

NAME OF THE ORGANIZATION	AFRICAN POPULATION AND HEALTH RESEARCH CENTER
PROJECT NAME	EPILEPSY INNOVATION PATHWAYS IN AFRICA
CONTACT TYPE	IDI WITH A MINOR PATIENT
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DURATION	00:35:54

I: We will begin our discussion.

R: Yes.

I: In your opinion, please tell me how did you discover that you are epileptic?

R: I usually see a snake get inside my leg.

I: You see a snake get into your leg?

R: Yes, my hand started shaking.

I: How did you find out that you are epileptic? What happened?

R: Our younger sibling had epilepsy, he was taken for prayers at Legio Maria (*a type of religion*), after the prayers the epilepsy got into me.

I: When your sibling was taken for prayers at Legio Maria the epilepsy came to you?

R: Yes.

I: Does he still have epilepsy or he is now recovered?

R: He recovered.

I: Then you got it?

R: Yes.

I: That is how you got to find out that you are epileptic?

R: Yes.

I: What happened that you discovered you are now epileptic?

R: I know that I am epileptic.

I: How did you get to know?

R: I knew the epilepsy had come from my sibling to me. With epilepsy, my hand, leg and body start shaking.

I: You have said it came from your sibling after prayers and came to you?

R: Yes.

I: Are there any causes of epilepsy that you know?

R: If I take sugar, I get epilepsy attacks and the body starts shaking.

I: Where did you learn from that when you take sugar your body starts shaking or when your sibling was taken for prayers that the epilepsy came to you, where did you learn from?

R: I learnt from Kayole.

I: Kayole?

R: Yes.

I: Who told you or how did you learn?

R: I used to live in Kayole.

I: You lived in Kayole?

R: Yes.

I: Who told you that the epilepsy came from your sibling?

R: I was okay before but now when I take sugar I sleep deeply.

I: Okay. Is there anything that can be done to prevent epilepsy?

R: I take medication, after taking it, when the attack comes my grandmother usually knows, she rebukes it.

I: Is there anything that can be done to prevent anyone from getting epilepsy?

R: I know that when I take sugar I start shaking.

I: You start shaking?

R: I sleep in the seat when the epilepsy attack comes.

I: Are there people you know who are not epileptic?

R: Yes.

I: What can they do so that they don't get it?

R: Some people rebuke the epilepsy to go to others.

I: Okay. How has been your life living with epilepsy?

R: It is bad.

I: Why?

R: I don't sleep well the entire night, the epilepsy gets in the leg, the hand and body starts shaking.

I: Anything else that has happened since you became epileptic?

R: Earlier, I was okay. I never used to destroy items in the house.

I: What about now?

R: When I am left in the house I destroy things.

I: When left at home you destroy things?

R: Yes.

I: Anything else? You have said when left in the house you destroy things?

R: Yes.

I: What activities can't you do because of epilepsy?

R: I know how to clean dishes.

I: What do you clean?

R: I clean dishes and clothes.

I: You know how to clean dishes and wash clothes. Do you wash currently?

R: I don't wash because I am epileptic.

I: You don't clean dishes and wash clothes?

R: My grandmother cleans the dishes, washes clothes and cleans the house, she does everything. I usually don't go to school when the epilepsy attack comes. I am requesting you to do away with this epilepsy.

I: What are your worries concerning epilepsy?

R: Epilepsy?

I: Yes.

R: I usually feel a lot of pain.

I: Where do you feel the pain or why?

R: I feel pain in my entire body.

I: Where does the pain come from?

R: In my leg and hand.

I: What other worries do you have concerning being epileptic?

R: My grandmother rebukes epilepsy when the attack comes. She does not sleep the entire night.

I: She does not sleep?

R: Yes.

I: She is forced to stay awake as she rebukes epilepsy?

R: Yes.

I: Are you under any medication?

R: Yes.

I: Where do you get the services from? The medication?

R: I do not have drugs for epilepsy.

I: You don't have any?

R: Yes.

I: Are you currently taking any medication?

R: Yes.

I: Which one?

R: The ones from the hospital.

I: Which hospital did you get them from?

R: We take a matatu with my grandmother, she shows me where the hospital is, she speaks and I am given the medication.

I: Anything else done to you at the hospital?

R: Yes.

I: Which one?

R: I am usually given medication for (*inaudible speech*).

I: What does it do?

R: It does nothing.

I: You take it?

R: Yes.

I: How does it help you?

R: It does not help me. My brother beats me with fists and a belt when I destroy things until my grandmother speaks out. My brother likes hitting me on the head.

I2: What if you don't take your medication? Is there a time you have stayed without taking your medication?

R: My grandmother reminds me.

I: What happens when you don't take medication?

R: The snake comes and gets into my leg and shakes it.

I2: The snake shakes the leg and hand?

R: Yes.

I2: How many? —

R: The whole body.

I2: The whole body?

R: Yes.

I2: How many drugs do you take? Are you able to know how many drugs you take? --

R: Three.

I2: Three?

R: Yes.

I2: At what times?

R: At night and in the morning.

I: You have told us you go for medication at that hospital, is there any other hospital you have or anywhere else you go for medication?

R: Only that one.

I: How is that hospital in regard to treatment and medication?

R: It's good.

I: Why is it good or what makes you say it's good?

R: It's helping me.

I: How is it helping you?

R: I usually go to school (*Inaudible speech*).

I2: What is good about that hospital or what do you like about it or what makes you happy about it?

R: That one?

I2: Yes.

R: That hospital has injectables and doctors.

I2: Do you usually receive injections?

R: No, I don't.

I: Anything else that makes you like the hospital? You have said it has injections and doctors. Anything else?

R: The hospital has a weighing machine.

I2: How are the doctors?

R: They are good once they measure my weight I am given medication.

I: Is there anything you would want changed about that hospital?

R: Changed?

I2: Is there anything you don't like about that hospital?

R: Yes.

I2: What don't you like?

R: Some people get injections and I don't get it.

I: Would you like to get the injection?

R: Yes.

I: Earlier you had said, epilepsy has caused you not to carry out household chores, your grandmother is forced to do them and initially you used to do them, is there anything else it's hindering you from doing and you used to do them before?

R: When that epilepsy attacks, I don't go to school, I don't clean the house, the dishes and clothes.

I2: What about school? Is there any activity you cannot perform? You go to school right?

R: Yes.

I2: What can't you do? --

R: When I go to school and the epileptic attack comes, my grandmother is called to pick me from school while other pupils remain. Help me (*Inaudible speech*).

I2: What about games?

R: I know how to play football.

I2: You play football?

R: Yes.

I2: They allow you? --

R: I was taken to play football, my grandmother told the coach I should be removed and be given medication.

I2: Is there a time you get the attacks when playing football?

R: Yes.

I2: What happened?

R: My grandmother is called by the teacher, she takes me home and other children remain. In that school, they cook porridge, ugali and rice. (*Inaudible speech*).

I2: Apart from football, which other games are you allowed to play?

R: (*Inaudible speech*).

I2: Which game is that?

R: Kogalo.

I2: Kogalo

R: Yes.

I2: Which game is that? How do you play it?

R: We hit a boy with our legs with other kids and they pick each other.

I2: They have never denied you an opportunity to play because you have epilepsy?

R: Yes.

I2: They allow you to play?

R: Yes.

I: Being epileptic, how is your relation with family members because earlier you had mentioned that your brother beats you when you destroy something in the house?

R: He beats me in the head a lot.

I: What about other family members, you had mentioned grandmother I don't know if there are others how is your relation?

R: I also live with my grandfather; you know grandfather?

I: Yes.

R: He buys me chips, beverages, and a bicycle. He buys everything. He goes to work.

I: How is your relationship with him?

R: Good.

I: You had said you also live with your grandmother. How is your relationship?

R: Good.

I: Anyone else you live with?

R: I have a sister.

I: How is your relationship?

R: Good.

I: When you say “good” what do you mean?

R: Good.

I: How do they take you being epileptic?

R: Bad. She cries.

I: Who cries?

R: My sister.

I: Why does she cry?

R: My elder sister cries because epilepsy is not good.

I: You have friends?

R: Yes.

I: How is your relationship because of being epileptic?

R: Good.

I: What do you do with your friends?

R: I stay with them.

I: Anything else you do with your friends?

R: I play with them.

I: Are there friends that do not sit with you?

R: I have three.

I: Are there friends who don't play with you?

R: None.

I: None have refused to play with you?

R: We all stay together.

I3: You have said your elder sister cries because of epilepsy?

R: Yes.

I3: What happens to you that causes your sister to cry?

R: Even grandmother cries.

I3: Why do they cry? What happens to you at that time that causes them to cry?

R: Epilepsy is bad.

I3: What happens to you at that time that makes them cry?

R: When the epilepsy attack comes, I start shaking everywhere.

1: How do other people perceive you being epileptic?

R: Some people don't want to sit next to me because I am epileptic.

I: Why don't they want to sit close to you?

R: I am epileptic. If I sit next to them, they will be infected.

I: Anything else they have said or they do because you are epileptic?

R: All people don't want to sit next to me.

I: Why?

R: I am epileptic.

I: Why do they refuse to sit next to you because you are epileptic?

R: If I sit next to them they will be infected.

I: Who said that?

R: I will infect them.

I: Who said that?

R: My grandmother.

I: Those people are the ones refusing to sit next to you or which people?

R: All people.

I3: Those people refusing to sit next to you, I have heard you mention your grandmother, anyone else?

R: My grandmother does not have a rural home.

I3: Apart from home, are pupils at school afraid of sitting next to you? Who exactly is afraid sitting next to you because you will infect them with epilepsy? You have said all people refuse to sit next to you because you will infect them? Who are they?

R: My cousins.

I3: Those are at home?

R: Yes.

I3: Anyone else? (*Inaudible speech*) like neighbors?

R: Neighbors refuse to sit next to me.

I3: Who else?

R: In school they sit next to me.

I3: In school they don't refuse to sit next to you?

R: Yes, I play with them.

I3: You play with them?

R: Yes.

I: As we wind up our discussion, how do you feel epilepsy will affect your life in future?

R: Do away with this epilepsy.

I: How do you feel it will affect you in future?

R: My cousins, grandchildren and our last born refuse to sit next to me.

I3: Who's last born?

R: Ours.

I: Is he the one whom you had said had epilepsy?

R: Yes, he is a small child. He is in the lower primary. Even my sister, I have one and she refuses to sit near me.

I: The one you had said she cries?

R: Yes.

I: She is the one?

R: Yes. I have a small sister as well.

I: You have an elder and a younger sister.

R: Yes.

I: Which one refuses to sit near you?

R: The younger one.

I: What about the elder one? How many sisters do you have?

R: One.

I3: She is the one who cries and also refuses to sit next to you?

R: Yes. (*Inaudible speech*).

I: Who is that?

R: He is a boy.

I: What has he done?

R: He refuses to sit near me.

I3: He is your sibling?

R: Yes.

I3: He is your brother?

R: Yes

I: In your future life do you feel people will refuse to sit next to you?

R: Yes.

I: Is there anything else you feel epilepsy will cause in your future life?

R: Nothing.

I: Anything you would like to tell us or ask?

R: There is none.

I: Okay, we are grateful for our discussion. There is something my colleague would like to ask before we finish?

R: Yes.

I3: You had mentioned that you use *matatu* with your grandmother to go to the hospital, do you know where it is?

R: (*Inaudible speech*).

I3: It's okay if you cannot remember. You had also mentioned that in the hospital there is a weighing scale, what does it measure?

R: Someone steps on it and it goes round.

I3: What does it show after it goes round?

R: It asks "how many kgs do you have"?

I3: It's for measuring weight?

R: Yes.

I3: Thank you.

I: We are grateful.

[End of audio]

