

NAME OF THE ORGANIZATION	AFRICAN POPULATION HEALTH AND RESEARCH CENTER
PROJECT NAME	EPIInA
CONTACT TYPE	IDI
FILE NUMBER	211130_001
DATE OF THE INTERVIEW	30/11/2021
DURATION	00:32:55

I: How are you?

R: I am good.

I: We will begin our conversation about epilepsy, as we start, in your opinion what do you think causes epilepsy?

R: According to me, the first cause of epilepsy is, someone can be born with it and so they will be falling, at times, a child may grow and upon reaching a certain age like 7 years he gets epilepsy attacks once and when he goes to the hospital he's told when he was born air did not enter his head.

I: So, air did not enter his head?

R: Yes. Also, someone can be taken to the hospital due to pneumonia, when he is placed in one place with those children who have epilepsy, he contracts the epilepsy.

I: How does someone with pneumonia contract epilepsy?

R: Someone with pneumonia goes to hospital, if there are too many children with limited beds, this child will sleep with other children who have epilepsy and they get the disease through that.

I: You talked of air not entering the head, can you clarify what air you are talking about?

R: A child is supposed to cry when born, if he doesn't cry it's too easy for them to get epilepsy.

I: Is there any other cause of epilepsy or any other way you are aware of on how people get epilepsy?

R: There is none. I am only aware of those three.

I: Kindly tell me how you knew you have epilepsy?

R: When I was in class seven it's when the sickness began. It came on its own. I didn't know what caused it.

I: When you were in class seven?

R: Yeah, all of a sudden, I became sick, I fell, and the next day I was taken to hospital and given medicine. The medicine given worsened the condition. I was taken to Hospital K on that day, the doctors carried me to Hospital M. At Hospital M is where I was given another medicine and I was told I have the illness. My health improved after being given other medicines and I use the medicine until now.

I: You said you knew of the illness while in class seven when you began falling and you mentioned the three causes of epilepsy; air not entering the head, a baby having pneumonia and contracting epilepsy from the other children. Where did you learn of these causes?

R: There are people who I know who have the condition through the causes and everyone has their different opinions. So that's where I knew it from.

I: Where did you learn that from? You said there are people who have it--

R: Yes, it's how they got it.

I: The person who told you that, got it that way?

R: Yes.

I: What about the other causes?

R: All the three causes were how the people got it, though mine is different from theirs.

I: What's yours?

R: Mine came all of sudden and I wasn't aware, I became sick, I fell and bite myself and I would regain my memory after gaining consciousness. There was a day we were going for Jazz, after Jazz I went to my friend. I hadn't taken my medicine and I knew I was well, I didn't reach my friend's house, I found myself sleeping in the house in bed.

I was told where I was going, I reached some place, I fell and that's when I was brought and laid here. That's when I knew I had fallen on the road.

I: What do you mean by the word Jazz?

R: It's a place where all pupils go to celebrate music education, that's where we had gone on that day.

I: When you talk about the causes of epilepsy, what do you think caused yours because you said you began falling?

R: I never used to fall but there is a certain plot we moved to live there. Where we were staying there was someone with this illness, we used to spend time with that girl. I always think my illness was caused by this because I have never known its cause but I always feel it was through transmission.

I: When you used to spend time with him? Is there anything that can be done to prevent epilepsy?

R: In order to prevent epilepsy because most of the times our parents lack the medicine. You can find in a family you are two people and are supposed to use 4 medicines in a day but you find a parent is not able to buy the medicine. She does casual jobs and the money she gets is not enough to buy those medicines. It forces us to take one drug and the other person one drug to help prevent so that the condition doesn't attack quickly. The reason that can make us prevent this sickness is we be supported to get medicine because that will be of help to us.

I: When we talk about prevention, what can be done so that someone doesn't get epilepsy?

R: What can be done so that someone doesn't get epilepsy is children having separate beds in the hospital so that those who don't have it won't get it.

I: After looking around, what else do you think could be done to prevent people from getting the illness?

R: Another one is, epileptic people in the hospital should have their own place and those who are not epileptic to have their separate place as well which will reduce the transmission of epilepsy.

I: Is there any other cause? like in adults, as you said epilepsy didn't begin while you were young so you were grown. What can be done in the community to prevent people from getting it?

R: By staying away from someone who has epilepsy because I used to spend time with someone who had epilepsy and I never knew I would get it but I later got it from the person. So if someone has it, don't spend too much time with them because it can be transmitted. So if you stay away from them you won't get it.

I: Any other you can think of that someone can do to prevent getting epilepsy

R: There is no other.

I: What is your experience living with epilepsy, what have you gone through or what has life been like?

R: I used to view life as difficult because my mother was not able to give us the medicine as required. One day I had to stop taking the medicine as prescribed by the doctor. I now had to take one yet I am supposed to take three.

I: You took one yet you are supposed to take three?

R: Yes, we are two of us who are epileptic--

I: In your house?

R: Yes, so I had to take one so the other person can also get the medicine. If we can get someone to support us to get this medicine, we would take them as required.

I: So, you are two? you don't go for your medicine individually?

R: We are two, I take three and the other person takes one. So I do not take the three, we take one each for the medicine to be enough.

I: Was he told to take one?

R: Yes, he was told to take one

I: Why do you take three?

R: I was told to take three because at the time the condition was very high.

I: What about now?

R: The condition reduces as time goes by.

I: How many pills are you supposed to take now?

R: I take two, if the two are available I will take them, if they are not available, I will take one and give him one. This condition needs one not to miss taking the medicine. If it's one do take it though it will be against the doctor's prescription of taking as required. We would be really grateful if we found someone to support us with the medication.

I: What activities have been difficult for you to do because of having epilepsy?

R: I was very bright before I got epilepsy. My thinking capacity lowered after getting it. I struggle education wise before I grasp a concept not like before. We can say the condition took my education backwards. When the condition comes my body feels weak.

I: You are left weak?

R: Yes.

I: What about house chores, how is it in relation to doing house chores while being epileptic?

R: I wouldn't be near fire or cook.

I: Do you come near the fire now?

R: Yes, I do but if I haven't taken medicine, I am not supposed to be near fire because you can never know when the illness comes. I wasn't able to do house chores back then; I would sit and relax until when I got well now I began washing utensils but I wouldn't go near a fire.

I: You said you are now better after taking medicine, when was the last time you fell, because you said back then it was bad but now you can do some chores?

R: The last time I fell was in 2020. This year I haven't fallen.

I: Because you take your medicine well?

R: Yes.

I: Apart from not being near fire, what other activity can't you do right now or you have fear of doing that you could do well if you were not epileptic?

R: Another thing I am not able to do is cutting vegetables because when this illness attacks you it comes with force you bite your tongue. So if you are cutting vegetables and knife is sharp you can cut yourself unknowingly.

I: Is there any other thing you are not able to do?

R: There is none.

I: How about games, do you have games in school?

R: Yes.

I: There are also games at home, how is your participation in those games?

R: If the game is about running, I am not supposed to play a lot because if I play too much I will start breathing heavily which brings shock and the illness is a shock disease. So when I play and I feel I am breathing heavily, I will stop. Because symptoms of this sickness began with shock. When you get the shock you suddenly drop something like a plate you were holding.

I: So, you limit the games you play?

R: Yes.

I: What can you say are the most pressing concerns that you have as a child who lives with epilepsy?

R: My fear is lack of medicine because when I lack medicine I usually fall.

I: Your concern is the medicine. Do you have any other concern, when you sit down and think about it you feel pressured due to the illness?

R: I avoid being in thoughts about the illness because thoughts cause headaches. I encourage myself that I know people heal and I accept myself the way I am until the day I will get well because thoughts bring in shock.

I: You said your only fear is medicine and you avoid the other things and you also accept yourself the way you are until the day you will be well?

R: Yes.

I: Where do you seek care and treatment like going to clinics for epilepsy?

R: We go to hospital M for the clinic, then we come and buy the prescribed medicine.

I: Which is this hospital?

R: It's near Muthaiga, the hospital is there. That's where we go. We are checked and told if we are okay and our progress then the medicine is prescribed and we come and buy them.

I: When you say you are checked, what happens then you are told you are well?

R: You go to the doctor who asks how your medicine intake is, how many times you have fallen, if you haven't fallen you are told to keep taking the medicine and he can also reduce the medicine. If you have fallen, he might increase the medicine and you are told to continue taking the medicine you will be okay.

I: You said when you go to the hospital the medicine is prescribed for you but you are not given medicine?

R: Yes, they prescribe.

I: After the prescription, where do you get the medicine?

R: After the prescription, you buy from the chemist because the medicine is not easily accessible. If you go to a chemist and say you want such medicine you won't be given, they ask for a letter showing you use the medicine. So, you have to go get the prescription, buy it then use it.

I: Which chemist do you get the medicine from?

R: The one at Kariobangi.

I: Where is it?

R: At Mwisho Plaza.

I: Do you know the name of the chemist?

R: I don't know.

I: Is there any other place you have gone before, a while back you said there is a time when you were in class seven you fell and were taken to a hospital then you were told—

R: Before I fell, no one ever knew it was that illness so they thought it was normal. The next day it worsened, that's when my mother took action and took me to Hospital at Kariobangi where I was given medicine. I went home and took them and that's when the situation worsened.

The following day I was taken to Hospital K again and they were told I have worsened and that's when I was referred to hospital M and that's where I began the clinic and it's where I found help. Because they changed the medicine I had been given at place K.

I: Which hospital at Kariobangi. Is it Private or Governmental?

R: It's a government hospital.

I: After being taken to Hospital M you have never gone to any other hospital?

R: When I went to Hospital M that's where they knew I was epileptic. They gave me medicine, they changed the ones I was given at hospital K. I began using the ones they prescribed and I kept getting better and I am still using the medicine.

I: Why do you seek care and treatment at hospital M?

R: I go to hospital M because it's where I was told to be going. I can't go to another place because they are the ones who helped me and they told me to be coming to clinics after one or two months.

I: When you say you were told to be going there, who told you so?

R: The doctors, I decided to go there because I saw change.

I: What do you mean by change?

R: Change means, when I was at hospital K, they weren't able to treat me but when they referred me to hospital M, they managed to help me more.

I: So, you feel it's good because you got tested on everything?

R: Yes.

I: What is your opinion about equipment at hospital M, is there a time you can lack certain tests?

R: At hospital M, you get tested for everything and check how your body is.

I: Do they have the equipment for testing?

R: Yes, they do have.

I: What do you wish changed with respect to the care and treatment you get from epilepsy where you seek these services?

R: What I would wish changed is for them to sympathize with epileptic people by giving them medicine that lasts a month, this will be good because most parents struggle to get these medicines.

I: Your wish is, medicine to be provided at least to last a month?

R: Yes.

I: Anything else you wish to be changed at hospital M?

R: Nothing else.

I: What effect does the condition have on your life now? The condition of you having epilepsy?

R: At least I am good now, I am not how I was a while back. When I go to hospital M, I am scheduled to return after three or four months but a while back I would be given 1 month.

I: What do you mean by being given 3 or 4 months?

R: If you are taking your medicine well, you are given space time before you go back to the hospital. When you go back after three months and you are well you are added another time because the illness keeps on reducing in the body.

I: What has this epilepsy condition prevented you from doing?

R: For now, there is nothing it has prevented me from doing, it's not like before when I couldn't do anything. Right now, at least I can do.

I: When you say at least it means there is that little you can't do, what is it?

R: I can't sit near a fire for too long but I can do the others.

I: You had mentioned about not sitting near a fire. What does it do to you?

R: Sometimes, I don't use medicine as required. I take one, when I sit near the fire, I get shocked. So, it depends, if there is medicine and I take as required then I am better off but if I haven't taken medicine as required, I will get the shock so I am not supposed to be near fire for long.

I: I understand you.

How has this condition affected your relationship with your family? Has your illness affected your relationship in any way?

R: It hasn't been affected in any way. We are good.

I: You haven't seen anything that you could say may have affected your relationship due to the illness?

R: No

I: What about your friends?

R: No

I: How they treat you because you fall hasn't been affected in any way?

R: No, most of the time we spend time together. When they know you have the condition, they stay around you so that when you fall, they can help you.

I: So, they understand your condition so when you fall, they help you?

R: Yes.

I: Any other on how you relate with your friends because of this disease?

R: There is none.

I: There is no negative thing you have seen from any of your friends?

R: No.

I: What about the community and neighbors when they know you do fall, is there any action that has made you think they are doing it because of your condition?

R: There is none.

I: Not even one person?

R: None, mostly they do help. Because the day I told you we came from Jazz they did help me.

I: You haven't seen any other?

R: Yes.

I: How do you think epilepsy will affect you in the future?

There is a future so when you say you take medicine and you also said you do fall when you don't take medicine, how do you think epilepsy will affect you. Talk about how you view your future will be?

R: When I started taking medicine, the doctor told me if I use the medicine as required you get cured. So I always feel that in the future I will get cured because at the moment the medicine is there and I am using them well.

I: You feel in the future you will get cured?

R: Yes.

I: Anything other thing you foresee for the future about the condition?

R: None.

I: Our conversation ends here, I am excited and keep on taking your medicine well, as well being focused and having accepted your condition. Right?

R: Yes.

I: I have my colleague who as we began our conversation may have not captured something well and needs clarification and when she is done you can say something then we will end our conversation.

R: Okay.

I2: Thank you so much for your good conversation. You said when you began going to hospital M you saw changes in your health than when you went to hospital K. What changes are those?

R: When I was at hospital K I was very worse, the medicine given worsened the situation.

I2: What happened when you say worse?

R: I kept falling, I would fall three times in a day but when I went to hospital M and I narrated my experience and a doctor from hospital K was there who also helped give more details about my situation then they changed the medicine. This is the change I saw because the too many falls reduced.

I2: The medicine being changed is the reason you stopped falling or what was the reason for the medicine being changed?

R: The medicine was changed because the ones I was taking were not right for my body. Before I stopped falling, I would fall three times a day but after the changed medicines the number of times I used to fall reduced.

I2: What do you mean when you say they weren't right for your body?

R: The medicines from hospital K didn't work well for me.

I2: Kindly clarify, did they make you fall more or how was it?

R: When I was given the medicine, they made my situation worse because I would fall once in a day so they were stronger for my body. When they were changed and I began taking those from hospital M, that's when I stopped falling.

I2: Those from hospital M were strong for your body?

R: According to me, the grams were high so they were reduced.

I2: The ones from hospital K were how many grams if you are aware?

R: I can't remember but the ones from hospital M were 200 grams.

I2: Okay. How many times a day did you take for those from hospital M?

R: Thrice a day.

I2: And those from hospital K you were to take how many times a day?

R: Once.

I2: Okay. As we go on, you mentioned that two of you from your house have epilepsy?

R: Yes.

I2: Who is the other person, is it a brother or sister?

R: It's a brother.

I2: How old is he?

R: He is 11 years old.

I2: You said yours began when you were in class seven, when did his begin?

R: When he was young, he caught pneumonia and was taken to Hospital E, beds were less so he was put together with those who had epilepsy. He was discharged but at the hospital E is where he got the illness.

It began as convulsions; he was administered an inhaler and that ended but then the epilepsy remained.

I2: What was his age at the time?

R: He was three months old.

I2: You also said you think you got yours from spending time with someone from the plot you moved into. Why or what thing makes you think you got it from the person?

R: I think I got it from the person because we used to spend time with her and she used to fall all the time. So it's us who would hold her and call for help for her to be carried. She was affected a lot because she used to fall many times so she could not be left on her own. One day she fell as she used to and passed on, and on that day in the morning is when mine started.

I2: Did she die because of that illness?

R: Yes. She did fall badly and never woke up.

I2: So, it's you who would hold her when she falls, what else did you do with her?

R: If she fell in a ditch, I would move her then call her parents to carry her to take her to the house.

I: Were you with your friend on that day he passed on?

R: I wasn't with her on that day, people were called and carried her.

I2: That's all, thank you.

I: Do you have anything you want to tell us?

R: What I can say is, anyone who has the sickness, I have friends who got cured. So I know someone can be cured as long as you take your medicines well, don't miss on it, follow the doctor's instructions and they will be cured. The person did not take medicine that's why he used to fall.

I2: Who is that?

R: My friend, that's why it worsened. If you miss medicine for a day, it comes two times stronger and you will fall really bad unlike the earlier falls, and if it's in the fire you will burn unknowingly and when you fall you bite your tongue until you can't eat for one week. Someone who has the condition must take the medicines well. Also, my wish is for any organization that can support the epileptic people with medicine to do so for them to not fail on taking the medicines. Because if you take the medicines well the illness will be cured completely.

I: Do you have any question or anything else to add on?

R: I have none.

I: You are okay? We appreciate for the conversation, keep taking the medicine well and continue being a champion to people or friends you know out here encouraging them to take the medicine.

Thank you

[End of audio]

