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I: How are you?

All: Fine.

I: As we had said it's a discussion on epilepsy disease in our community, as we talk let us be free, no judging, no right or wrong answer everybody is right. It is just a conversation, right? Let us remember we are talking about our community people who are affected by this disease for instance these children whom you might be staying with and what you do in the community in terms of taking care of them. You are welcome, and to begin with, how do we refer to the epilepsy disease or what names do we use to refer to it?

P6: The names we use to refer to the disease? In our community we refer to it as the epilepsy disease.

I: Any other person?

P7: The falling sickness.

I: Ok P7 has said the falling sickness, any other person?

P2: We do call it epilepsy.

P5: It is the condition of falling.

P1: Epilepsy.

I: Ok P1 has told us it is epilepsy. Before we go on, do we have any person we are leaving out and they know other names used here. Those are the only names you know? Okay, so what signs show that someone is epileptic? What sign do you look at to know someone is epileptic?

P2: Falling down and trembling.

P4: There is another symptom you can identify them with because you will find they will never lack a mark; a head mark, on the mouth. Mostly you will find them with many body marks. At times they fall on a hard ground or something which injures their faces or hands.

I: P4 has added, he says at times you find this person with marks.

P5: Some don't fall but when seated somewhere you can feel them vibrating, shaking their body and won't fall.

P1: Some have injuries, some look mad due to head damage when they are falling, and some have saliva flowing through their mouth.

P6: You will find another one where they are seated, they are on their own. They are not social, they are seated alone and like P1 had said you will find that they do lack self-awareness.

I: Ok moving on with these issues, still taking on epilepsy symptoms how do you identify someone with epilepsy?

P8: They are unconscious. You find that when they fall they would have already lost memory, and when they wake up, it takes time to regain consciousness, it will take time before it comes back. The more they fall the more their health keeps on deteriorating. It doesn't remain the same. In such a way, you find they keep on losing their memory and also bite their tongues until they bleed.

I: Any other?

P2: At times they urinate on themselves.

P7: Some before they fall they become very harsh, they shake for a while before falling. When they wake up they are still harsh but after some time they will become normal.

I: Any other person, any sign we are leaving behind?

P4: Some have tears and after the whole process of falling you will find them crying for no reason.

I: This is after falling?

R4: Yes, after falling they will be in tears, they feel guilty but they can't tell what has happened.

I: Any other, on signs. Ok thank you, you have explained different signs on what you can see on the epileptic people. Now in your opinion, what do you think is the cause of epilepsy?

P1: Some are family inherited. In some families you will find that it starts from the elder person and it is inherited from one person to another.

I: So P1 says sometimes it is inherited from one child to another.

P3: On my side I would say it is not a family thing, it is just a disease because when this person is treated, their conditions become better and changes later and through medication they become fine but after sometime they will start falling again. Even if you use the traditional remedies, they never help. I feel it is a disease.

I: Well and this is why we are asking, what do you think is the cause of this disease?

P3: They develop the condition at birth, when they are young or the condition is present at birth.

P4: In my opinion, I feel scientifically, such people have issues with blood circulation, heart beats and the functioning of the body. This shows there is something missing in the body, might be oxygen or they can be short of oxygen for some time making them skip something in a short span which leads to them being unconscious and as a result they fall down. In my opinion I feel that in their body functioning, there is a way the normal person's body function is supposed to; they lack something for a specific period which makes them fall.

P8: On investigation, we find that sometimes the veins have issues. So it is either the oxygen or blood as he has put it that does not reach the brain and that's why they fall. This is why you will hear they have chest problems when congested and they can't breathe, it leads to that problem.

I: Any other person on the causes?

P7: Prolonged labor at birth, they stayed for so long before delivering.

P8: Somebody else has said antibiotics, such as Amoxicillin. Some children are born with chest complications. So they can take these drugs for a long time which also has an effect. So it is a side effect of those drugs.

P2: Some say, before birth the child inhaled the mother's dirt.

P3: Yes, the water.

I: Water, how?

P3: The amniotic fluid.

P6: From what we hear, sometimes the mother did not adhere to all the injections they were supposed to get while pregnant. At times you get it is how others are affected which we are not very sure but we are told if they don't follow the directives, things can affect the baby while in the stomach.

I: Any other person with what might be the cause. Well, so what are the effects of epilepsy to the victim? How are they affected in life?

P1: The first risk, I had a friend with epilepsy who fell in a trench, near the police station. So people thought he was a drunkard or something because it was around 7pm. The guy stayed in that pool of water and he died. At least they need someone to help them avoid things like fire and water. They are not supposed to be close to fire.

P7: Adding on P1, they shouldn't stay alone. They should be monitored wherever they go. Because they can be attacked where there is no one, but when they have someone who can attend to them, they can help them.

I: Well P7 has added on P1's that they should be monitored every time. Do we have any other person?

R6: These children face a lot of dangers which are not good. For instance, I have one lady in the community and she has her own home. Last week she got burned because the moment she falls down she becomes unconscious. She fell while cooking and there was no one else in the house. Before people knew what had happened she had too much burns, she is in a critical condition right now. So they need lots of care, they should have someone close. For instance, if it is me and they know I have this problem maybe my husband knows I have the condition at least in his absence he alerts the neighbor to keep on peeping my house because my wife has this condition. Additionally, it is risky for them to walk alone; they can go and fall somewhere. Right now you see how it is hot, they can fall on the road, before identifying them and attending to them bearing in mind this is Nairobi, many will ignore. They need too much care and monitoring.

I: Thank you P6.

P8: I can say the epilepsy problem has been neglected; the epilepsy people need their situation handled in the hospitals as other diseases. Because, if you go to the hospital getting epilepsy medication is a challenge, that is number one. Number two, they must be bought daily because they are used. Number three, following up on the doctor becomes an issue; you might find the doctor after treating one for long will advise you to try elsewhere. I think we need to have a laid down protocol because it is only EEG that they do, and when they finish that they don't have anything to do with that.

I: What is EEG?

P8: EEG, the one they put on the brain, they weigh and it reads, this is the main thing they do [inaudible] but after it there is no other thing. If the drugs are not helping you, it becomes hard. They only have about two medicines that are common: phenobarbital for children and Tegretol for adults. So it should be dipped inside to understand this disease at least to see how it can be helped.

I: Now looking at their lives as you are saying, you feel they can't access the medication well. Still on their condition, what do you think they can't do because of epilepsy?

P8: Okay, they can do things but on the considerate someone should be around. You need to monitor them so that you can know when they are about to fall. At times it is like an accident and you can't restrict them from being like normal people. So sometimes once in a while you can tell them to prepare tea, do this but they cannot live a normal life unless the one who has got some medicine which can serve them, because it is similar to high blood pressure and diabetes. So it is a daily basis medicine.

I: What do you mean by normal life?

P8: Where they can go by themselves by leaving them freely. They need constant monitoring but as they move on some can go to work, hospital and back. They can do everything, but they are stopped by the falling. I have a girl she can cook, she can do everything but the problem is her falling while cooking and that's why my sister P6 is saying it will be a problem. So they can do but the moment they fall, things change. I remember there was a business lady with an epileptic child, so in the evening she used to leave the child behind for business. The houses are tiny, a table here and a stool there, the child fell and the way they throw themselves, the child put her head in the stool in the process of throwing up herself the stool was also…on coming back she found her daughter dead. This is why they can't stay alone most of the time but if it is somewhere free they are okay, they can get marks but at least there is nothing that can strangle them.

I: P8 whatever you are trying to say is, they must be monitored constantly. Is there any other?

P2: At the same time, I would prefer if they had an I.D or a label which they should walk around with.

I: So this will--

R5: This will make them feel they are discriminated and these people need to be embraced. They feel they have friends. After that incident they are angered and their mind shows them different issues so there is a need to bring them closer. They shouldn't realize what the problem is and if they will come to realize later they need to stay normal.

I: But maybe P2 can explain to us what he meant?

R2: So as it should be known you are sick.

I: We want to understand why you feel they should have those labels but let us also remember we are looking at what they can't do in their epilepsy condition.

R8: Before I forget, just as P1 has said sometime they look like they are mad. You know some people take advantage of them especially when they are ladies. So they can get them impregnated or infected so this is why we are saying they can't live a normal life. Sometimes the stigma we are talking about can make them fall for someone showing them some little affection, because they need the love. They need to stay like the other people, they need to get married, so in this situation, you find them pregnant and no one will marry them. This is the burden to the family.

I: Any other person?

P4: There is something very important which should be remembered. These people need a lot of care and love, they should be shown affection. I would like to say they don't know each other; we have them in the community but they don't know each other. If we could get people with humanity to come sensitize on such matters in the community for enlightenment that there are people we are living with and have a specific condition. People do run away from the victims. It should be something such as support and constant sensitization. The community will be aware we have people with epilepsy because there are some people who believe it is infectious but this is not the case, it is a normal disease. People fear them; to help them we need support groups every time. The community together with the victims to be sensitized, we interact with each other which will actually help in the community awareness.

I: Looking at the support groups, these people with epilepsy stay with other people right, so how do people in the community treat them?

P1: When we were growing up we used to be threatened by our parents, if someone who is epileptic urinates somewhere and you jump the place you will be affected. We used to live in fear, fearing them. At school, if they fall down in class we used to run away. In the class I was rude for instance, I would go home because if I jumped over the urine I would also be epileptic. But now that I am a grownup, I know if this guy falls down, I used to see some lady in the community come with a spoon and place it on the tongue so as not to bite themselves. I realized you can attend to them without being affected, but we had been threatened as children so much. Anytime they used to fall we could run to our parents. [All laughing]

P7: As P1 has said it is evident there is stigma to the epileptic. He has said they were told not to jump over the urine. In our case we were told, if the person falls down and farts, you in turn inhale the air, you are infected already. This is already stigma, because when you see them fall you will have to run. You are told if they fall they will fart and since you don't want to inhale the gas you had to run. What we had forgotten is, it was stigma. Let us say P3 has epilepsy and I am close to him and I run away, he remembers if he skips the urine he will be sick, everybody in turn runs away. This is the stigma in the village.

If these people are put together for them to know each other, I give my views and they give theirs, there will be support in the community; people won't be running away from them even at a family level. They totally need support, because if we avoid them and let us say they come and enter here, they will damage themselves with the chair or if there was food boiling on the stove they will get burned. So they need love and support. If we happen to get an NGO or any organization that can empower even the parents, they also need empowerment and teachings on how to live with the epileptic and be shown these are normal people like the rest of the people who need love and affection and to be involved in everything we are doing. If we have such a meeting, we put one of them here to feel the love from our discussion. You will find out this disease is in the mind you never know or blood and if you bring them closer it can help reduce this disease. They need support and involvement in whatever is happening around

I: P6 has said she feels people run away because of ignorance. Any other person on how people are treating these people?

P8: If someone falls down no one will attend to them. If they fall far away from their home, they will sleep there until they wake up by themselves. It becomes a bit tricky because people discriminate them. I wanted to say, it is similar to other disabilities though this is to do with the brain. People do not understand. According to most people if they get medication and use for a long time it ends and this is why I was saying, even though the doctors say it never ends, if they get good drugs it ends. Now we have so many generic drugs so if you get someone to help they might be using generic drugs. So the situation keeps on healing.

I believe if it was taken seriously many people could be saved. Imagine this illness advance so quickly. On the other side I am a teacher. Recently while in class, while the children were sleeping all of a sudden one child started throwing herself, she convulsed for a long time. So we called the parent, who said it began at a tender age and when they went to hospital L he was treated but at the end of the day going back she was told it was not the condition and they should go get traditional medicines. The child is now 6 years old and there is no treatment she is getting. We advised the parent that the child can’t stay this way and you can see the child's performance is deteriorating--

I: Where were they advising her to get the traditional medicines?

P8: I am not aware.

P4: From a witch doctor.

P8: We ended up talking to them to go to hospital M, we had told her to come back but we didn't see her. The next day the child didn't come back and we were told he was sick again. There are so many things affecting children especially in the slums, the parents give up because of the poverty levels and they give up following up on their children. You can imagine at 6 years the child has started convulsing, how will he be when at age 10 and we also say it also affects the brain.

I: You are saying that parents also neglect them?

P8: Yes, they also give up.

R1: I would like to make a request, if we could have a donor who can come up with the same as you have come out to do the research. They should give people classes on how to stay with these people because whatever was in my brain before was changed after I saw someone attending to one. A lady attending to a certain boy at a motorbike stage. We as motorbike riders we were worried if such a person falls here how we will help them.

I: You feel people are running away because of lack of information?

R1: We don't know what to do, if we were informed on the actions like when we are at the football and someone gets an injury we normally know first aid for this and if we are unable we can rush them to the hospital. If we had information about this epileptic one, we could have known how to help them regain their consciousness easily. We need such classes in the village.

I: P1 has told us most of the time people run away because they are not aware, also as we have been told it is because you are scared because of what has been there, if you do this you will be infected which leads to such treatment. Any other reason?

P3: Again its information from different people, everyone comes up with their own suggestion on what you can do, you end up doing all these things and they don't help the victim because you are in a mixed mind reaction.

I: You get confused?

P3: Yes, you need to stick to one thing: if it is going to hospital it should be it, so that they can help the victim.

I: You have mentioned and P8 had mentioned sometimes the parents at some point starts giving up on these children, they get mixed up. What do you think the situation of the family members affects the life of the victim? For those who stay with the patients, how does the disease affect them? In your interaction in the community, how is the family affected by the child's condition?

P6: I will say it affects them so much because I'm the breadwinner and I have a sick child, it affects me because if I go for some casual work, I'm not at peace while at work because the disease has no specific timing and with no hours. This affects the caregiver of the child who is epileptic because I must be there. Another thing which is affecting me is that the child uses medicines which without money I can't get the medication for them. This is the burden to these caregivers due to lack of medicines for the child or the victim.

I: You have said at times it is the lack of drugs and it is hard leaving them alone to go work.

P7: Lack of cash affects this child due to lack of medicines and other things. Additionally, if the child is pregnant they can't give birth at our local hospitals they will be referred, I have never understood why.

I: We don't have a hospital that can attend to them?

P7: I am not aware about the rest but there is one--

P6: The council.

P1: They come to the City Council Hospital. They also come to our place, and there is a doctor who attends to them. I don't know how they treat them but there are some special doctors for the epileptic.

P7: During the pregnancy if they look at the history and they find out they are epileptic they are told to go give birth elsewhere and by then the family is not ready for referral so it affects them.

I: Which Hospital? Is it private or public?

P7: It is Private.

P6: Adding on her point, for example I have had the situation, right now I am pregnant and I have been attending the clinic, there is a way when you go to the facility or any other facility they will look at my life history so they will know I have such and such complications. If they realize you have an impending complication they feel it is better, you be referred for the sake of emergency because here at our hospitals we have no things for emergency. If they look at the life history, they are then referred because of an emergency.

I: In other words, you are saying they are referred due to emergency possibilities?

P6: Yes.

I: Okay.

P8: The City Council hospital, sometimes someone goes there when they are ready to deliver. They will have to do the delivery but they have medicines. They are difficult at times but they have medicines which if they know you are epileptic there are the medication that they give you for that time. It's a challenge to be given medicines when from the hospital. Do you know it is hard for this people to be employed, no one will employ them knowing their history they are just there, they can't go to work or do anything and maybe they have finished school but then due to their situation nobody can hire them and that is part of the reason we are saying their life is not normal.

I: Now looking on the family they stay with, how are they affected?

P8: I had said before, the family must buy medicines and most of the time there must be someone so you rotate. Sometimes you have to leave them alone because you must fend for them and it becomes a burden. As I have told you, sometimes if they get someone who will take advantage of her you will have to handle HIV and the condition and as well as taking care of the children. Remember when they give birth at the start, the child starts with ARVS. So remember you are not depending on this one to give the baby the medicines, it is you as the caregiver to know the timing for the medication. For her when she loses herself that is it. It will be upon you to know how to take care of the baby until when they will finish the medication so as they get out negative at least for them to grow. It is not easy; it is a burden. Even if you hear parents get tired at times, it has its price.

I: Any other person?

P3: I have something; many families are overwhelmed. For those I know in the community depend on donations because this child has finished all their resources, going to hospital. For instance, going to hospital N and it being a private hospital, imagine a guardian who is jobless, only a casual laborer going to the hospital N, admission fee alone is around 500/=. The expenses incurred; the transport to the hospital and so on. It is overwhelming and they don't have anything. Some depend on the dumpsite, so you find that these families mostly are vulnerable and the child has exhausted all their resources. There is also stigmatization in the community; they identify you by the sickness. You will hear some say to the one with epilepsy, as a parent you feel stigmatized. In the community they refer to you as, "the mother to the epileptic child". Those names leave you restless in the community; this is why I said in the beginning, it is good to sensitize others to understand these are human beings as the rest.

I: You as the community members do you see hope for these children in their future lives?

P2: Talking about their future life depends on their caregivers. If they decide to abandon them, the patient will suffer but if the caregiver is willing to help the child… from the commencement of the disease until the end you need to keep an eye on them. It will therefore depend on you how you will sacrifice to help. There is no way you will part ways even in their adulthood unless the parents are not there, but if they are alive they will monitor them to the end.

I: You mean they need close monitoring?

P2: Yes, they should be attended to and monitored. Most of them suffer due to stigmatization. No one attends to them, looking at them as a burden, they shouldn't be stigmatized. They should be embraced for easy monitoring.

I: Yes, another person. Any hopes for these children?

P8: I think if it was in my shoes, right now they are taking tablets but if we had aid, at least there is need for an injection which they can be injected and other reliable things which can help them as I had said it is costly. Imagine one tablet is 10 shillings and it has to be there every day. Also, I am not sure if it is the effect of the medicines but they eat a lot and if they don't get enough food they will fall. So if they stay long without falling it means they have adhered to the medicines and they have had enough food at the right time. You can't say today I don't have food so they won't eat lunch, it means in the evening you should expect their fall. As much as we are trying to say the caregivers, they really need help and this is why we said it's good they should have their own clinic in an area, also in the public hospitals so that they can monitor. You realize if you are to monitor you can't do so much, but if we get a doctor to monitor them, they can know when to go to a specific hospital until they reduce. Their doctors seem few, it is a mental problem let us accept it. If we accept it as a country that this is a condition and it needs to be taken into consideration, I am sure we can defeat it.

I: In our discussion I have heard you mention about medicines, so, I would like to know in this community those who are epileptic, where do they get the treatment or Medicines?

P8: There is hospital K on Tuesdays, Hospital HL on Thursday and Friday.

I: Where is Hospital HL found?

P8: Here in Huruma on Thursday and Friday only so the rest of the days you go to hospital M.

P2: Also hospital N at any time, it is a private hospital.

I: Any other place?

P4: But we normally say in case of any emergency, we rush to the nearest hospital because if you depend on the other hospitals for Fridays and Thursdays... It is better for those at the hospital to refer them. But we take them to the nearest hospital.

I: Which one?

P8: If at Korogocho we take them to Hospital O, if they fall near any hospital we first take them there for first Aid.

I: What challenges do people meet while accessing services for the epileptic? Yes, they have gone to the hospitals but what challenges do they face?

P8: If you go to hospital HL you will finish the whole day there, you cannot go and come do something else, it is a day spent because you see it is on Thursdays and Fridays and it caters for people from all places. The challenge is their treatment is minimal and that's why we are saying they need to expand to more hospitals. We have also said it will be good for every dispensary for the City Council to have the clinics. If they change it we shall know on Tuesday there is hospital K, Wednesday's hospital O, Thursday hospital X, so, if someone falls they know they can get the medication on spot with or without money. If they can make the HIV one free, then what we are fighting for now is the epilepsy treatment to be free as well. You shouldn't be looking for 50 shillings or a hundred, for a medicine in a chemist, let it be free because it is growing rapidly. And if it continues this way in 5 years to come we shall have to accept we have a problem, because it is rampant but there is a lot hidden in the houses.

I: Okay, any other challenges?

P6: It is the money because I have this patient, I have to attend the clinics at hospital HL and I need to go on Thursday or Friday, I cannot go with this patient to the hospital by foot, I need fare. As P8 has said, this is a sick person I'm with, who needs to eat and mark you, we shall spend almost the whole day there. Without money, to feed this child will be a challenge. So if we get a hospital close to us it will be very good.

I: P8 had mentioned there are those who are hidden; do they know where to get these services?

P8: You see if they are hidden they can't get any help.

I: Do they know where to get the services?

P8: Some don't even know because they haven't made follow ups. As they offer the cash transfer some should be taken to epileptic people to help the parents.

P3: Those who are hidden, we tried to follow up and they said this is not a disease to be handled at the hospital but traditional, so they treat these victims... because we wanted to know how they treat these people. They use traditional medicines though I talked to her and she said she will go to the hospital.

I: If she says it is not a hospital condition--

P3: If she takes the child to the hospital the child will die.

I: They see no need to go to hospital?

P3: Yes, they even know where the disease is from, at their home.

I: How do they get the traditional medicines?

P3: They believe it in their minds; they come with it from upcountry.

P6: Those are Myths we have in the community which are present but lucky enough we can be proud to say we have helped some move from the traditional herbs. You explain to them, as we said they need the knowledge and empowerment for them to know it's just a disease as the other disease you see. If I am from home and I meet a colleague, they will convince me and if I don't have the knowledge they will convince me to go to the traditional medicine men and I will get the medicine. But we have been talking to them slowly and slowly. This is a disease like the other diseases, if you will use these medicines let us first go to the doctor to advise us on how to help this child and many have accepted.

I: Any other contributions?

P8: Sessions can be put even in the radio and the T.V for those who have come into terms with the disease to share. This will reach a lot of people for them to know the disease is manageable in the hospital. They can also be told where to get the treatment, this can also help.

I: Still on this, looking in our community what can be done to sensitize the community? I have heard you say some people don't know the cause or what it entails and that is why they don't know what to do. To prevent all this, what can be done to sensitize them about epilepsy?

P1: As I had said before, if there can be some seminars, they can help some people who will in turn help other people. In Korogocho we have Koch FM; if we have a doctor talking about the issue maybe from 3pm-4pm that 1 hour is enough to reach several people. If it is like Radio Jambo and Citizen it is mostly listened to by Kenyans, because even if you are travelling to upcountry you will just hear Citizen. If we hear over Citizen even if it's from 1pm-2pm that 1 hour it is enough to teach almost three quarters of Kenyans or the entire Kenyans.

I: Who will be teaching them, you have said the victims?

P1: There are those who have experienced it. We have a parent who knows how they have been handling their child or husband, or wife. If we get such a person and a doctor who handles such issues, when we are in the radio station you and I, I can ask you a question and you answer right, the person listening to the radio can know how to deal with such a problem in case they encounter it. So the problem will be solved step by step and there will be minimal cases in the community.

I: P1 has told us to sensitize, we can use Radio stations like Koch FM or the most known as Radio Jambo.

P7: We can have support groups, train the Community Health Volunteers [CHVs] who will in turn train the community. We should have clinics in our hospital, with doctors around and medicines. So when people have been taught if we go to the village and meet a client we can refer them where to get the services free of charge. The biggest problem in the community is money.

I: So we should have the doctor, seminars, and medicines for free.

R4: On what P7 has said its very important to have outreaches; here we reach out to the community members. We can announce through our CHV in the community or radio stations, we can say on a specific day if you come to St. John all who are affected shall have treatment with specialists with medicines to help you even for a single day. With those outreaches in every place, at Koch today, tomorrow Kariobangi, it will help those who are hidden to be brought out, because they will realize there is a way we can get the medication and this will be easy because we shall find the way forward through them.

I: As we wind up, although you have already touched there. How can we help these people who are epileptic to get services for a better life? You have indeed mentioned they can be sensitized and given medicine, how can they be helped for a better life?

P4: Just like we had said in the beginning. We have these cash transfers if we happen to get an organization which can boost them with the cash transfer it will be very essential. Because you will find out the family is very vulnerable, the child has exhausted all the resources, they don't go to work, she doesn't have time for the sukuma they sell out there, people are scared of buying due to stigmatization in the community so you get this person is very vulnerable. Secondly, we can get empowerment on how they can do some micro financing, show them you can do this work, look after the child and give them some boost in the business, it will help them in one way. On the other side, the community after sensitization they will know that this is one of us, we shouldn't isolate them. So we get them involved in some community matters. This will be easy for them to be helped but if we say by mouth without help it will be a challenge.

P1: The other way to help them is to be friendly, be close to them and show them love. Even if we go to the field to play football, we have them on the field because we already know how to handle them if they fall. Sometime back we had a mad person and we used to play with him, we even kick the ball outside he goes on celebrating [all laughing] and he was a great footballer. At times we include him in the team when we have leagues. While on the bench during the last minute the coach allows him to play, he feels part of them. Let us accept them.

P6: We also have organizations which have been so supportive known as Light and hope; I heard they go with stages for classes for specials. At some age they say this one must go to Mathare though I am not sure where specifically at age fifteen or sixteen because they can't be grouped with these in lower classes since they are grownups, it's only that they can't go to secondary. At school they are not taught, they are there for love and people close to us. Light and hope after Mathare have closed; they group them together in groups of 10. Instead of being in the community they host them, they are there to sit, you will find them playing football, they are there unlike being in the community because of stigma or absence of the parents, so they are being hosted there. As now they are in their midterm they come normally like school going children. They cook for them, they might have not taken breakfast, they prepare porridge for them, in the evening they are given bread they can carry home, they love me so much they will tell me today we have been given bread at least they're happy when they go home. At least they go home happy they have received the support. Many people should host these children. They are now mature, some are 20, 21 and 19 years old but as we have said about their future they should host us, boost the light and hope such as feeding them and other needs they should chip in and support Light and hope because they have sacrificed themselves for these people.

I: Where are they found?

P6: They are here at Grogon A.

P4: Another very important thing, these people need therapy. You see they spend too much time sitting so they get exhausted, they become fat and the more they fatten the more some disease invade, but if they are given therapy the exercise it will be very important to them. So if we get a specific center for them where they can go for exercises for their body and they know the places where they are known if they fall they will respond.

I: Any other person?

P4: I was saying on matters of medicines, if we could get organizations which can help with the medicines because they are very expensive to the caregivers of the patients. You will find that they are casual laborers and they need this medicine daily, so if we can have an organization which can cater for half of the cost, it will really help the parents.

P8: I was thinking, for the future business, the support groups my colleague has said, there can also be a support group where they can go to a place and take some things, they can stay there for the whole day for the adults, they can make bead works. They are busy so when they come in the evening they are tired and they have done something, they will feel part of the country. If they get people who can buy these items, these people can get at least something to keep them instead of staying in the house until evening where they will indulge in sexuality leading to pregnancies which doesn't help. So if they can get a supportive place such as an NGO, they can get support here and they can be taught to make items which can be sold. The community does not have all individuals who are poor, if they bake birthday cakes, you will find that instead of going to Naivas they will support them with time. Things such as beadwork, parcels if they buy from them they can get something and continue with life.

I: At this point I'm so grateful for the discussions, I would like to welcome my colleague if she needs some clarification or something she didn't get well to explain and after her anybody with a question will ask or any other additional information they would like to contribute.

I2: Thank you I will start with P1 because you mentioned something like "Kochari" because we might understand it but for somebody who is listening what does that mean?

P1: Okay I mean football coach. Team coach.

I2: P6 you have talked about an organization known as Light and hope, if I got you clearly you only talked about the way they have been hosting these children and helping them, but normally what does light and hope as an organization do?

P6: Normally it deals with the disabled, people living with disability, not only epilepsy but everyone; you understand that epilepsy is part of disability. So they deal with people living with disabilities, especially the children.

I2: You said they help the epileptic kids mostly?

P6: Yes, these are those who are beyond some certain age, out of school. This is why I said, they go to Mathare but I'm not sure where exactly in Mathare.

P8: Huruma.

P6: It is Huruma, just like we have the young ones in school, we have a special at Baba Dogo which deals with epileptic children at primary level. When they attain age sixteen they are sent to Huruma. They deal with adults, those beyond that age. I have heard several times that they nature their talents, if you like singing, cooking because they can't be taught. One who likes sewing and so on. They follow up on the talent. For instance, right now they are in midterm, when they close they are hosted at light and hope instead of staying in the community and maybe the parents are not around. For the sake of their security, Light and Hope will call them, even if they close schools they know on Monday I will be going to Light and Hope, they go from morning to evening.

I2: Thank you for clarification, to you R7 you talked about teaching support groups to create awareness and you also mentioned that CHVs should be trained and on the same, I will combine with what R4 said about outreaches to spread the information on epilepsy as

well as R1 who said people should be trained to train others in the community so on all those who should do the seminars, the outreaches and the trainings?

P7: The stakeholders, for instance you, APHRC. If they can have an epilepsy project they come to the communities' train the CHVs then call the caregivers and the children to be in support groups.

I2: How about trainings, who should do them, apart from such organizations that you mentioned?

P4: If we get an organization such as APHRC the way we are here and we have youth groups in the community, for a group in Grogon, High ridge let me talk about my village like Korogocho we have nine villages, if we take 3 people from each group in a specific community for classes the next time they meet as a group they will share the information with their specific groups.

I2: Apart from organizations do we have other people who can conduct these seminars?

R4: I feel that's a good idea my colleague has come up with, P1. I feel there is a responsibility by the county government, we have such facilities by NMS constructed recently, and we have facilities at Ngomongo. If we happen to get a partner who can collaborate with these centers of the facility, we have people like CHAs who belong to a facility but they have a community unit, which are manned by the CHVs who have households they visit daily on a regular basis. During the sensitization let's say through the CHAs who will in turn reach out to the CHV with a responsibility of reaching out to those in the community. It will be easy when combined with these groups my colleague is saying which makes it a very big team which if we have a major outreach say at St. John Catholic we shall have many people. As CHV we shall have the chance to advertise and reach out to the community which will be a very successful outreach. On the other side we normally have P.A system, during the outreach we shall be moving out into the community to sensitize them, so the more we move into the community teaching them it reaches to the parents of the children. That is step one, step two you will find they will now start reaching out to us, asking if we are having outreaches. It will be so easy to sensitize them.

I2: Thank you, back to R8 when you were talking about challenges faced you used an example of hospital HL saying, someone ends up spending the whole day there, so what would be the issue?

R8: There are so many people there, it is a center hosting almost the entire Nairobi. You also pay, there is consultation fee and you also buy medicines. So you might get you have spent your 200 or 300 shillings spending the whole day there and going back this child still needs to eat. This is why we say it is costly.

I2: To mean there are a lot of people or--

P8: The doctor is either one or two.

I2: The doctors are few. Onto the last one P1 you used the term "chizi" for someone listening, tell us what it means?

P1: That is a mad person.

I2: R6 you also used "kushuta" we might all know but for the listener there might be another meaning?

P6: Release of gases, or farting.

I2: That is all, thank you.

I: Okay we are grateful; do we have anyone with a question or somebody who wants to add something?

P6: This is my request, on the views of the community; epilepsy is a pandemic that is too heavy for us as we have discussed here, it should be investigated with too much concern. As we have tried to bring out those who have been hidden it's our prayer we get support, to prevent them going back to the situation. If we and the parents lack the support you see there will be someone left at an unknown place. We are praying just like APHRC has come up with the discussion about the epileptic they should take with great concern; it shouldn't stop on the way. This is my prayer.

P1: If we can have the classes which can reach the radio for the youths in the community to listen. Same as the scouts, if you go camping you are assigned a task according to your hobby. If you like cooking, collecting firewood, if we can have more classes on how to deal with these people in the community this will be great. As we are here, if we get three people who can deal with this issue we can't encounter so many challenges in the community in case one falls. We have these three people who can handle them, when the rest are running away we are dealing with the victim. They will even stop to and ask "if these people can attend to us why should I run away?"

I: Any other person before I lock them out?

P7: If we can meet with those in-charges of the facilities in Korogocho and Ngomongo so as in case there is an organization or a donor on ground we should talk about epilepsy because it has been regarded as a minor issue but in real sense if you get into the community it has really affected people up to these women. So it should not be that any other activity is about hand wash or Covid, let them deal with these small issues together with the CHVs, they are really working in the community but without the support where will you take the sick?

I: What do you mean by support?

P7: For awareness there is epilepsy in the community, it has not been taken seriously like the corona issue in Kenya.

I: Thank you very much for the time and discussion. I hope you will keep up the good work you are doing in the community and God gives you strength to go on. We shall end there.

[End of audio]