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I: This is an FGD with community members for the epilepsy project in Viwandani. Thank you so much. Let's try and be audible enough as we speak. Okay. Let us commence! We are going to talk about epilepsy, how do you refer to epilepsy here?

R1: *Kifafa.*

R2: *Mung'aro.*

R3: *Kigaguro.*

R4: Sickness of falling down.

R5: *Ndurumee.*

R6: *Endurumee.*

I: They are almost similar!

R7: *Mung'athuko.*

I: Those are the terms you use to refer to epilepsy in mother tongues?

R: Yes.

I: How best do the community understand it despite there being different ethnicities?

R1: *Kifafa.*

R2: Sickness of falling down.

I: Thank you so much. Is there a reason that makes people come up with those different references for epilepsy in mother tongues? For example: *Endurumee*, does the term refer to anything in particular, what does it mean?

R6: It means losing consciousness, then regaining it after some time.

I: Okay. So it means losing consciousness and regaining it back?

R6: Yes.

I: Does the word have any other inner meaning?

R6: The person falls down and does not die but regains consciousness after a while.

I: How about *Ndurumee*?

R5: It is a disease that makes you fall straight on the ground while gushing saliva from the mouth, while others urinate on themselves. Whenever one would fall; those around them would get frightened and stay away, this is because we believed that the disease would be contracted through contact. Therefore, we would give an epileptic person space in order for them to get fresh air until they regained their consciousness.

I: Why do people refer to epilepsy as the sickness of falling down?

R4: Due to the fact that people simply fall down.

R1: Falling down or epilepsy, the person falls down. When you say that a person falls down, people in the community simply understand that they have epilepsy.

I: Okay.

R1: People back in the village still fear persons with epilepsy. They believe that it can be contracted through inhalation of these people's farts. My boy child used to have epilepsy; when he fell, he would bite his tongue. Since the community believed that the disease could be contracted through contact, I wouldn't just let him suffer just because of their beliefs and hence I stepped in and helped him whenever he went into the episodes. All I had to ensure is; I was careful when inserting a cooking stick in his mouth so that he wouldn't bite off my finger under these attacks. Whenever he fell by the road, those who tried to help him would insert dangerous objects into his mouth which would damage his tongue and teeth, he is now well.

I: Okay.

R5: The disease is referred to as the sickness of falling down because a person falls anywhere and without warnings: by the side of the road, in rivers or while cooking.

I: Yes, R6.

R6: I once came to the aid of a person who was epileptic making french fries. I was so frightened at the moment because when I saw him gushing saliva from his mouth; I was pretty sure that he was going to get burnt by the hot oil before I could get to him. Luckily, I managed to get him out of danger.

I: Why do you refer to epilepsy as *Mung'aro*?

R6: We call it *Mung'aro* because a person is half dead and eyes protrude from their sockets.

I: Okay. Is there any other reason as to why you use the names to refer to epilepsy?

R7: I understand *Mung'aro* as *Mung'ang'athuko* because a person stiffens and loosens as they fall. This makes us refer to it as *Mung'athuko*. My cousin was epileptic, this made me know when he was under attack because most of the time I was around him. Associating with an epileptic person sometimes makes you understand when he is about to get an episode. When he regained consciousness, it would take some time for him to fully come back, therefore, we had to be around to restrict him from embarking on journeys because he had no knowledge of what was happening around him. Back in the village, we would run away when an epileptic person fell because we were made to understand that when these people fainted, we would contract the condition.

I: R7 has said it is easy for her to tell that a person is epileptic, what symptoms should one look for to tell that a person is epileptic? How do epileptic persons behave?

R8: For me, it is not easy to tell whether a person is epileptic or not unless I'm prior familiar with their condition. By looking at the marks in the body; one can't tell whether they are for epilepsy or other things such as drunkenness. My boy child is epileptic and a carpenter. There is a day he fell as he was painting a certain hospital; this was the second time for him to fall down. Let's say that; it is not easy to tell whether a person is epileptic unless they fall while you are present.

I: Yes, R4

R4: It may not be easy to tell but you may observe some signs. There is a woman who is a friend, I never knew that she was epileptic until she began behaving weirdly as we talked, she would also not reply to our conversation until the attack was over. Without understanding what she is going through, you may start thinking weirder things about her too. I came to notice that; before she went to the stage of falling down, she had to

lose consciousness first. She may be somewhere buying something and when the attack happens, she forgets her change behind or even falls there.

I: Thank you so much R4.

Yes, R1.

R1: Some epileptic individuals love stories, they really enjoy them and even want you to keep on talking. You may not notice it at first but as you continue with the pleasantries, it gets to your attention that the person is not well. There was a girl who behaved in a funny way whenever I talked to her. One day as she was alone I asked her if she was okay, that is when she confided in me that she sometimes fell and would experience episodes at around 3:00 am, she also said that she always knew when they were about to happen. Since then, I would make her happy when we talk.

I: Yes, R2.

R2: I think that before epilepsy prolongs, these people experience severe migraines. My child fell twice and during this time she would always complain of migraines. When it establishes itself, the migraines are no longer portrayed. After the falls, these individuals experience fatigue and you may tell that something is up or is about to happen. There is a certain woman back in my village who would not go close to the fire when she started experiencing fatigue. After the episodes were over; she would resume her duties. During the attack period, her child would help around the house. Falling down, gushing of saliva from the mouth and urinating on oneself are some symptoms that don't go away.

I: Okay.

R2: When an epileptic person leans on you for support or holds your hand; they don't let go easily, you may end up falling down together because they are very strong.

I: Yes, R5.

R5: The signs I'm familiar with are those of finding something to hold on as they fall down, protrusion of eyes from the socket and straightening of hands and legs as they fall.

I: Okay.

Yes, R6.

R6: Epilepsy also attacks small children. Back in the village I had a neighbor whose child got the condition while he was very little. The mother was unaware until the child got to four years of age when he was admitted in Facility M and Facility N. She was forced to sell a section of her land in order to afford treatment and the cost of drugs because they were very expensive. She really did her best in looking after her child but unfortunately, when he finished fourth form he succumbed to the illness.

I: Yes, R8.

R8: I can attest to epilepsy treatment being expensive. My boy's episodes began after he got involved in an accident, his life has never been the same again. The drugs are so expensive but I keep pressing on, it is now two years since he became epileptic. There was a time I felt like giving up and since he wasn't experiencing the fall downs; I didn't resume with the treatment. The child had also become tired of the treatment. I have also witnessed that epilepsy happens in a different way to different individuals. There is a neighbor back in the village, whose epileptic girl behaves in a weird manner when she is about to go into the attacks. She once fell into a fire and sustained severe burns in her private parts. The mother, sisters and brothers secluded themselves, only the dad looked after her. During this time, the mother did not even help clean her up. Her being a fully grown up lady; the dad had to look away and do it himself. She is more in touch with the father unlike with the rest of her family. Most of her help comes from the neighbors because she is unable to carry out tasks such as cooking for herself when the dad is away. Whenever she is given something to eat; she ensures that she remains a little for later in the day because she fears lighting up the stove when no one is around. When she has no food to eat, she walks into a shop and gets herself milk. She is aware of the symptoms before she gets to the point of falling down. Others are also able to tell these signs just by observing her.

I: Yes, R7

R7: I know epilepsy is there but when you are sick it reaches a point where one looks insane. I'm able to tell when my brother is under attack, his talks are what shows that he is not sane. Nowadays, he doesn't fall down but gets lost in thoughts. For

drunkards; they call it *gathitima*. It is therefore very hard for one to tell a drunkard from an epileptic. I had a cousin back in Korogocho where I lived; he used to abuse alcohol very much, one day he fell down and was taken to a hospital where he was diagnosed with low blood level. The doctors said that he would stop falling down once he quit drinking but he wasn't ready to do so. He continued taking his medication along with alcohol and he died. The medication he was using was for insane people, he was going to Facility M. So I heard that people with epilepsy are supposed to use medicine from Facility M [Inaudible].

I: Yes, R8.

R8: It's as if epilepsy is associated with insanity. Whenever my child fell down, if there was no one around he would straighten up. He continued until he seemed insane, you hold him, he would run away after regaining consciousness and we would be forced to run after him. He received his treatment in Facility M and Facility K; the doctors said that he wasn't insane, rather it was because his head had taken a lot of blows from falling down and his prior car accident also contributed to the issue. The medication that he was given was from Facility M and others from Facility K because he was put in an ambulance and rushed to Facility K. Therefore, I would urge those who treat epilepsy to make follow ups on individuals who are epileptic, non-accidental and also evaluate its connection to insanity.

I: Thank you so much.

Yes, R3.

R3: Some epileptic individuals stare at one place for a long time, not all fall down. There is a man in my area who helps carry luggage around, he is very active. He stares at one place and his body shakes. During this time, he doesn't respond and his eyes pop out of his sockets. Initially we thought that he was a bhang addict. Later, we learnt that he was epileptic. He stays for about 10 minutes when shaking until the attack ends.

I: So people thought that he used bhang?

R3: Yes. I was convinced that he used drugs. But I wondered because that person works hard and I had never seen him smoke. That's when I heard he has epilepsy.

I: Thank you R3. R1?

R1: Insisting on a point that was mentioned earlier, the condition is different to different individuals. Others fall once a week, month or after a very long period of time. The time also differs; a person may fall for only a few minutes, half an hour and another in an hour. It doesn't have the same strength on the individuals who have it.

I: Okay. Yes, R4.

R4: The one my colleague has mentioned for falling, not adhering to medication also contributes to falling down. I came to know one may be born epileptic or get the condition in adulthood. The woman I had mentioned earlier got epilepsy during delivery. She gave birth to twins unfortunately, one was disabled (Had cleft) while one was healthy. Sadly, the healthy baby died and the one with cleft remained; she did not comprehend the situation and this prompted depression, as this progressed she began falling down. The child is currently seven years old and to date the mother still falls down. Due to the stress, she asked the doctor why the cleft child survived and it would have been nicer had it died along the healthy one.

I: What other reasons do you think cause epilepsy?

R4: Depression is one cause. Not accepting reality can cause depression and as it progresses, it gets worse. The woman told me that when she got a glimpse of what she had delivered too, she tried to get away from the hospital and leave the twins behind. When the doctors tried to talk her into the matter, she would not come into terms.

I: Thank you R4.

R1?

R1: I think epilepsy is inherited. It is not easy for a healthy individual to get the condition.

R4: The woman confirmed that there are no such cases in both the husband's or her family. Her epilepsy emanated from her not accepting the situation during delivery. It got to her mind and she would just stare.

I: Yes, R1.

R1: The reason as to why I say that epilepsy is inherited is because it is not contracted through contact. It is similar to hypertension, diabetes and cancer. This makes it easy

for others to step in and help these people. You should not be scared because you can't get it through contact. We should help them out when you find them near water. You should just move them from there.

I: Yes, R5.

R5: Diabetes or hypertension patients sometimes fall when their conditions worsen. We should be able to differentiate between patients suffering from epilepsy and those with diabetes or hypertension. Epilepsy individuals fall with a lot of force while straightening their legs while those with diabetes or hypertension fall down in a slow motion. I once witnessed an epileptic individual fall slowly and it was different. I realized it was not diabetes but epilepsy. The way his hands and legs moved and his eyes had popped out, I knew he was in danger. That's what I always check for when I come across people with epilepsy.

I: Can someone differentiate it with diabetes?

R5: Yes, when someone falls and sleeps that is not associated with bad things but for epilepsy it's a must they punch or hit you with their legs. I am always careful because I once saw a patient kick another person. That person wanted to beat him up, and yet he was sick.

I: Yes, R6.

R6: Those who abuse drugs sometimes get epilepsy. There is a certain woman who lived in Kerugoya and used to abuse alcohol a lot, one day she fell into a fire. When she is drunk she doesn't understand herself so she went on cooking for her children. She fell on a charcoal stove and slept on top of the fire. So here I feel it's because of using drugs a lot so she got it. Because before she didn't have epilepsy.

I: So using drugs can cause epilepsy?

R6: Yes, it can.

I: Yes, R8

R8: In my opinion, I think epilepsy is not about inheritance because someone can get it through accidents and depression. For drunkards; they mostly say that they are taking alcohol to get rid of stress, then the problem grows into depression.

I: That is true...

R8: When they get depressed, they may experience falling down. Let's say; the only person who can tell for sure if the condition they have is epilepsy or not; is only a doctor. Drunkenness may also lead to emanation of other conditions such as diabetes or hypertension. This is because the drunkards don't even find time to eat properly. There is a difference in how they fall the way my colleague said earlier. A person who falls because they have pressure or diabetes you will know because they don't struggle but for a person with epilepsy, they always stare at one place when they fall. If I saw him fall and move towards one direction, I used to hold him where he was and look for a person. We lay him down where nothing would injure him when he threw his hands and legs.

I: You have said the reasons are accidents, depression and alcoholism?

R8: Yes, even alcoholism because if they don't drink too much where will depression come from...

I: Yes, R2. What are factors that lead to epilepsy? You may include things on religion, traditional customs, churches, tribes and so on.

R7: My two brothers are epileptic. One got it while he was in school and therefore I can't go into details as to how it started, the other one was from too much abuse of alcohol. When we went to the hospital he said he used to abuse every kind of drug; bhang and so on. He was told that is what caused him to have low blood level. He was also told if he didn't continue taking his medicine and instead continue taking alcohol, he would get epilepsy. So I knew his was because of alcoholism. I also came to understand that accidents can cause epilepsy when my third born boy became a victim after he got into an accident with a motorbike. We took him to hospital and knew he had recovered but he would still complain of severe migraines. Later we came to learn that his brain had been affected when we took him to hospital. Had the problem not been treated, it would have led to epilepsy. But now he has recovered and is on the road.

I: Yes, R2.

R2: My child got admitted twice due to falling down. Therefore, I would say that high fever also affects one's brain. Whenever he would get a high fever as a small child, I would

keep on rushing him to a hospital because I was scared of him falling down. I feel high fever can cause epilepsy. If quick follow-up is not done, it can mature in a child. One day I took him to my mother and grandmother back in the village who gave him traditional medication which made him sneeze. Now he is a grown up, currently in college.

I: What did his grandmother do to him?

R2: There are some leaves that they used to grind and put on his nose and he would sneeze a lot. When my step mom came to the hospital she told me if I was not careful, the issue would mature and become epilepsy. She is the one who showed my parents that medicine that is put in the nose. He would sneeze a lot until mucus came out. When coming to Nairobi, they used to grind that medicine for me and I used it on him until he did not fall the third time.

I: Yes, R3.

R3: I think that witchcraft may lead to epilepsy. Because I have witnessed a child who had just relocated to Nairobi from the village when he was in class two. The reason for bringing him to Nairobi was not by choice. The child used to fall, remove foam from the mouth and stiffen. We used to live in the same plot so it's something I am sure about. The child would fall, stiffen and stay for five hours. When he stopped going to the upcountry, it was just prayers. He is currently in form one and has never experienced the falls since he came to Nairobi. But when he was living in the upcountry, it was just screams all the time. The child would stiffen even at night.

R: [Cross talk]

I: Yes, R1.

R1: I think that the epilepsy drugs issued in hospitals are not working well. Therefore, people should try to access that traditional medication for sneezing. We give them to the patients so that they can get well. Because I don't think the medication from hospitals are working. I see people falling down all the time. I have never come across a person who got healed from this disease. Bring us that medicine... [All laugh]

I: Yes, R4.

R4: Sometimes customs lead to epilepsy; this is because I had a neighbor who had an epileptic child, when I asked the mother about the condition; she told me that it started when the father and herself separated. She also said that the child's father told her that; she and the hospital would be one until she buried the baby and if she wanted to free herself from this nightmare, she had to return the child home. Whenever the child went to see the dad, he would stay for a year without falling down. I tried to talk her into returning the child but she said that it would be a loss both to her and the father had the child died and therefore, she would rather keep him. She buried him in April. I feel customs contribute to this, the way people say "Our children can't leave, you will suffer with them." She suffered with the child because she used to rush him to the hospital in the middle of the night and when she took the child back to the father, he would not fall sick at all.

I: Other reasons you are familiar with?

Yes, R6.

R6: Stress is also another cause.

A woman may be pregnant and she is really stressed. Some even try to abort it. When they are not successful; the child may be born having epilepsy. Yes, the child might grow but they keep on falling down. I think some of these problems begin when the child is not yet born. If the mother was stressed and tried to do abortion in the wrong ways.

I: Yes, R5.

R5: What I have discovered is stress, depression and anxiety are also factors especially when one is epileptic they keep on getting the attacks. I have friends who have had the condition and they get the attacks in bad places such as, in fire, along the road or even in a crowd. You even wonder how it has happened. I'm always ready with a spoon close by because it helps. I once witnessed a man bite his tongue so badly, there was too much blood. What I would urge us to do is; when we go out there we should do research on the signs to look for and the first aid given, this would make us informed on how to help these people when under attack.

I: Thank you so much. What is your opinion on how the day to day life of an epileptic person is affected? Yes, R8.

R8: Epileptic individuals are discriminated against. They also don't get employment opportunities. My child was a carpenter and those who had employed him revoked it when he began experiencing falling down. Even companies that know him can't employ him because of the same. I also did not want him to go far from me for work because I thought he would also fall. They have difficulties finding someone to call a wife. My son was married with one son, when he began falling down; the wife abandoned him, leaving behind a one-year child. She came back after he was well again. Therefore, someone is hated and this affects them. It also gets hard for them to look for money because they may have the skills but are unable to secure any employment.

I: Yes, R2.

R2: The disease may stigmatize a person. You may fall in mud or in the midst of those you respect. When you begin experiencing the symptoms like eyes popping out of the sockets, people may begin to wonder. You don't feel free when you have it, HIV/AIDs is better because when you take your medication, you live a good life.

I: Yes, R5.

R5: I would like to plead that people with epilepsy be educated first. The government should also ensure that the drugs are given freely to these people because they are very expensive and not all can afford them.

I: Yes, R3.

R3: Epilepsy affects the whole family both emotionally and economically. The school performance of the epileptic child is adversely affected. His self-esteem is also lowered because he keeps on repeating the same class and growing up in the process therefore, while studying he is not freely able to interact with those he learns with. The parents also suffer economically because they have to spend a lot of money on the child. When it comes to mental stability, they are always troubled.

I: Yes, R6.

R6: One problem I have seen with this condition, its unlike other diseases where you can receive help from health centres and level 4. For those suffering from epilepsy, they only get help from big hospitals, where they find doctors who can attend to their needs. The one hospital we see them get treatment from mostly is Hospital M, but it has many departments. A place like that is private hence you can't be treated quickly like for other illnesses. I would say if possible health centers and other lower facilities should have doctors who can treat epilepsy.

I: Thank you.

Yes, R4.

R4: The illness makes these people hate themselves. The one I know can't go to the upcountry on her own, she has to wait for when her husband will say they are travelling. Individuals who care for them won't allow them to go anywhere on their own unless accompanied by someone because they feel they might fall down along the way. Also, they are not accepted by other people because they think the individuals may fall down and that would be a burden to them. Others have not accepted themselves, because if you tell them you go together, they wonder what if they get sick along the way. So they prefer to stay in their houses.

I: Yes, R7.

R7: The illness makes one hate themselves. My brother was educated but could not secure himself employment due to his condition. He was an only child and the mother was very protective of him because she was scared of him falling down. After the mother passed away, he went through a rough period since he had never done anything by himself before. He was forced to relocate to Nairobi in Mihang'o and broke all ties with the rest of the family. When we meet; he claims that we hate him and that is why we never look for him. He has never secured a job; he does casual labor. He also feels bad that the colleagues he studied with have jobs and he doesn't. He even gave up his land and he doesn't want it.

I: Yes, R8.

R8: It's true that people with epilepsy hate themselves. Although my child had stayed for long without falling down; he is an adult who has done a course but people could not employ him. He refused to return to the city after we went to the upcountry, and his wife had already left him. His reasons were that he didn't want to be in a place where people laughed at him. I was therefore forced to employ a sitter for him. He has never returned to Nairobi to look for work, he is now in Kirinyaga. I would also say it would be good if drugs were made available in hospitals such as Facility L, Facility O and Facility C which are close to us. So that if people in the community fall sick they can go get medicine from there and also have a counselor who can offer guidance and counseling if it's depression that has caused this problem. If treated, maybe the disease can be cured.

I: Yes, R6.

R6: Persons who have epileptic individuals think that witchcraft may be the cause. If support groups for epilepsy were made available, it would help these people ease the burdens among themselves.

I: Thank you.

Yes, R5.

R5: I think door to door initiatives would help identify people living with epilepsy. After that, groups should be established and registered by the government so that people with epilepsy can be accounted for.

I: Like the one for disability?

R5: Yes, even people with diabetes have those groups.

I: You have mentioned how epilepsy affects the life of an individual. What tasks can epileptic persons not handle? Or what do people believe epileptic patients can't do?

Yes, R8.

R8: Cooking. A person may have studied catering but when they get the condition, they can't secure employment because they can fall in the fire. The epileptic individuals also

fear for their life; this is because they are unaware of the time to expect the falls therefore, they can't risk going close to fires. Fetching water is another thing especially when they are in the upcountry. Epileptic individuals may not risk getting carried away by water sources. There are many tasks that an epileptic person can't do.

I: Yes, R2.

R2: I think that epileptic persons can handle any kind of work. What should be done is that; they should be taught on how to identify and communicate their symptoms, so that they can rest. Then after the attack they can embark on their tasks. This is a person who has hands and legs, they can do everything. Like my mother doesn't go to the kitchen when she starts experiencing those symptoms, when they finish she continues with her work.

I: Okay. Yes, R1.

R1: I think that epileptic persons can't do some tasks. They should not be assigned tasks such as cooking when they fall in fire they will die. Also doing laundry in rivers because they may drown. I also think that people discriminate against epileptic persons. Example when people are travelling, they sideline them because they might get the attack which according to them is embarrassing. Even children who study with those who have epilepsy are forbidden from playing with them because they think they might get epilepsy. People feel patients with epilepsy should not be where other people are.

I: Yes, R4.

R4: I think that these people can do any type of work but under supervision. The person I know doesn't experience the symptoms. Even when you ask later she doesn't remember anything when she falls. One day she got the attack in the morning and her child came to call me. I am the one who dressed her to go to school and later the child is the one who tells the mother that someone helped her get ready for school. They are supposed to do all the tasks but they should have someone nearby. Even if it's a driver the employer should tell them to open up to others about their condition.

I: Yes, R7.

R7: I believe that one can get cured of epilepsy. When I lived in Kariobangi, some doctors from Facility M used to come and look after epileptic individuals. Some of those who got the drugs from them were cured. I would therefore request that we be assigned some doctors from Facility M here in Facility L. Anytime the medication was out of stock, they would send people to Facility M.

I: Yes, R5.

R5: I think that people who get the condition should accept themselves as they are and also feel at ease when interacting with other people. They should not keep quiet. I'm familiar with epileptic individuals who even drive themselves around yet people say they can't. They should be educated and that will be okay.

I: Thank you.

R3?

R3: I think that epileptic individuals can handle any task. I know of epileptic individuals who live by themselves; others are orphans and do all their tasks by themselves. Having caring neighbors helps these people a lot because in case of anything they are well taken care of. We once received a case where an epileptic individual got the episodes while he was lying on his stomach, because he lived alone and there was no one around at the time, he died because he was unable to breath.

I: How do Viwandani people behave when they come across epileptic individuals? What is the reaction of the neighbors when they encounter epileptic persons?

R4: We take them as normal because these individuals may be our brothers and children. A neighbor of ours who is epileptic had just finished cooking, the attack happened and the stove was still on. My daughter who is really close to her got there and found her in the condition. The reaction she had was to put the stove off and help her sit down then look for help. The neighbor was not aware of what was going on and she got up to go and take a bath; when she fell, she had closed the door from inside. I had to go and call other neighbors, on knocking her door there was blood. She had hit her head pretty badly and began bleeding. I had to break the door so as to rescue her. We should be close to these people and show them love even if they are sick. We don't see them that way.

I: Yes, R6.

R6: We went to a diabetes seminar and the patients were given a tag which showed that they were diabetic, it was supposed to be hung around their chest and would help when one got into trouble because a person who found them would easily identify their problem. I would urge the government to come up with such initiatives for epilepsy patients so that they get the help they need in ease. Most people assume that men who fall are drunkards but with such a tag, they are able to point out epileptic persons among the crowd.

I: Yes, R8.

R8: They should have bangles that show they have the condition. There will be a difference with a person who falls down because of diabetes. Many diabetic patients have that bangle and those who don't, have a machine. People will be able to differentiate that a person is not diabetic or drunkard but epileptic. Due to stigmatization, epileptic individuals despise themselves. There was a young lady who was a neighbor; she was very pretty and lived alone and had no female friends. This is because they used to back bite as well as laugh at her, the only friend she had was a working male. One day the man left for work and when the episode happened, she died because no one was around to help her. These people should be taught on how to interact with one another. They should also have support groups where they are able to freely interact with one another. This also helps them have confidence in setting up their own businesses.

I: Yes, R2.

R2: There are people in the community who volunteer to help them while others would rather stay far away because they are scared of them.

I: R5?

R5: The clinicians who take care of the epileptic should be educated so that they handle them with care, others run away and give referrals for Facility ML or Facility P to patients because they don't know how to treat. So both the community and the clinicians should be educated.

I: R2 mentioned that some people volunteer to help while others don't, why do you think that is the case?

R2: Some people love themselves so much and assume that they or their generation can never get epilepsy. Therefore, they don't concern themselves with their neighbors who have the condition. That's why they hate that person and when they get the attack they would rather stay away from them.

I: Yes, R7.

R7: If one of your family members has the condition, you aren't fearful. If a neighbor is epileptic, you believe that you can contract the condition from their farts. That's why when they find them fallen they don't want to go near them. I believe that's not the case as it's an illness just like any other. It's like it doesn't have a cure.

I: Yes, R6.

R6: People really fear this illness. When a man marries a woman who is epileptic, his family pressures him so much because they believe that she is a liability in the family. They understand that this person must be assisted from time to time, when they fall, or gets sick. Mostly they are in the hospital. Other family members also discriminate against this woman. Therefore, you find that it is very hard for epileptic women to get a home of their own. The same case applies to a man who is epileptic. Mostly, they are discriminated against.

I: So the major issue is discrimination against?

R: Yeah. Nobody wants to have ties with these epileptic persons.

I: How does living with an epileptic person make one feel? What is the feeling of having to look after an epileptic individual?

R4: It is pretty hard. It is also mind troubling because you have to ensure that they take their medication correctly, eat properly and also don't attend to some chores such as cooking and fetching water. You have to babysit them and ensure that everything goes on well. You have to be close to them. When you are far away you have to talk to the neighbors to look after them.

I: Okay. Yes, R3.

R3: Those who have epileptic children are always mentally troubled and asking themselves a lot of troubling questions that have no answer such as “why me? what will I do?”, especially when it is an illness of inheritance. And maybe the source of the illness is from long ago which is hard to identify.

I: How does living with an epileptic person affect the lives of other people in the family?

R8: It affects other people because they have to spend a lot of money on both drugs and the foods these people eat. Not eating healthy foods makes epileptic persons have side effects such as dizziness because the drugs are so strong. When they don't eat at all, the drugs may overpower them. As a family, you have to fend for the children of the epileptic person if they have any. These people also have to fit in your daily to day schedule as you have to ensure they have everything they need. Having an epileptic person to care for affects one both mentally and economically.

I: Yes, R6.

R6: It affects. Mostly, if you are a parent and you have children, there's that child who is like a burden to others. There are those who will take care of the epileptic child and others won't bother to do so. This may cause disputes in the family. You find that most of the time, one person in the house is the one who mostly care for the epileptic person until they get tired.

I: Yes, R2.

R2: Epilepsy can cause enmity between neighbors. Whenever something comes up, a neighbor may always use your weakness as a weapon against you. This however, may cause fights and even death when one is pushed hard against the wall. It may also lead to suicide. When there is exchange of words now and then; a person who is not an expert in this section, may opt to commit suicide leaving the epileptic person without anyone to care for them.

I: R1?

R1: This disease really affects the family. Because if a person has no money and epilepsy medication is not free like those for TB and other conditions. If the family has no

money, it really affects them. This person encounters so many problems, they may even die.

I: Where do epileptic persons in the community get their treatment from?

Do you know of places where epileptic individuals seek treatment?

R4: The one I know doesn't go to the hospital, she gets drugs from chemists nearby.

I: She buys them from a chemist?

R4: Yes. She told me one tablet cost 50 shillings and at times 40 shillings. The other day she told me she wants an injection. I asked her if she knew of a place she can go for clinic just like for these other conditions but she didn't know of any place. I referred her to Mareba to inquire more about it. But I told her there must be clinics for this condition and it's good when she follows up on medication she is sure about. It must have stages, not just buying medicine for one week and when they run out she goes for a refill. She told me there is an injection and she wants to change to that. I encouraged her to go to the hospital and get help and at least she will buy medicine prescribed by a doctor.

I: Yes, R7.

R7: People believe that epilepsy has no cure, this is what makes them seek drugs from chemists even after experiencing falling down. They don't know that if they take the medication prescribed properly, they will no longer fall.

I refer people to Facility M. I came to know of the facility when I lived in Kariobangi, most people lack this information. A parent is the most affected by this illness because they wonder why of all the households in a family why it had to be theirs with a person with this disease.

I: Is the Viwandani community informed of places to seek treatment for epilepsy?

R5: A lot happens in this community. A person may come across a herbalist who will give them traditional medicine and this person's life deteriorates. Others use medication while others use herbal medicine. There is a problem here where people believe in herbal medicine, witchcraft and others are unable to buy medication and they are

epileptic. Even neighbors can't help because they are also unable to buy food or even pay school fees for their own families.

R: Others rely on prayers.

I: What do you mean by herbalists?

R5: Traditional medicines.

Therefore, people should be educated about epilepsy and also about places to seek treatment because many people are suffering due to lack of knowledge. We should do research first just like the one that was done and a big number of people about 700 were identified to have diabetes and hypertension.

I: R2.

R2: For the caregivers of these patients, when the illness began, they used to go to hospitals for follow-up but when they realized it was long term they relaxed and took the situation lightly. They don't follow up on anything. People go to chemists to buy drugs for a number of days when they get the attacks.

I: Yes, R7.

R7: Some people believe that it is associated with witchcraft and even if they go for medication, they get tired. Even if you are taking the person to hospital, you say you know who has bewitched this person. If someone follows up on using medication as it is supposed to, even the child might get well. Myths make people not to take the condition seriously. I once heard that among the Kikuyu tribe, if an epileptic individual ate a dog their condition would go away. But I never saw anyone eating the dog even the patient we had, so I don't know if it's true or false. Others say other people look at them with bad eyes out of jealousy because their business is doing well. Epilepsy is just like any other condition.

I: What else do people believe can cure epilepsy?

R1: The community has different types of people. Some people believe in prayers, they even refuse their children to be vaccinated because they believe it's demons. They

view prayers as a weapon. So some people believe it's witchcraft, demons or someone looking at them with bad eyes. For example, a child was plump when young hence a certain woman looked at her with bad eyes and they got the condition. [All laughs]

I: R6

R6: Other individuals believe that dowry payment can take away epilepsy from a person. If an adult gets sick, they believe that their parents made a mistake. Maybe they did not pay dowry the way it's supposed to and that's why the situation came about. When the child gets this problem, they don't bother to go to the hospital. So they focus on dowry payment and don't bother with treating the child.

R7: As my colleague has said, others believe it's because they didn't pay dowry. Also, others believe that honoring the wish of a dying person may lead to an epileptic person getting cured. If they do not do so, they get cursed. The person who asked for these things is not there but the child keeps on suffering.

I: R3.

R3: When you follow up well on traditions and customs, I feel it works. Because when these things are done, that person who was falling gets well. Especially in our community, when that issue is followed up well in detail--

I: Which community?

R3: Kikuyu community. When everything is done as it is supposed to, this person gets well.

I: Yes, R7.

R7: There is a certain lady who is a tailor but she used to fall. When she came to the community a certain friend of hers welcomed her. The friend started following up on why this lady used to fall. They went to the uncles because this lady's parents were both late. The uncle mentioned that there's a part of the dowry that was not completed and they had to bring a goat. They did what they were told and the lady got cured. She is now in South Africa. For us we believe in these things, we call it '*Maruta*' it's part of dowry. It's usually important because it can bring about such illnesses.

R5: I witnessed this when my first son died, then I wondered what was happening. My second child almost went through the same. I followed up on what I had not done on my wife's side and paid the dowry. My son is living a good life now, he has everything. Therefore, these things affect us as Kikuyus. When we don't pay, it brings problems to the family.

R8: In my tribe (Kamba) if a person doesn't pay dowry for the wife, when their children get married and they use that dowry, they start getting sick. Even a lady who is not married and she is of age, she pays it for herself. If a parent passes away and the dowry has not been all paid, people start getting sick, it can even cause epilepsy. In Kamba it's called '*Kirumi*' or '*Mugambo*'. Someone's voice and that person is dead, that affects the child. If they are able to go and pay the remaining things, the child gets well. So traditions and customs contribute to epilepsy.

I: Thank you. What challenges face people who seek treatment for epilepsy?

R7: There is a problem because maybe they are my brothers, you are not employed. You have to look for money and when you go there they will tell you what they want, maybe a cow, you don't have money but you have to pay because you have a sick person. If it's the hospital that's still a problem.

R6: The problems I see those patients going through when seeking treatment one is inadequate funds. The treatment is so expensive. When you go to the hospital, they ask for a head scan and yet you cannot afford it. When one asks for help from the family; most are not in a position to help. For some conditions such as cancer, people fundraise and they get help. We can even see it in the media. But when you are sick, it's really hard for people to come together, they just see you to have problems, that's why this illness has come about. So people with these conditions find it difficult to seek treatment.

I: So the issue is financial?

R6: The tests done are very expensive, for example a head scan, they are not available in many hospitals. Even the blood tests that are supposed to be done are very expensive. One also spends a lot as they move from one hospital to the other trying to find a cure.

I: Most of you were CHVs and therefore are familiar with places where to go for epilepsy treatment. Is the Viwandani community aware of places where to seek treatment or access drugs for epilepsy?

R1: I'm not aware of where a person with epilepsy can go to seek treatment. That might also be a problem to those who have the illness. Because even if you have money, where will you go if you have not been directed?

I: Yes, R8.

R8: You will have money problems, not knowing where to go and also you are unaware of the condition. Even if they are falling down you won't know it is epilepsy. When you rush to Facility L, they refer you to Facility P and they don't tell you what the issue is. When you get there they ask for a head scan and yet you don't have the money. The patient keeps on getting worse. Then again you are referred to another hospital. By the time you find a place where your patient can receive treatment it takes a long time.

I: Yes, R7.

R7: Another problem with epilepsy is when a person falls, you might not get money the same day. When you take the patient to hospital the next day, they seem okay. Hence it becomes hard to explain to the doctor that they have epilepsy. It's hard to treat epilepsy especially when you don't find a doctor who understands it well. There's a time I listened to a doctor on radio and he was asked what epilepsy is, and he referred to it as lightning because it comes very fast.

I: Yes, R3.

R3: There's a certain person I met and his face was swollen. He told me his face was swollen because he had fallen, he had epilepsy. I inquired further on where he seeks treatment and he said he went to Facility L, was given a prescription but he lacked the money to buy the medication. He borrows money for food and instead buys medicine from the chemist at 20 shillings each. He takes the medication when he begins feeling dizzy. This person does not take a full dose.

I: What other challenges do people go through as they seek treatment for epilepsy?

R2: Finding means of transport is another issue. When an epileptic individual goes into an attack at your place, you find yourself in a tough position because you are the one to

look for transportation means to go to the hospital, because that person can't walk. On reaching there, finding a specialist for epilepsy is difficult so you end up wasting money. It's also time consuming because you may get a referral from one hospital to another and when you get there late, you are told to come the following day. Other hospitals don't follow prior history and new tests have to be done, this consumes a lot of time. Tediousness because one gets tired as they undergo a long and tiresome process. Distance is another factor that affects those seeking treatment. Places where these people go to seek treatment are mostly far away, this affects the time and money used for transportation. Also, high cost. When one gets an epileptic person to a hospital, they have to buy them snacks because they can't stay hungry throughout the process.

I: R8?

R8: Some doctors are not familiar with treatment of epilepsy as they major in normal conditions such as malaria and colds. I took my child to a dispensary close to my home once when he got the third attack along the road; when I gave the doctor the medical history, he began to ask if he had been screened for HIV/AIDs. The child stormed out of the room and when we went home he said that if I thought he had HIV, I would rather let him die. This also troubled me mentally. It took time before he received treatment because I was trying to convince him to do a HIV test. In my mind, it's like the doctor had seen he had HIV/AIDs and it affects the head, I didn't know. It took time before I could remember he had an accident earlier and it had affected his brain, because these episodes began way later. I would therefore urge the government to establish many centers for treatment of epilepsy, they should also ensure that the doctors assigned to these posts qualify for the same. Because if that doctor knew about epilepsy well, he would not have stigmatized the boy and I. He would have treated epilepsy as he was supposed to.

I: Thank you so much, any addition on the same? What initiatives should we take to educate the community about epilepsy?

R8: We should establish epilepsy centers or a department of epilepsy in hospitals. Even if a person doesn't want other people to know they have epilepsy, they can take themselves. The way HIV/AIDs or diabetic patients do. Once a person knows their condition, they are able to handle it. Doctors place should also have counselors who should counsel epileptic persons and when the number rises and it becomes hard for them to do the counselling on their own, the government can offer training to caregivers, community members they stop discriminating them and the patients so that they don't hate themselves. When community members know a person has epilepsy, they won't discriminate them because they will know when a person falls they can't infect them with epilepsy hence they can help them when they fall. Also the patients will know there is no stigma and they can talk to other people about their condition and they won't get laughed at. Then the doctors will know epilepsy cases and offer treatment.

I: R4?

R4: They should do it the way diabetes patients do. There should be group formation for people suffering from epilepsy. This would help them interact with other different individuals and also ease the burdens they face. It also eases stigmatization and help them accept themselves.

I: R6?

R6: When corona affected Kenya, a lot of things changed rapidly. There were several effects because many people were stressed. Mental health specialists are now in many health centres. In my opinion, they should do the same thing for epilepsy. Qualified doctors should be assigned to different hospitals to care for epileptic persons and signs should be put there so that any caregiver of a patient with epilepsy can be aware that the services are available.

I: Yes, R3.

R3: Door to door initiatives should be established. This will ensure that every epileptic individual, even those in hiding, are found. Chief barazas is also another thing, it ensures that a large area is covered in getting the information. Announcements should

also be made in places such as churches about where people can be taken for treatment.

I: R5?

R5: I think that when epileptic individuals come together, they should elect a chairman, secretary and treasurer who would help them seek medication in ease. They can get medication from MEDSAF at affordable prices when we lack medicine here. They can make contributions so that in hard times, they can still find a way to look for medication.

I: Okay. Thank you.

R8: They should have centres nearby and feeding programs should be established. This will make every epileptic individual present themselves. When they do that they can meet with the doctor or counselor. When a person falls, they seem to be weak. My neighbor who is a tailor, stays alone and because people know she falls, they don't take good clothes for her to make. They only take the ones for repair. If she doesn't work, she won't get something to eat. Because some are even stigmatized by their families, they don't get someone to ask for help. The feeding programs will also form a basis for a support group which will enable them to share the challenges they experience and reduce depression and they may end up getting well even without the medication.

I: R2?

R2: I think that well laid organizations similar to those of tuberculosis, pressure and HIV should be established for epilepsy people. Epilepsy drugs should also be free and in plenty, so that patients don't lack medicine.

I: R1?

R1: Epilepsy should be managed as a disaster just like other diseases.

I: Epilepsy should be treated with urgency?

R1: Yes.

I: Yes, R7

R7: Door to door visits should be conducted. I heard some people will come looking for patients with epilepsy. I once got a visit from a man in Sinai, he conducted checkups on me and confirmed that I had pressure. Later he came and did further testing and found me to be diabetic. Had this not been the case, I wouldn't have known my status. I was referred to Facility L for treatment. He also advised me on what foods to avoid and what to take best, he really helped me because the condition didn't worsen. Therefore, door to door visits would help identify epileptic individuals and control their situations before they worsen. Some don't even have time to go to the hospital.

I: Yes, R8

R8: I would like to encourage my friend here and tell her that; these people are on their way to her door soon.

I: How can we help epileptic individuals live better lives? How can we improve how epileptic persons live?

R8: We can accept them as part of us, we should also love them. But they should also accept themselves first because if they fall and you help them once then they do so another day in your absence, how will you know? It is hard for some of them to open up that they have epilepsy. Therefore, they should have centres with doctors and counselors and support groups so that they can be able to open up. They would also be encouraged about the importance of having a good relationship with their neighbors which makes it easy for one to help, but first they should be told to accept themselves because they are so isolated.

I: Any other?

R2: We can advise them on the importance of taking their medication all the time so that they don't skip dosage and the disease matures and increase the number of times they fall. Because when they take medicine, they can stay for even three months without getting the attacks. But if they don't, they can fall every day and even end up falling in the fire. If they take medication this illness calms down.

I: R1?

R1: They are people we have in the community. We should show support and guidance to them.

I: R5?

R5: We should be friends with them and ensure that we visit them. We should also teach them the symptoms to expect which will make them aware. Because there are some who have the condition but they don't know the symptoms. Also, referring these people to places like Facility L where we know they will get help.

I: R6?

R6: If possible the community should be educated on epilepsy so that they do not discriminate against these people. They should also know it is a disease like any other.

I: Yes, R3

R3: Follow up programs should be enhanced for them.

I: Thank you so much.

Anybody has anything else to add?

My fellow colleagues, do you have any questions?

Thank you. As we conclude, anybody has any questions?

R2: Some individuals get epilepsy in their childhood while others come to get it in adulthood, what do you think is the source of epilepsy?

R5: Does epilepsy have development stages?

I2: We are not specialists, our focus is on research therefore, the best person to answer your question would be a doctor.

R7: We Kikuyus believe that when an epileptic person gets burnt, the disease can't get cured. According to your research; do you think that this is true?

I2: We can't answer that as of now. We first have to finish the research so that we are able to assess different opinions from different people.

I: Yes, R4

R4: How do we answer people who ask us; how do you people help them after knowing that they are epileptic?

I: We are able to know how informed the community is; when that is not the case there will be introduction of programs in the future which will impact epileptic persons' lives. Research helps identify the gaps and makes initiatives to close them. Thank you.

[End of audio]