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<b>ORGANISATION</b>	APHRC
<b>PROJECT</b>	EPInA
<b>CONTACT TYPE OF INTERVIEW</b>	FOCUS GROUP DISCUSSION WITH COMMUNITY MEMBERS
<b>FILE NUMBER</b>	<b>211122_001</b>
<b>DURATION</b>	01:12:34
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**I: Thank you, as we start the discussion, I would ask everyone to feel free, so that we don't have only one person talking, let all participate please. As we start, what are some of the names used in the community to refer to epilepsy?**

R4: He falls...falling, fainting

R2: Epilepsy

R8: Sickness

**I: Is there anyone else with a name that is used to refer to epilepsy?**

R5: Possessed by spirits.

**I: Any one with another name?**

R1: Battery low.

**I: And R1 can you tell us what that means?**

R1: You know when the battery is low it switches off. The moment it switches off he falls down, he was battery low so he has switched off, and he falls.

**I: Is there anyone we have left out?**

R5: Mentally retarded.

**I: Is there anyone else who has heard another name?**

R9: Others use network is lost.

**I: And why do they use that network is lost? Do you know?**

R9: When they fall, the brain does not work, it's like the network is lost.

**I: Have we left anyone out? As we continue, what are some of the symptoms of epilepsy?**

R4: They get angry a lot, if you tell them something small they get angry, and also when they are almost falling down and they forget things.

**I: And what makes them angry, R4?**

R4: Like even when you tell them to remove that cup and put it there, it's as if you are forcing them, or you picking on them.

**I: R3 I can see your hand up?**

**R3:** On my side, I see my child when he is almost getting the attack, he laughs a lot even when I am with him I see he is laughing a lot, I just know it's the attack.

**I: And exactly what time or instance does he start to laugh?**

**R:** When he is about to fall, he laughs a lot, even if it's just something that has passed, I wonder what the child is laughing about, and then he can't stay even for 3 hours before he falls down.

**I: R2 I have seen your hand up?**

**R2:** For me I am a person who lives with epilepsy, and that disease you lose consciousness first, and it comes in two ways; one, you don't even realize when it comes, and the other, when you walk a lot you are unable to breathe, do you understand? Then you feel dizzy, there are times you can control and you sit down, but other times you are unable to control, so mostly its start with the head, you feel dizzy. So this disease has no alert, so when you are feeling you have pain and you decide to sit down, it comes at any time, no alert, even when its sunny, it attacks you. Like for me mostly, I faint anywhere, in the fire, I got burned, fell in the toilet, you understand? It can get you anywhere, so you cannot say you have pain that you will sit somewhere. But mostly I lose consciousness. And you cannot walk a lot, like even climbing these stairs, I am not able to breathe.

**I: Anyone else who can tell us the symptoms?**

**R9:** When it's cold it also affects, when it is cold that's when we say there is no network, you find that the person is absent minded, if you are not aware that the person has epilepsy, you will hear them screaming suddenly, and they fall down, and throwing their legs. I had a friend of mine, but I hadn't known that he fell. That day I knew, we were just sitting by the road chatting, and he fell, I just saw that thing, made him stiff and he fell. I thought he had... and it was when I was told by the relatives that he is epileptic. We carried him and put him aside, since he had fainted in a ditch.

**I: So the symptom is falling when it's cold?**

R9: If they stay in the cold, the illness comes and attacks.

**I: That's R9's opinion, I don't know if there is anyone else?**

R8: You were asking about the symptoms?

**I: Yes.**

R8: The symptoms according to me are shaking, and mostly when the person falls down, they foam from the mouth, and the majority also urinate on themselves.

**I: I don't know if there is any other person we have left?**

R2: This illness of epilepsy, you sometimes bite your tongue and mostly you don't think, you cannot think of anything, when you start thinking, the attacks come.

**I: Is there any other person with a symptom we might have forgotten?**

R4: Another symptom is when the moon is young they fall most of the times, and also when the moon is almost disappearing they also fall a lot.

**I: Can you elaborate what you mean, when you say the moon is young?**

R4: Sometimes when the moon appears, like when the Muslims say they have sighted the moon, in times like those they fall a lot. Again when it disappears they don't fall anymore, just like that until when the moon is almost disappearing they start to get the attacks.

**I: Anyone else who wants to say something?**

R5: There is another symptom, of losing memory, if someone was learning, he doesn't understand anything in the class, the memory is lost, or if you talk to them, you might be discussing about something and then suddenly they switch to talking to themselves.

**I: Okay thank you for that, and as we continue, what do you think causes epilepsy?**

R2: Loss of memory, and also pain in the neck, mostly when I am almost getting the fits, I feel pain on the neck, then the medicine they give for the illness, you cannot take before eating, you must also make sure you eat, you cannot take it without eating first.

**I: That's R2's opinion, who else has an opinion on what causes epilepsy?**

**R8:** I think what mostly causes epilepsy is the lack of oxygen in the brain, if during birth a child is born without the oxygen getting into the brain, that person gets epilepsy.

**I: Another person with a different opinion?**

**R4:** Also destruction of the brain, the message, communication does not get into the brain in the right way.

**I: That's R4s opinion; I can see R5 hands up**

**R5:** It can be that someone fell, and got injured here... (Pointing on the head)

**I: When you say they fell, what do you mean?**

**R5:** Maybe they got in an accident, and got an injury on the head, which.... (inaudible speech)

**R2:** This epileptic illness comes when women are giving birth, because like for me I was not born with it, I got it when I was giving birth, you understand, when I went to the hospital to give birth, it's when I started getting the attacks, because of that moment when you lose breath when pushing the baby. I got the illness immediately after I gave birth.

**I: So even as the parent you can get it when you are giving birth?**

**R2:** Yes when giving birth? For me it's been 8 years since when I went to give birth and I got the illness.

**I: That was R2, anyone else with a different opinion? R1 you are very quiet?**

**R1:** What I can say about what causes epilepsy is you see when someone sits in the sun for a long time, or near the fire, that can cause the fits and then someone falls down.

**I: I have heard all your opinions. What about when we talk of our social cultural and spiritual beliefs, what do people say about the cause of epilepsy?**

**R5:** They say it's witchcraft...

**I: Maybe you just tell us more about that R5?**

**R5:** They say it witchcraft or that the family of the sufferer were murderers, and so the spirits of those dead people are turning to the person and making them get fits. Others say many things....

**I: Let's hear from R3, I can see her hand up?**

**R3:** For me my last born is a girl and she has epilepsy. When she started having the fits, it was in the upcountry. Now my mother and grandmother were saying that someone poured it on the road and she stepped on it, or someone sent it to her. Someone had the illness and sent it to her.

**I: How does he send it to her?**

**R3:** They say that it's made, like charms are made and poured on the road, and the child steps on them, or spirits, they send them to the child. For my child she was not born with it, and she is young. When it started we were in the upcountry and I just saw the child shaking until she fainted. When she gets back to consciousness, she urinates, or even soils herself, then after some time she gets fully conscious.

**I: The charm that is thrown on the road causes only epilepsy or even other illnesses?**

**R:** Some say that; like for me I was told that's what happened to the child.

**I: Let's hear from R9...Then we come to R8?**

**R9:** In upcountry, we were being told that if you pass where an epileptic person had fallen and he urinated, you also got the illness, so culturally we were told not to pass where that person had fallen and urinated, isn't that what they say? So that's how it's transmitted to people.

**I: And also we can talk about the spiritual beliefs as well, I can see R8 wants to say something?**

**R8:** According to many traditions, they believe that epilepsy is a demonic illness. It's not an illness that you just get like that, the way the medical people say its lack of oxygen and so on... many communities or people believe that's it's demonic or spiritual, that if someone has a grudge with you or they don't wish anything good for you, they send it to you with witchcraft practices.

**I: Thank you for that, and as I continue, there is something (name mentioned) said about, her being an epileptic patient, she cannot walk a lot, sit near the fire. Now I would like to hear your opinions on how epilepsy affects the lives of those living with it.**

R2: It affects me since at times I am almost raped, mugged, because you lose consciousness. Like there was one time someone came to assist me when I was unconscious, for me to only get back my consciousness and find my dress was half way, if I hadn't gotten back my consciousness he would have raped me. You cannot also sit near fire to cook food, and some other stress that just bring side effects.

**I: I can see R4 your hand is up?**

R4: An epileptic person cannot go near a lot of water, because if he falls in that water, and he is alone, there is no way he can help himself.

**I: I can see R5 wants to tell us something?**

R5: An epileptic person cannot be left in the house sleeping alone.

**I: Why can't he sleep alone?**

R5: Because you never know when the fits will come, it might come at night, when they are sleeping, the blanket might choke them and you find they died.

**I: What other effects does epilepsy have on those living with it? R9 you want to tell us something?**

R9: Also, they cannot stay alone, because when they are alone and maybe they were cooking, they can fall on the stove and burn themselves, and this will worsen the illness. That's why you find they have scars, because the fits maybe they came when she was cooking, or eating

**I: Is there... R8**

R8: For a parent living with a child who is epileptic, the economic status goes down, because the parent has to spend all the time with the child as he cannot be left alone....

**I: Sorry for cutting you short R8, but how does epilepsy affect those living with it? the patients themselves, and how are they affected?**

R8: Okay it's the patients?

**I: Yes**

R8: Side effects, one is that the drugs themselves have a side effect, it can harm them.

**I: What activities can't they do because of their condition?**

R8: Most of the time they cannot play with other children, or sit with others because once people know that you are epileptic they even fear you... (inaudible speech)

**I: While we are still on the same, how do ordinary people behave towards those living with epilepsy in this community?**

R8: They take them as people possessed by demons, that's one, so the community or many people do not associate with such people, for example if your child has epilepsy, you find your neighbor telling their child not to play with the epileptic child, because you heard some say that if you pass where they fell or urinated, you get it too. So they tell their child not to play with a particular child since he has epilepsy. And if it's an adult, you find he only has a few friends because when you fall it's stressful as people do not know what to do or where to start, so many people will avoid it.

**I: Anyone else with an opinion of how people who do not have epilepsy, behave towards those with Epilepsy?**

R9: Also, you know majority of them are discriminated because they are seen as if they will transmit the illness to other people, but there are some who know the symptoms, and can take good care of them, but there are those who will even run away, because they don't want to be told they are the friends of the person who falls down, and they might think you are all the same.

**I: Let me go back to (name mentioned) she had raised her hand, so that she can tell us how ordinary people behave towards the epileptic.**

R2: At times, when you look for work, they don't want you near, they think you are spoiling their business, they say that if you fall there the illness will get them. Some believe that if you have the illness, you will give it to them, because many times you look for work and they say if you faint here your demons will turn to us, you are not able to work. At

times they say if you faint here our business will end. So you find if people have information that you have it, you can't get work and you cannot stay with people.

**I: Let's hear R4 S's opinion about the epileptic patients and how they are treated by these other ordinary people.**

R4: For people living with epilepsy, if it's a woman you find that getting married is a problem, because people think that she will give birth to children with epilepsy and also they have a lot of expenses because they cannot stay alone. Again in the house the woman cannot go near the fire, and mostly men will marry to get someone to cook for them and such like things, going to wash in the river, but now for the epileptic person all this is risky, and so a man will not be able to stay with them. If it's a man, getting a girl to marry is a problem, because she will fear that the guy will faint and even working for the daily bread is a problem, and to support the family. They have a problem when it comes to marriage. And then, when it comes to giving birth, if it's the woman, they give birth to children with no fathers, because when they faint and fall someone comes and rapes them, and they become pregnant. So you cannot even tell who the father of the child is. Then even bringing up the child is a problem, because when she faints and the child is young, breastfeeding the baby is a problem, so the person with such a woman will have a hard time, so friends avoid staying with them.

**I: That is R4's opinion, I don't know if there is anyone else? Okay as we continue, how do you think taking care of the epileptic person has affected your life?**

R8: I don't have an epileptic patient but I know a person who is epileptic and most of the time the thing that stresses them is medication. Sometimes it is difficult to get the drugs, they are expensive, and thirdly there is a drug called...and you cannot be sold the drug if you don't have a prescription from a doctor, because many people have misused it as a drug abuse. Taking a child who is epileptic for check up every 3 months is a challenge, because if I am the caregiver, it affects me as I have to dig into my pocket and support the child, to go see a doctor, and get prescription after every 3 months, to be able to get the drugs. So it's a challenge.

**I: Another person on how their lives as a person taking care of an epileptic person, has been affected?**

R4: Another challenge is that if you have an epileptic person in the house even going to work is a problem, and even while at work, most of the time you are worried that they might get an accident like burns. Their life is also very expensive, like they must eat very properly, and nowadays you find maybe you are jobless and sustaining such a person and feeding them is a problem. Your economy is also affected since some cannot go to work, as you take care of the sick.

**I: So even the life of the other family members is affected?**

R4: Yes.

**I: I can see R9 raising his hand, so he can tell us, how the life of the person taking care of the epileptic person is affected?**

R9: For the person who is looking after an epileptic person, they can get high blood pressure, because all the times he is stressed up, he doesn't know what time the patient might fall, and maybe he wants to go to work, and she might be a single mother who is alone, and she wants to go look for something to even help the ill person. So it affects them mentally.

**I: And also as community members, tell us how you see the lives of those that are taking care of people living with epilepsy, being affected, it's not a must that it's you who is affected but also other people with such patients in the community.**

R5: For those that have epileptic patients, they cannot go far, because if it's a child you have to look after them. You cannot go for work that you are invited at a distance, and you have this ill child. You cannot go since it will take you long hours, so it will force you to do something that's around, that can allow you to take care of them as its required. Since you don't know at what time they might fall. You also find that money is a problem to this people, because they cannot go far, because if it's like selling clothes and you want to go sell in Kabarnet, Eldoret, at least to do a meaningful business, you cannot go because if you are there and it requires you to spend 2 or 3 days there, before coming back, you cannot leave the child alone, so you just have to take what is around. At the same time, they need food, drugs, they need to live well just like other people, but you find they cannot meet all this needs, because you cannot go look for (inaudible speech)

...and you are a single mother who has other kids too, not just the sick one, who you need to educate, but now all the attention is on the sick child.

**I: I see R8 wants to contribute**

R8: Another challenge for people living with epilepsy is getting employment, because when you are epileptic, there are no symptoms that you can look at someone's face and say they are epileptic, but maybe they went and asked for work and they are given, and then maybe after 1 week or 2 months they get fits at work. You find they will get a dismissal letter from the boss. So it's very easy to lose a job, and once it's known they have that condition it is not easy to get even casual jobs.

**I: (Name mentioned) you want to say something?**

R2: For epileptic patient you are discriminated by many people during celebrations, like in a wedding, you cannot be invited, because they think you will spoil their wedding or their party, they discriminate you just because of your illness. They say if you fall at the party you will pass them your demons. So you are discriminated during celebrations and even in mourning events.

**I: That when you are a patient?**

R2: Yes.

**I: And what of the person who takes care of you?**

R2: That is what I am saying, even those that look after me, like when my neighbors hear a cup falling down in the house they will come running thinking that I fell down, it shocks everyone not just the people in the house but even neighbors, those outside. Now when you are in the house, you are forced to put things down slowly, like a *sufuria*, even if by mistake a plate drops to the ground, or a child drops a spoon, they think I have fallen down.

**I: And as we continue, what hopes do the epileptic patients have for the future?**

R2: There are those that God has helped and they got well, there are some who were born with it, but later they get well. Even when you go to hospital, doctors give you morale, they tell you that there are those that got well, because it's not all who... (inaudible)

speech). Like there is a neighbor lady I have who had epilepsy, when she gave birth, the illness went away.

**I: I want to hear from R3 because she said he has an epileptic daughter. As a mother to that child, what hopes for the future do you have for your daughter?**

**R3:** On my side just what my colleague here said I hope that maybe God can help her and she gets well, gets married... (in audible) maybe even finish her studies, and she is able to help herself.

**R: Okay, R4?**

**R4:** I have 2 children who are epileptic, and they are female, the first one got married. She is still with the husband; despite that she falls down. But the second daughter gets married, she gets children, and then they get tired with her and they chase her away. Like now, I am with her at home. The hope I have is that there is a time they will get well, because when they get their medication consistently, the number of times they are falling reduces. If for example they were falling 3 times in a month, and they take the medication consistently, they only fall once. And again they have gone to school; one went up to form 3 and the other up to form 2, so I have hopes that one time they will get well.

**I: Who else has an opinion as a community member, on their hopes for the future of the epileptic patients? R5 I see our hand up?**

**R5:** I see there is hope, because if you see how we started...we started on how the illness is known to the community members, and what people say that its demonic, but as we continue we hear that if you go to hospital, and get medication, it reduces the fits, and the person reduces the number of times they faint. That is the first hope, because back in the days you would find a patient falling 3 or more times but after going to the hospital, and getting medication it has reduced the fits. That is hope that this illness can be controlled and a patient leads his life and do activities that he couldn't have done previously. Another thing is that in taking the medication, the patients should be consistent, and adhere to the day and time, attend clinics, they will find their life improving, and fits will reduce. There is one patient I know who used to get fits even 4

times a day, but when they took their medication, they stayed for 5 years, without fits, but what had caused the fits to come back was that they had gone to a boarding school. When he went there he had the medication with him, but since it's a child, he was not taking them as required, so the illness came back in a more severe way, but when they took the medication well while in a day school now it reduced again. So there is hope that an epileptic patient can get well, and his life continue well, if he takes his medication well, and we can see there are researchers who are trying to find out how the diseases can be treated completely, and we also hope that medication will be found to treat it. I believe so.

**I: Thank you for that, and as we continue...where does the epileptic patient seek treatment?**

R3: When my child faints, I am forced to carry them and take them to the nearest facility, and there I see they inject her or they give us medication.

**I: Which is that facility that is near you, R3?**

R3: Now you know at times it is at night and the government hospitals do not operate at night, so there is another hospital near Gongga Njaa, Gomongo that I take her.

**I: Do you know its name?**

R3: It's called....st...it's called? It's inside one chemist.

**I: Is it a private hospital?**

R: Yes it's private.

**I: Okay, apart from that Gongga Njaa, is there any other place where you get services for epilepsy?**

R4: For me, there is another hospital I used to take my first daughter, in Mathare, near Huruma, but it's my wife who used to take her, she would get a prescription, and we would buy the medications at times it's too expensive, and we don't have money...

**I: Is it a private hospital or Government?**

R4: It's a government hospital...

**I: It's in Huruma?**

R4: Yes... she used the drugs but we didn't see any change. The other daughter gets medication from a dispensary at Kariobangi and even when she became pregnant, she attended her clinics at the same health facility, and she would be given prescriptions and we would buy the drugs at 10 shillings each.

**I: At Health Facility G, was she getting services for epileptic patients?**

R4: Yes, she got a medication prescription and we bought per tablet at 10 shillings.

**I: I have heard from R4 Huruma and Kariobangi, Gongu Njaa, any other place?**

**Several voices: Not Gongu Njaa, it's a chemist opposite Gongu Njaa police station.**

R5: I think what R4 was saying in Huruma is a facility called Lions, and an organization called KAWE, (Kenya Association of People living with Epilepsy) comes there every Friday, and there are appointment for epileptic patients. There are doctors who come to see the patients, and prescribe medications, and even they give you the prescription, you still buy from them. You know their drug are generic, and you pay 100 shillings for consultation. Then once you are given the prescription, you buy the drugs just outside there, from them, and they book you the next appointment. I also know there is Health Facility K, where there is a clinic for epileptic patients, and also Health Facility B.

**I: You said KAWE is in Huruma?**

R5: Yes, you know Lions, behind Redeemed Gospel Church, every Friday, every week.

**I: Is there any other place you have heard from apart from Health Facilities G, K,B?**

R4: Even Health Facilities L and M.

**I: And apart from the hospitals, are there any other places for epileptic patients to seek treatment and care?**

R4: Most of the time even if a person is brought to these health centers like in Korogocho or Karobangi, they refer, because even getting the drugs there is not easy, or even the doctors who can treat epileptic patients, is not easy. So they just refer to a higher level.

R5: What they can do is just maybe if you were brought unconscious, they inject you to bring you back to consciousness, and then they find you an easy way of getting treatment at the referral.

**I: And apart from the hospitals, is there any other place where these people get treatment?**

R2: Yes, there is, mostly at the chemists. I go to the chemists most of the times, I went to Health Facility M, and I did a scan in the head, and because I was fainting a lot, they prescribed some drugs for my head. Now the medicine of different types, like the one I am using right now is...(Inaudible)and I still fall even when I take. There is another that is sold for 1300.Because they did (Inaudible) they are different, and this one doesn't help a person with epilepsy, it's just for emergency, and this one you can find it at the chemist. There are those that you cannot get at the facility, if you go back to the hospital they say the drugs are out of stock, go and buy, those drugs are different, and some have side effects for the head and fainting, because when you faint you lose consciousness. You don't know where you went or when to come back, because it can bring you side effect to the head, you at times decide to just sleep in the house...(Inaudible) so its quality matters. There are 2 types, one for the head and the other for epilepsy, so you don't find it in all chemists. I go to Health facility L, they said they don't have it, that I should go to Health Facility K. At times I still don't find it, and I go to Eastleigh to buy at a chemist.

**I: So hospitals and chemists, is there any other place?**

R4&R2: No, there isn't.

**I: Okay, and do you think information on where to seek care and treatment for epilepsy is readily available in this community?**

R4: It is not, because these hospitals do not have specialists to treat the illness, and so they don't have the drugs for epilepsy as well. You know the drugs can only be available if there is a doctor who can treat. But now the doctors are not there. Again there is an issue that there are traditional healers that can heal the illness, you find that when you go to the herbalist they give the herbs but there is no change.

**I: And where do you find the herbalists?**

R4: They are in this community...

**I: And they deal specifically with epilepsy?**

R2: That's just business because they know you are sick, but if you go they don't help.

**I: While we are still there, R4 has said there are no specialists to treat epilepsy, so that's one challenge of availability of information and care for epilepsy in this community?**

R9: What I can say is that the government has not done enough research in places where these communities are. If they had done their research, we would have gotten the services very easily, but now because they have not done so that's why we are seeking services for epilepsy very far. If they did their research, we would be accessing care and treatment very easily.

**I: So what should the government do research on?**

R9: Epilepsy disease.

**I: We have heard there are no specialists, not enough research done by the Government on availability of information on epilepsy, any other challenge?**

R4: I also think the community needs to be educated that epilepsy is not a demonic disease, they should get full information.

**I: Who will educate them, or who should give the full information?**

R9: Organizations like Aphrc, Government and even stakeholders and even CHVs.

**I: Any other challenge?**

R2: There should be one hospital specifically for epileptic patients because epilepsy does not alert when coming. It can attack you any time, and the hospitals out there, you go you are told there are no drugs and this is risky to your life.

**I: R2 has brought us to the discussion where I want to ask, what can be done to the public, to make them more aware about the disease of epilepsy and its risk factors.**

R4: Another challenge, there are those who have epileptic children and they hide them in houses. They don't want people to see them because they are ashamed to be known that they have epileptic patients, and they faint or fall down. They think the community will laugh at them. We have that challenge.

**I: What should we do so that they don't hide those children?**

R4: They can be educated on that, and just like my colleague said, there is at least one clinic that caters for epilepsy.

R9: The community should know that this disease cannot be transmitted from one person to the other, because that brings fear to the community. They think that if, it's like what my colleague said about, if it's a business place they say if you fall here, you will transmit it to others, or it's like bad omen that will be transmitted, either through demonic transmission, bad omen, and the rest. Those are not medically true ways of getting the illness.

**I: R6, when you say, ni *kama swara*? Kindly elaborate to us what you mean?**

R6: You might find like if he serves customers and the fits attack her, the customer will run away and maybe to never come back, and even tell others not to go there so the owner loses customers.

**I: R1, I have seen your hand up, you want to tell us something?**

R1: I was saying even before they build us the special hospital for the epileptic patients, they can send us at least one specialist in the facility. You see the way you find in a facility a room for a particular illness, at least if they bring the specialist and say this is the room for epileptic patients, it will be easy and even those parents living with epileptic children will not hide them and they will be free. Such that when they get the attacks, they know they can get the specialist at the facility, and also the drugs to be made available.

**I: And what challenges do community members face when they are seeking care and treatment for epilepsy?**

R8: The first is transport, because it's obvious when you have an epileptic patient, and you go to either Korogocho or Kariobangi, you get referred. So many parents prefer to go straight to Health Facilities K, B or L. So you find, money for transport is a challenge.

**I: Another challenge, R8 has told us about money?**

R5: I wanted to say money to cater for the patient, because they went to the facility with the hope of getting treatment and even drugs, but on reaching there, they are told they should buy and at that moment you don't have money to buy the drug.

R2: They should also give us emergency cards, because in all hospitals you are expected to queue, and at the time you are sick, and the more you stay there you may fall down, but if you get the emergency card you can be treated anywhere, (inaudible, noise in the background)

**I: I have heard about financial challenges, (name mentioned) has talked about queuing in the hospitals, any other challenge that the epileptic patients face while they seek care and treatment?**

R5: There are times when there is discrimination in the families with the epileptic patients. The husband discriminates the wife, and says this is your child, he doesn't want to hear about a child who faints. He says it's the mother who caused it and not him. Most of the families discriminate... unless the men are educated, you will find that it's the women who are left with the children. To try and find ways of how the child will get better.

**I: So they are educated on where to seek for services or about the illness itself?**

R5: About the illness, because most of them will think that if a woman gives birth to a child who is epileptic, she is the one who knows where it came from. The husband doesn't see his role in that. The child now is the mother's responsibility, he can even just go and leave you with your child.

**I: Are the community members aware of where to go and seek for those services and treatment?**

R2: It's difficult because the drugs are different, just like the way the epilepsy disease itself is of different types, there is that one that you foam in the mouth, others will bite their tongue, sometimes...(Inaudible). So even those doctors when you go to the hospital, the doctor is different...those drugs are(Inaudible)

**I: So the challenge is not knowing which type of drugs or the place where to seek services?**

R2: Yes.

**I: So you are aware of the hospitals, where to get services?**

R2: Like if you go to Health Facility L, they will give you drugs, but the next time you are told to go and buy, they mostly send you to chemists, and even those chemists, like here in Kariobangi, don't have the drugs we use. They give you (In audible). There is no indication on the drugs, that this is stronger than the other.

**I: I see R9 wants to say something?**

R9: Another challenge is, you find the patients got the fits at night, but there is no security, and maybe the drugs are to be bought very far, and there is no security. If it's a woman who is alone, there is no way she can go out alone to get the drugs if all the chemists are closed and maybe the only place that is opened is Huruma or Mathare, and she is alone, so security is also a challenge, and the patient continues to suffer, before morning he will have suffered a lot, because maybe the drug would have helped a bit but he didn't get.

**I: We are almost finishing, how can people living with epilepsy be supported towards care and living a quality life?**

R6: Their biggest problem is that they should get their clinic and a specialist who is for epileptic patients only. That will help, and they will come out in large numbers.

**I: Another way they can be supported? Let me start with R4, then I will come back to you R8**

R4: Another way since even getting employment is a problem, and their drugs have to be bought, for them and those living with them, the Government should put aside some funds to at least help them.

**I: Another way, R8 you can tell us?**

R8: I wanted to say the most important thing to be able to help the people living with epilepsy, is first to give information, like first aid, because you will find just like my colleague said you get the fits even in a place you don't know, and you find also that when you faint everyone runs away. This means a lot of people don't know about first aid for epileptic patients. When a person with epilepsy falls near you, what should you do? I think there is that empowerment either to the CHVs or the parents who have epileptic children, so that when the children fall in the house and it's at night you can know what to do. Like the other day, I was walking near the roundabout, and a young school going boy child had fainted on the road. So everyone ran away, and one man was the one who picked the child, and put him on the road. He didn't remove the uniform, shoes, and everything else. So you find a sick person like that one continues to suffer, and the only person near them does not have first aid skills. If people can be empowered with first aid skills to help epileptic patients, it can make work easier, before they are rushed to hospital.

**I: Any other person with an opinion on how to support the epileptic patients?**

R5: They can help with how they can get drugs and be educated on how to use the drugs properly, so that the drugs are of help to them.

**I: R1, you tell us something on how they can be supported?**

R3: Also as much as they are to help them with drugs, they can also be given food so that they take the drugs. Because even before they take the drugs, they need to eat something so that the drug can work effectively.

R9: Just like what my colleague has said, about the epileptic patients be given...(inaudible)the way the Government and its partners have supported HIV/AIDS programs through TV, so even this epilepsy is a dangerous disease they should also come in and look on how to empower those parents, or if the patients are grown up

people who can fend for themselves. Instead of relying on their parents, they can be helped with how to self-employ themselves, like small businesses. To help themselves even buy their drugs, without asking anyone for help, get their own food, without depending on any one. Employment is important for them.

R2: I would request you create much awareness about epilepsy in the community, educate them on epilepsy. That's not demonic, we should love them, be mindful of them even if you find them fallen down, don't just leave them there, take care of them through giving first aid. Like the ones we were requesting we be given as CHVs, and also the parents to the epileptic patients.

**I: Is there anyone with suggestions...R4 wants to say something?**

R4: People should be educated that the illness is mostly not an illness, it is just that a person loses consciousness and loses control over themselves, because people take it as an illness, and with that it brings stigma.

R8: My colleague has just mentioned that it's not a disease but you can't say that it's not an illness...it's an illness because it even has medication. If you say it's not an illness and yet it has drugs people take to treat it...isn't that true? And if you say it's not an illness, there you are confusing us a bit.

R4: But people should know it cannot be contracted from one person to the next, like HIV/AIDS. Even if you sit with a person who is epileptic, you are free, or even if you are neighbors, you are free from the illness, since that being unfree is what makes even when one knows how to help you, they refuse to participate.

R8: Then there is that tradition I used to hear that you slaughter a dog for an epileptic patient, and once they eat the dog meat, you tell them later that they ate dog meat, and if they get shocked the disease goes away. I don't know if you have heard that?

**I: Who used to say that first?**

R8: Men in the olden days. They give you meat unawares.

R4: They prepare soup with the dog meat, when you have eaten is when they tell you that you have eaten a dog...; But there is no one we have met that said they ate dog meat and got cured of the illness.

R8: Those are just stories from olden times, but we have not seen.

**I: Thank you all for the discussion...I don't know if there is anyone with a question, comment suggestion, any additional thing that we did not touch on?**

R9: I wanted to say, I appreciate Aphrc a lot for this discussion, to look at how to help the epileptic patients, in our community, who are suffering with the illness. By the way, it is a big challenge, and what we have discussed is the truth, and so like partners they should come and work together on how to help our fellow community members. We appreciate, it was a good discussion, we have gotten some knowledge. Some things we had never had, like the dog meat I had never heard, but all in all we trust God will do something and those doing research should not end it here, but continue to help.

**I: I also want to thank you all for your time and your contribution...but before we finish, I don't know if my colleague has any question or clarification she would like from us?**

**I2: I will also just like to thank you for the discussion, and just like R8 has said, it was a discussion where we have learnt more, and as he said the discussion we hope it will not end here, though this is just like creating awareness.**

**I: I don't know if (name mentioned) has a question, I know you were part of this?... okay.**

R4: I have a question, is there a special drug for this illness that you can use and get cured?

R1: My brother had this illness for long, but when we took him to Health Facility B, he got a senior doctor there who said his had been caused by TB, and when he used the TB medication he got well, as he used to bite his tongue, soil himself, urinate on himself...(inaudible)such that you couldn't go near him.

R4: So this was in TB form...?

R1: For him it came in the design of TB...

R4: So they treated TB, and not epilepsy?

R1: No, when they treated him the illness went away.

R2: You know the illness comes in many ways, like me I told you I got when I gave birth...

R1: You might find others because of bullet wounds...

R2: ...It's now 7 years since and I still faint and fall, and there are times I can faint 3 or 4 times.

R4: So we can say it doesn't have any specific medicine or what?

R8: Maybe I can answer a bit, it's a disease like any other disease and every disease has its causes. The biggest mistake that most parents do it's because they don't understand is you find a child is born or when they are grown up and they have epilepsy, their parents do not take them to hospital on time to seek treatment, at that early stage. They hide them in the house and the illness gets worse. So by the time they are being taken to the doctor it's an advanced stage, and they are forced to start medication to manage the illness, but it's an illness if taken to hospital early, and the doctor checks where the problem started, it can be treated.

R4: Do you know why I am asking this, it's because my children, since they are 2 of them, it started when they were 9 years old, and I started taking them to the doctor on the spot, it was not that I delayed, and still they haven't gotten any improvement up to now. That's why I am asking if there is medication to cure the illness because I have struggled a lot. I have tried this and that, even I have been told to do scanning, and that what's I haven't done to these children, because it attacks them when they are already grown up, and later get married and from there they give birth and from there...

R2: But on scanning, like for me when I went for it, they found the injury because of the falls, and when I used drugs, I stopped urinating on myself, because I would fall and urinate on myself or bite my tongue, but when I used the medication, it controlled urinating or biting the tongue.

**I: As we finish, what I can tell you R4 on your question is that the staffs of Aphrc who are here we are not trained on that... to be able to tell whether there is medication to cure or not, but the question has been recorded and also noted down, and these are things they will later publish and share even in the community, so your question has been heard and we shall forward it. Thank you all for your time and we don't take it for granted for all that you have contributed.**

[End of audio]

