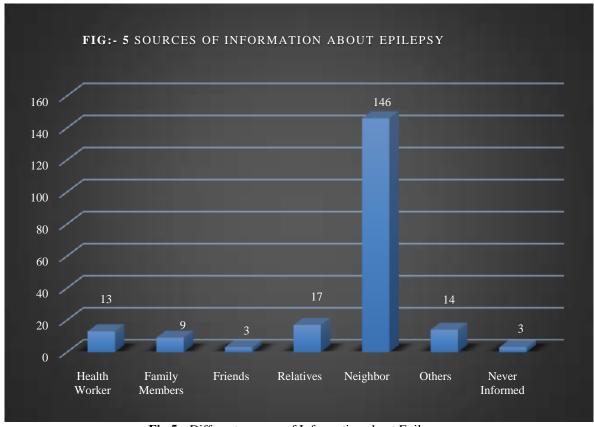


Fig 5:- Different sources of Information about Epilepsy.

The above bar diagram showed different respondents get information about diseases from different sources. Some get from neighbor, some from friends and relatives, and some from different health workers. In this study out of total 205 respondents, 06% (13) got information about Epilepsy from different Health Workers, 04% (09) got information from Family Members, less then 02% (03) got information from Friends, 08% (17) got from Relatives, 71% (146) got from Neighbors, 07% (14) got from other different sources and less then 02% (03) never informed (fig 5).



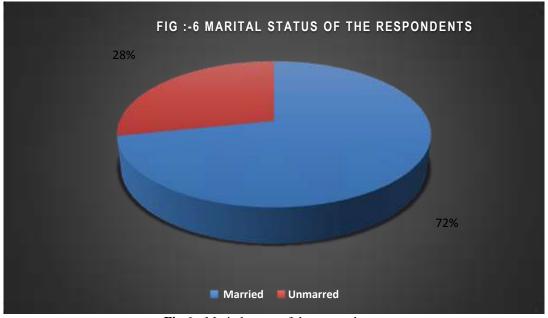


Fig 6:- Marital status of the respondents.

The above pia diagram showed that, among the total respondents 72% (147) were married and 28% (58) unmarried. So maximum percentage of population have been found married (fig:-6).

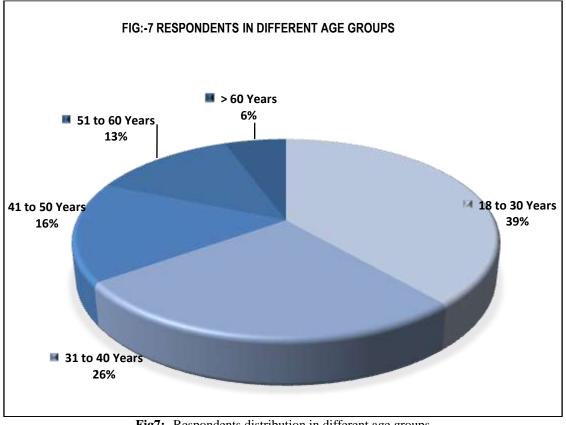


Fig7:- Respondents distribution in different age groups

The above pia diagram represents the respondents in different age groups. 39% were in

18-30 years age group, 26% were in 31-40 years age group, 16% were in 41-50 years age group,



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13% were in 51-60 years age group and 6% were in

>60 years age group (fig:-7).

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	Table 1:- Frequency and Percentage of Respondents Knowledge About Epilepsy					
Sl. No.	Individual Question	Types of Answers	Frequency	Percentage		
1	Have you ever heard about	a. Yes	202	99%		
1	epilepsy?	b. No	03	01%		
Total 205 100%						

In Table 1 We observed the frequency and percentage of respondents who know about Epilepsy. Here 99% (202) respondents replied 'Yes' answer when they were asked "Have you ever heard about epilepsy ?" and 01% (03) replied 'No'.

Table 2:- Frequency and Percentage of Respondents Having Acquaintance with Epilepsy					
Sl. No.	Individual Question	Types of Answers	Frequency	Percentage	
	De ver have en acqueintence	a. Yes	18	Percentage 09% 20% 71% 100%	
2	Do you have an acquaintance with epilepsy?	b. Little	41		
	with epitepsy:	c. No	146		
Total			205	100%	

In Table 2, We obserbed 71% (146) replied 'No', 20% (41) replied 'Little' and 9% (18) respondents replied 'Yes', when they were asked "Do you have an acquaintance with epilepsy?"

Table 3:- Frequency and Percentage of Respondents Having Family Member Diagnosed with Epilepsy				
Sl. No.	Individual Question	Types of Answers	Frequency	Percentag e
3	Do you have a family member	a. Yes	23	11%
5	diagnosed with epilepsy?	b. No	182	89%
	Total	205	100%	

In Table 3 We observed that, 11% (23) respondents had at least one family member who diagnosed with Epilepsy and 89% (182) of respondents replied 'No' as they do not had a family member diagnosed with Epilepsy.

Table 4:- Frequency & Percentage of Respondents Knowledge about different epilepsy related diseases					
Sl. No.	Individual Question	Types of Answers	Frequency	Percentage	
4	Do you know different epilepsy related	a. Yes	12	06%	
	diseases?	b. No	193	94%	
	Total	205	100%		



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The Table 4 Shows the frequency and percentage of respondents knew about different epilepsy related diseases. Here 6% respondents replied 'Yes' when they were asked "Do you know different epilepsy related diseases?" and the others replied 'No'.

Table 5:- Frequency and Percentage of Respondents Knowledge about Epilepsy Treatment by Drugs					
Sl. No.	Individual Question	Types of Answers	Frequency	Percentage	
5	De men len en it is terestable ber	a. Yes	57	28%	
	Do you know it is treatable by medicine/ drug?	b. No	78	38%	
	medicine/ drug !	c. Don't know	70 34%	34%	
	Total			100%	

Table 5 Indicates the frequency and percentage of respondents knew Epilepsy is treatable by drugs or not. Here 28% (57) replied that Epilepsy is treatable by drugs, 38% (78) replied not treatable and remaining percentage did not know about the Epilepsy treatment.

Table 6:- Frequency and Percentage of Population having witness a patient experienced seizure attack					
Sl. No.	Individual Question	Types of Answers	Frequency	Percentage	
6	Have you ever witness a patient	a. Yes	160	78%	
6	experiencing seizure attack?	b. No	45	22%	
	Total	205	100%		

In Table 6 We observed frequency and percentage of respondents had witness a patient experiencing seizure attack. Here maximum percentage 160 (78%) of respondents replied 'Yes' when they were asked "Have you ever witness a patient experiencing seizure attack?". The other percentage replied 'No'.

Table 7:- Frequency and Percentage of Respondents Awareness on Different Causes of Epilepsy				
Sl. No.	Individual Question	Types of Answers		
		A. Trauma		
		B. Maternal causes		
	The causes of epilepsy (You can select	C. Infection		
		D. an evil spirit		
-		E. Brain disease		
7	more then one)?	F. Mental health disease		
		G. Blood disease		
		H. Congenital disease		
		I. Genetic		
		J. Don't know		

Sl. No.	Answered Options	Frequency	Percentage
01	Don't Know	87	42%
02	An Evil Spirit	42	20%
03	BCEH	12	06%
04	BCE	11	05%
05	Trauma & Maternal Causes	08	04%
06	Mental Health Diseases	08	04%



07	Maternal Causes	07	03%
08	Trauma & An Evil Spirit	06	03%
09	Congenital Diseases	06	03%
10	Genetic	05	03%
11	Blood Diseases	04	02%
12	Trauma	03	02%
13	Trauma & Congenital Diseases	04	02%
14	Trauma & Infection	02	01%
	Total	205	100%

BCEH :- Maternal Causes, Infection, Brain Diseases & Congenital Diseases.

BCE :- Maternal Causes, Infection & Brain Diseases.

Table 7 Indicated frequency and percentage of respondents responded different

causes of Epilepsy. In the reply of the question "The causes of epilepsy?" the respondents marked different options from the list. Here we observed, 87 respondents replied don't know, 42 an evil spirit, 11 (maternal + infection + brain diseases + congenital diseases) etc. (table 7).

Table 8:- Frequency and Percentage of Respondents responses on Societal Perception on Epilepsy
Patient

Sl. No.	Individual Question	Types of Answers	Frequency	Percentage
		a. Yes	98	48%
8	Is society receiving positively?	b. No	30	15%
		c. Don't know	77	37%
	Total			100%

In the Table 8 We observed that, 98 (48%) respondents believe that Society receive Epilepsy positively, 30 (15%) respondents believe that Society do not received Epilepsy positively and remaining 77 (37%) respondents did not know about it.

Table 9:- Quantity and Percentage of Respondents Knowledge about Treatment of Epilepsy			
Sl. No.	Individual Question	Types of Answers	
	The best treatment of epilepsy is- (You can select more then one)?	A. Medical Treatment	
		B. Herbal Treatment	
9		C. Traditional Treatment	
		D. Untreatable	
		E. Don't know	

Sl. No.	Answered Options	Frequency	Percentage
01	Don't Know	60	29%
02	Medical Treatment & Untreatable	54	26%
03	Untreatable	48	24%
04	Medical Treatment	31	15%
05	Medical, Traditional & Untreatable	06	03%
06	Medical & Traditional Treatment	04	02%
07	Traditional Treatment	02	01%
	Total	205	100%

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Table 9 Indicated the frequency and percentage of respondents responded about treatment of Epilepsy. Here respondents replied different answers when they were asked "The best treatment of epilepsy is-?". The the majority 60 respondents replied don't know, 54 respondents believe medical treatment but untreatable, 48 respondents replied totally untreatable etc. In the table 14 types of individual frequency and percentage of respondents have been listed with their answers in multiple options (table 9).

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Table 10:- Frequency and Percentage of Respondents Awareness on Epilepsy is a Neurodevelopmental Disorder				
Sl. No.	Individual Question	Types of Answers	Frequency	Percentage
	Is it neurodevelopmental disorder?	a. Yes	28	14%
10		b. No	20	10%
		c. Don't know	157	76%
	Total 205 100%			

The Table 10 Showed the frequency and percentage of respondents responded is Epilepsy a Neurodevelopmental Disorder or not. About 28 (14%) respondents replied 'Yes' when they were asked "Is it neurodevelopmental disorder?", 20 (10%) respondents replied 'No' and majority 157 (76%) did not know about it.

Table 11:- Frequency & Percentage of Respondents Knowledge on is Surgery Available for Treating Epilepsy					
Sl. No.	Individual Question	Types of Answers	Frequency	Percentage	
	Surgery is available for treating epilepsy?	a. Yes	07	03%	
11		b. No	41	20%	
	treating epitepsy?	c. Don't know	157	77%	
	Total 205 100%				

In Table 11 We observed that about majority respondents 157 (77%) did not know about it, 41 (20%) did not believe it, 07 (3%) respondents believe that surgery is available for treating epilepsy.

	Table 12:- Frequency & Percentage of Respondents Awareness About Different Symptoms of Epilepsy					
	SI No		Individual Question	Types of Answers		5
				A	. Seizure	
				B	. Muscle stiffness	
	12		What are the symptoms of	C. Tongue bite		
		epilepsy (Can select more then	D. Dripping of salivation			
	1.	2	one)?	E. Unconsciousness		
				F. Stool/urine incontinence		
					G. Fall down on the ground	
				Η	. Don't know	
S N			Answered Options		Frequency	Percentage
0	1		Muscle stiffness & Fall down on the ground		38	19%



02	Seizure or Convulsion	34	16%
03	Seizure & Unconscious	24	12%
04	Muscle stiffness & Dribbling of salivation	23	11%
05	Seizure & Fall down on the ground	22	11%
06	Fall down on the ground	17	08%
07	Seizure & Tongue bite	11	05%
08	ABDEG	11	05%
09	ABCDEFG	08	04%
10	ABCE	07	03%
11	Seizure & Stool/ Urine incontinence	06	03%
12	Unconscious	04	02%
13	Don't know	03	01%
	Total	205	100%

ABCDEFG:- Seizure, Muscle stiffness, Tongue bite, Dribbling of salivation, Unconscious, Stool/ Urine incontinence & Fall down on the ground. ABDEG :- Seizure, Muscle stiffness, Unconscious & Fall down on the ground. ABCE :- Seizure, Muscle stiffness, Tongue bite & Unconscious Table 12 Indicated the frequency and percentage of respondents responded about different symptoms of Epilepsy. In the replied of the question "What are the symptoms of epilepsy?" the respondents marked different options from the list. We observed 38 respondents replied muscle stiffness and falldown on the groud, 32 replied seizures or convulsion, 24 replied seizure and unconscious etc. (table 12).

Table 13:-Frequency & Percentage of Respondents Awareness on Is Epilepsy Contagious Disease or

Sl. No.	Individual Question	Types of Answers	Frequency	Percentage
	Do you think it is contagious?	a. Yes	20	10%
13		b. No	147	72%
		c. Don't know	38	18%
Total			205	100%

The Table 13 Showed the frequency and percentage of respondents responded is Epilepsy Contagious or not. Majority 147 (72%) respondents replied 'No' when they were asked "Do you think it is contagious?", 38 (18%) did not know about it and 20 (10%) respondents replied 'Yes'.

Table 14:-Frequency and Percentage of Respondents Knowledge about First Aid of Epilepsy				
Sl. No.	o. Individual Question Types of Answers			
	Do you know the first aid of epilepsy (You can select more then one) ?	A. Take them away from danger		
		B. Put a spoon or cloth inside the patient mouth		
14		C. Forcefully hold to stop involuntary movement		
17		D. Leather shoes should be given to the nose		
		E. Self-cure		
		F. Don't know		

Sl. No.	Answered Options	Frequency	Percentage
01	Don't know	49	24%
02	Leather shoes should be given to the nose	44	21%



03	Take them away from danger & self cure	23	11%
04	Forcefully hold to stop involuntary movement	22	12%
05	Take them away from danger, Put a spoon or cloth inside the patient mouth & Forcefully hold to stop involuntary movement	18	09%
06	Take away from dange & Leather shoes should be given to the nose	13	06%
07	Take away from danger	08	04%
08	Leather shoes should be given to the nose & Self-cure	06	03%
09	Self-cure	12	06%
10	Put a spoon or clothes inside the patients mouth & leather shoes should be given to the nose	03	01%
11	Take them away from danger, Forcefully hold to stop involuntary movement & Leather shoes should be given to the nose	07	03%
	Total	205	100%

Table 14 Indicates the frequency and percentage of respondents responded about First Aid of Epilepsy.Here respondents replied different answers when they were asked "Do you know the first aid of epilepsy?" majority 24% (49) respondents replied don't know, 21% (44) respondents replied Leather shoes should be given to the nose, 11% (23) respondents replied take them away from the danger & self cure etc. In this table 11 types of individual frequency and percentage of the respondents have been listed with their answers in multiple options (table 14).

V. DISCUSSIONS:

In this cross sectional questionnaire based study there was 46% (94) female and 54% (111) male among the respondents (fig:1). So it could be said that male participants were more than female.**In the farming community of the subdistrict of Meskan and Mareko in central Ethiopia**, where the prevalence of epilepsy is knoen to be 5.2/1000, a door-to-door survey was undertaken in 1546 sampled households to find out public attitudes to epilepsy. Nearly 64% of the respondents were in the age group of 14–50 years, and 58.6% were women^[33]

Out of 205 respondents :- 140 were Illiterate, 39 were completed Primary Education, 19 were completed SSC, 6 were completed HSC and only 1 respondents found to completed Graduation (fig:2). Among the total respondents maximum number of respondents were illiterate. So due to uneducated the respondents were not that much aware and could not get enough knowledge about Epilepsy. In the farming community of the sub-district of Meskan and Mareko in central **Ethiopia**, the majority 86%) were illiterate, and 94% had incomes of a subsistence level^[33].

When we observed the occupational status of the 205 respondents :- we found 68 were Self-Employed, 12 were Housekeeper, 24 were Daily Labor, 13 were Shopkeeper, 16 were Office Employee, 6 were Religious Worker and 66 were Jobless (fig:3). Here we can see a big portion of the respondents were jobless, some of them were daily labor and maximum of them were self-employed. **Syrian refugees in Jordan -** the survey asked about household income during the past 12 months from 40 different sources, which are grouped into major sources of income: wage income 61%, selfemployment income 3%, private transfer income 14%, property income 1% and other income 11%. [34]

We observed that out of 205 respondents:-158 were earning < 5000 BDT, 35 were earning in between 5000 - 10000 BDT, 11 were earning in between 10000 - 15000 BDT and only 1 were earning > 15000 BDT (fig:4). When we observed the monthly income a huge number of respondents were earning <5000 BDT which is really very low amount to survive in this time period and mean time they have been receiving ration from WFP, ACF, Government authorities but it's not enough to save their life according to the respondents. Syrian refugees in Jordan: February 2019:- Monthly rents in the range of JD120 to JD150 are common everywhere, except in Other governorates, where the mean rent is about JD80. And It's more then Kutupalong rohingya refugees camps, Cox'sBazar, Bangladesh^[34]

Different people get information about diseases from different sources. Some get from



some from neighbor, some from friends and relatives, and some from different health workers. In this study out of 205 respondents :- 13 got information about Epilepsy from different Health Workers, 9 got information from Family Members, 3 got information from Friends, 17 got from Relatives, 146 got from Neighbors, 14 got from other different sources and 3 never informed (fig 5). The source of information about any disease is very important, because reliable, authentic and genuine source of information is very much important to be aware and conscious about it. Here we found the maximum number of respondents got information about Epilepsy from their neighbor. So what they informed about Epilepsy was depending on their neighbor's knowledge, belief and attitude about Epilepsy. Current beliefs and attitudes regarding epilepsy in Mali : The main source of information regarding epilepsy was significantly different for the two groups. For parents of children with epilepsy, traditional healers (for 27% of the participants) and health-care professionals (for 24% of the participants) provided most of the knowledge, as well as the neighborhood, friends, and relatives (27%), while for parents without affected children, most of the information came from the neighborhood, friends, and relatives (for 51% of the participants)^[35].

Frequency and percentage of respondents responded different causes of Epilepsy. In the reply of the question "The causes of epilepsy?" the respondents marked different options from the list. Here we observed, 87 respondents replied don't know, 42 an evil spirit, 11 (maternal + infection + brain diseases + congenital diseases) etc. It means most of the respondents didn't known real causes of epilepsy. A cross sectional survey was conducted among Government workers and the general public in Accra, Ghana. A total of 380 persons were interviewed. Almost everybody could describe accurately, an epileptic person. However, 172 (45.3%) out of the 380 respondents did not know the cause of epilepsy, and 37.6% did not know how it could be treated. Out of the 358 responses to the cause of epilepsy, 114 (31.8%) said it was inherited disease, 100 (27.9%) said it was due to witchcraft/juju or spiritual [36].

The frequency and percentage of respondents responded about treatment of Epilepsy. Here respondents replied different answers when they were asked "The best treatment of epilepsy is-?". Some respondents tick ($\sqrt{}$) marked in multiple options. The the majority 60 respondents replied don't know, 54 respondents believe medical treatment but untreatable, 48 respondents replied totally untreatable etc. In the table 14 types of

individual frequency and percentage of respondents have been listed with their answers in multiple options (table 9). A cross sectional survey was conducted among Government workers and the general public in Accra, Ghana. With respect to treatment, 150 out of 333 responses mentioned sending the individual to the medical doctor, 95 (28.5%) said the use of herbs/visits to fetish priest, 59 (17.7%) suggested prayers, 20 (6.0%) said to do nothing ^[36].

We observed frequency and percentage of respondents who know about Epilepsy. Here 99% (202) respondents replied 'Yes' answer when they were asked "Have you ever heard about epilepsy?". It is surprisingly interesting that 99% of the respondents heard about Epilepsy. But in Table 2, we observed 9% (18) respondents replied 'Yes', 20% (41) replied 'Little' and 71% (146) replied 'No' when they were asked "Do you have an acquaintance with epilepsy?" maximum (71%) respondents did not acquaintance with epilepsy. The awareness, understanding, and attitudes toward epilepsy in 1,278 men and women were surveyed in Henan, China in 1988. Results showed that 93% had read or heard about epilepsy; 77% knew someone who had epilepsy; 72% had seen someone who was having a seizure; 57% would object to having their children associate with persons with epilepsy in school or at play; 87% would object to having their children marry a person with epilepsy; 53% believed that epileptic persons should not be employed in jobs as other persons^[37].

We observed the frequency and percentage of respondents having witness a patient experiencing seizure attack. Here maximum percentage 78% (160) of population replied 'Yes' when they were asked "Have you ever witness a patient experiencing seizure attack?". The other percentage of respondents replied 'No'. Here maximum respondents had witness a patient experiencing seizure attack. So they did know the symptoms when a patient suffer from epilepsy in particular time. The awareness, understanding, and attitudes toward epilepsy in 1,278 men and women were surveyed in Henan, China in 1988. Results showed that 77% knew someone who had epilepsy; 72% had seen someone who was having a seizure; 57% would object to having their children associate with persons with epilepsy in school or at play [37]

We found out that, 48% (98) respondents believe that Society receive Epilepsy positively, 15% (30) respondents believe that Society do not receive Epilepsy positively and remaining 37% (77) respondents did not know about it. According



to the Table 8 information, we can say that, maximum of the society people received Epilepsy positively. It is really a matter of joy and fortune. But still in society some people believe in miss concepts. Some people go to Kabiraj, Uza and other wrong persons to treat Epilepsy patients. **Community Members' Perception of Epilepsy** and their Attitude towards Persons Living with Epilepsy Disorders in a Rural Community of Bavelsa State, Nigeria 2015:- 73.3% said it is unwise for parents to send children with epilepsy to school for fear of ridicule by schoolmates,100% will not marry neither allow their children marry any person with epilepsy and 63.3% will not disclose to their children's spouses before marriage if son/daughter has epilepsy^[38].

The frequency and percentage of respondents responded is Epilepsy Contagious or not. Majority 147 (72%) respondents replied 'No' when they were asked "Do you think it is contagious?", 38 (18%) did not know about it and 20 (10%) respondents replied 'Yes'. Still a portion of the respondents believe that Epilepsy is contagious though majority believe that it is not contagious. In the farming community of the sub-district of Meskan and Mareko in central **Ethiopia** where 45% of the interviewees, the disease was believed to be contagious through physical contacts during an attack. Although there was sympathetic concern in the community for the person suffering from epilepsy, negative attitudes were strong on matrimonial associations, sharing of accommodation and physical contacts with affected persons, particularly when there were obvious signs and frequent attacks by seizures. The study demonstrates that the rural community has very poor knowledge of the causes and nature of epilepsy, and this has resulted in social deprivations and at times, rejection of the sufferers ^[33]. Another study in Rural Community of Bayelsa State, Nigeria :- 55% thinks epilepsy is a highly contagious disease and transferable^[3]

About 3% (07) respondents believe that surgery is available for treating Epilepsy, 20% (41) did not believe it, and majority 77% (157) did not know about it. We can see that maximum of the respondents did not know about the surgical procedure of it where some respondents do not believe in surgery for Epilepsy but a very few respondents believe in surgical procedure for it. A **nationwide telephone interview was conducted on a random sample of Italian schoolteachers -**46.8% declared it incurable, and only 10.5% knew surgery is a therapeutic option ^[39].

The frequency and percentage of respondents knowing Epilepsy is treatable by drugs

or not. Here 28% (57) replied that Epilepsy is treatable by drugs, 38% (78) replied not treatable and remaining percentage did not know about the Epilepsy is treatable or not. So maximum people believe that Epilepsy is not treatable by drugs and some did not know about the treatment of it.**Knowledge, attitude and practice toward epilepsy among rural residents in Tanzania** 36.8% believed epilepsy could not be cured and 17.1% believed it could not even be controlled; 45.3% believed epilepsy could be treated by traditional healers, and only 50.8% believed hospital drugs were of any use ^[40].

The frequency and percentage of respondents responded about First Aid of Epilepsy.Here respondents replied different answers when they were asked "Do you know the first aid of epilepsy?". Some respondents tick ($\sqrt{}$) marked in multiple options. Majority 49 respondents replied don't know, 44 respondents replied Leather shoes should be given to the nose, 23 respondents replied take them awy from the danger + self cure etc. In this table 11 types of individual frequency and percentage of the respondents have been listed with their answers in multiple options (table 14). The respondents believe in multiple options as first aid of Epilepsy.Therefore, there is a need for health education on epilepsy in Rohingva refugees camp at Cox'sBazar and these results are forming the base for design and execution of a health education and a primary health care program in awareness and knowledge of epilepsy. Knowledge, attitude and practice toward epilepsy among rural residents in Tanzania Concerning what is to be done when a seizure occurs, 33.5% of the respondents would keep away and not touch the person; 16.5% would take some potentially harmful measure such as forcing a mouth gag or forcing a drink such as water (1 even mentioned urine); 5.2% would take unnecessary measures such as rushing the patient to a hospital. Only 35.7% of respondents would perform at least some of the currently recommended first- aid measures ^[40].

VI. CONCLUSIONS:

As we know Epilepsy is a neurological disorder characterized by recurrent unprovoked seizures which is transient with abnormal, excessive and synchronous neuronal activity in the brain. It is also a chronic disorder. Patients of different ages may suffer with it. This cross sectional questionnaire based study has been conducted in Rohingya refugee camp of Cox's bazar. In this study we found that maximum of the respondents were illiterate and lot of people were



jobless where most of them were earning <5000 BDT per month. So it indicates a very lower and poor socio-demographic status. As the community is migrant from another country, their culture, belief and attitude are different. Though some respondents had experience as they had family members diagnosed with Epilepsy and some had witness of sudden Seizure attack, still many of them did not know about first aid of Epilepsy and symptoms of Epilepsy. Some respondents believe that Epilepsy is not treatable by drugs and still a portion of the respondents believe that Epilepsy is contagious. It is a matter of strange that most of them did not know that it is a neurodevelopmental disorder.

But there were some good things also, for example - majority of the respondents heard about Epilepsy, some portion of the respondents knew about the symptoms and first aid of Epilepsy. Some believed in surgical procedure of Epilepsy treatment. This is because some participants were educated upto primary, SSC and HSC, some participants were doing job and business and they got information about Epilepsy from reliable and authentic sources.Poor knowledge about epilepsy and unfavourable attitude towards a person living with epilepsy are likely to have an important impact on stigmatization and treatment seeking behaviour, and it should be given due attention. It would be better if health educators give special emphasis for the individuals with predictors of poor knowledge and unfavourable attitude.

VII. RECOMMENDATIONS:

- The Rohingya community is living in poverty, unemployment, poor sanitation condition and without education. They were living in poor sociodemographic condition. So it will not be wise to expect proper knowledge, awareness and consciousness regarding Epilepsy from the community.
- \div As it is a neurodevelopmental disorder and chronic disease, it is not similar to other normal diseases by symptoms, treatment and diagnosis. So being unfortunate with education, income and employment the respondents might have not proper information, knowledge about Epilepsy.
- The Rohingya community must be educated enough, should get touch of light of improved society and their socio-demographic status should be developed.
- The community people must be counselled and trained about Epilepsy, its diagnosis, first aid and treatment procedure.

- Different community health workers and NGO health workers can perform the task to educate them about Epilepsy.
- Awareness and consciousness very much depend on proper knowledge on particular issues.

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Appendices

Appendix A Informed Consent



I Mr/Mrs..... has read all the statements in the consent form and I do hereby agree to voluntarily participate as a subject in the study of "Awareness and Knowledge of Epilepsy among the Population of Rohingya Refugee Camp in Cox's Bazar, Bangladesh". I have clear idea of this research including its purpose, duration and the procedures to be followed. I have understood that all information will be kept confidential. My name will not be published in the study report and I will not be entertained with any financial benefits or incentives.

I have been given opportunity to ask questions concerning research procedures and for further questions. I may contact the research workers. I have also been given information on the risk and discomforts for participating in this research.

I understood that I have the right to leave or cancel my consent and withdrawal myself from the study at any time for any reason without penalty. I have been informed that I shall be given a copy of the signed consent to keep.

I, the undersigned, certify that I have signed this document willingly to participate in the said research work myself or in presence of the following witness.

Participant's signature/Thumb prints

Name:

Date:

Investigator's signature

Name: Mohammad Musahidur Rahman Khan

Date:

Appendix B Questionnaire Page 1

Dear participant,

I'm, doing my MS course in Master of Public Health at UCTC. As a part of my course, I have to conduct a research work. The title of my research is "Awareness and Knowledge of Epilepsy among the Population of Rohingya Refugee Camp in Cox's Bazar, Bangladesh". This is purely academic. Some information is needed from you in this regards. This information will be used only for this study and confidentiality will be maintained strictly. I seek your kind co-operation as much as possible. Your co-operation would highly be appreciated.

SL. NO	STATEMENT	CATEGORY
1	ID No	
2	Age in years	
	Gender	a. Male b. Female
3	Educational Status	a. Illiterateb. Primaryc. SSCd. HSCe. Graduate
4	Occupation	a. House wifeb. Housekeepingc. Daily Labord. Doing Notinge. Employee
5	Monthly family income in BDT	a. 0-5000 b. 5000-10000 c. 10000-15000 d. More then 15000
6	Which area do you live in?	



8 From where you get information about epilepsy? 9 Do you have an acquaintance with epilepsy? 10 Do you have a family member and the pilepsy? 11 Do you have a family member and the pilepsy? 11 Do you have a family member and the pilepsy? 11 Do you know different epilepsy related and the pilepsy? 12 Do you know different epilepsy related the pilepsy related the pilepsy related the pilepsy? 13 Have you ever witness a patient experiencing seizure attack? No 14 The causes of epilepsy? No 15 Is society receiving positively? No Conductable the pilepsy is Final factor the pilepsy is The best treatment of epilepsy is No Conductable Conductable Conductable Conductable Conductable Treatment The best treatment of epilepsy is Surgery is available for treating epilepsy? No Conductable Conductable Conductable Conductable Conductable Conductable Conductable Conductable Conducth	7	Have you even heard about epilepsy?	a. Yes			
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5 6 6	20		a. Yes			
		Do you things it contagious	b. No			
			c. Don't know			

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21	Do you know the first aid of epilepsy (You can select more than one)?	 a. Take away from danger b. Put a spoon or cloth inside the patient mouth c. Forcefully hold the person to stop involuntary movement d. Leather shoes should be given to the nose. e. Self cure f. Don't know
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Appendix C



University of Creative Technology Chittagong (UCTC) Department of Public Health Master of Public Health Program Chandgaon, Bahaddarhat, Chattogram, Bangladesh

Certification of the Ethical Clearance

To Whom It May Concern

This is to certify that, we the members of the Research Ethical Committee have carefully checked and read through the Thesis proposal protocol and decided to recommend to the Department of Public Health, University of Creative Technology Chittagong (UCTC) for final approval of this Research work to conduct. The entitled Thesis proposal is, "Awareness and Knowledge of Epilepsy among the Population of Rohingya Refugee Camp in Cox's Bazar, Bangladesh" that has been submitted by, **Mr. Mohammad Musahidur Rahman Khan** bearing **ID: 190712024** has been reviewed and approved by the Research Ethical Committee.

The candidate is highly recommended to follow the ethical guidelines and also to be honest, sincere and dedicated to perform the research work.

Appendix D Limitations of the Study

- The study was totally cross-sectional. Full study designed on Questionnaire based data analysis.
- In some cases responses from the respondents were not satisfactory and not also presentable.
- Due to un-educated, the respondents did not understand many things properly.
- The study represents information regarding Epilepsy awareness and knowledge among only a sample portion of Rohingya community in Cox's Bazar refugee camp.
- The conversation during data collection was not smooth due to language barrier, different culture and social belief.
- The time frame was not enough to complete the study properly to cope up the real pictures.
- Due to inclusion and exclusion criteria the findings might be associated with biases a little bit.



Time line of the study:												
Sl No.	Activities	Years	2020									
		Months	8 th	8 th	9 th - 10 th	10 th - 11 th	11 th	11 th	12 th			
	Research Proposal											
	Submission											
	Physical Map of Research											
	Conduction											
	Data Collection											
	Data Entry & Data Analysis											
	Report Writing											
	Draft Submission											
	Final Report Submission											

Appendix E Time line of the study: