NAME OF THE ORGANIZATION	**AFRICAN POPULATION AND HEALTH RESEARCH CENTER**
PROJECT NAME	**EPInA**
CONTACT TYPE	**IDI WITH A FEMALE PATIENT**
FILE NUMBER	**211121_0931**
DATE OF THE INTERVIEW	**23rd NOVEMBER 2021**
DURATION	**00:31:29**

I: We can start our discussion. According to you, what causes epilepsy?

R: The Causes?

I: Yes.

R: I can’t explain the causes because it gets you off guard and you see someone has fainted. They talk of a few things, like premature birth.

I: According to you, what do you think is the cause in your own opinion, regardless of other people’s opinions?

R: Where I was born, the doctor explained to me that, when I was born, I was born tired, I never cried as babies do after birth, I cried after three hours. This caused it.

I: Okay. Where did you learn about causes of epilepsy?

R: I learned from doctors, where I go to the hospital, in Health Facility N and Z.

I: Okay. From what you learned, what exactly did they tell you?

R: About?

I: About epilepsy.

R: Prevention?

I: About the causes.

R: They told me it starts when I start gazing, I take too long to finish a task.

I: In your opinion, do you think there’s something that can be done to prevent epilepsy?

R: Epilepsy is a sickness like any other.

I: Do you think there’s something that can be done to prevent epilepsy?

R: Going for clinics early enough for expectant mothers, so that they can be given the right care.

I: Could you please tell us when you realized you have epilepsy?

R: In the year 1998.

I: What happened?

R: It started as Pneumonia. I went to the hospital, they told me I have severe Pneumonia, then I started feeling dizzy.

I: Then after that?

R: I went to Health Facility N, and I was scanned.

I: After the scan?

R: They told me not to be sitting near the fire.

I: What names do people use here at Viwandani to refer to epilepsy?

R: Dizziness, epilepsy, convulsions, these are the main three which are used often.

I: Dizziness, epilepsy, and convulsions?

R: Yes.

I: Are there any reasons why people use these names to refer to epilepsy?

R: Pardon me?

I: You said people call it dizziness, convulsions, or epilepsy, are there any reasons as to why they give epilepsy these names?

R: It's an individual opinion.

I: Do you think the community understands the causes of epilepsy? The Viwandani community, or the whole community in general?

R: Many of them are not familiar with epilepsy. If one has never had epilepsy, they cannot understand.

I: Those who understand, what do they say about epilepsy?

R: They say it's a normal sickness. You visit the hospital, get treated, and start taking medication.

I: What is your opinion about how the community supports people with epilepsy?

R: Pardon me?

I: The kind of support the Viwandani community gives to people with epilepsy.

R: They don't assist much, they sideline you, people term it as a bad illness.

I: They sideline you; they term the disease as a bad one, what else?

R: They usually think epilepsy is contagious, but it is a normal sickness.

I: How can you rate the level of support you get from the community? Very high? Very low?

R: Very low.

I: Is it very low because of the reasons you have given me? What other reasons, apart from being sidelined, and the disease termed as contagious?

R: I can give an example with my own family, when I go to my rural home, they feel I don't belong there. They tell me, "Go sit somewhere else alone, we will call you when we need you". They think when they stay with me or I sit next to people, I will faint in front of them.

I: Now that is your rural home?

R: Yes.

I: Do you think here in Viwandani the community has the ability or information on how to deal with epilepsy?

R: Not a lot of people, just a few.

I: What do you think is the reason?

R: I don't know how to explain it to you, because if you try to tell someone more about epilepsy they are not interested.

I: The people with this information are very few?

R: Yes, they are very few.

I: How do people in your community perceive your epileptic condition?

R: For an epileptic person like me, I can't go near a fire, for example I can't cook alone. I must look for someone to help me whether it will take me a whole day and by bad luck, if I don't get anyone, I just take my medication and sleep on an empty stomach.

I: What about the community members who live around you, what do they think about your condition?

R: At least the people I live with understand my condition but other people fear my condition. I can't even go near anyone.

I: They are afraid of you? Why do you think they are afraid of you?

R: They usually tell me, "Please stay away from us, we might get epilepsy through you" they think it's contagious.

I: They are afraid of you because they think the disease is contagious, what other reason?

R: That's the only reason I know of.

I: Does this come from your family members?

R: No, not my family members, from people who are not close to me.

I: What about the people you live with?

R: I live alone because I realized I will always have misunderstandings with people because of my condition.

I: The neighbors are the ones who are afraid of you?

R: Yes.

I: You have said the main reason for them to be afraid is because they think the disease is contagious? They don't have any other reason.

R: Yes.

I: In your own opinion, what are the myths that people talk about epilepsy that are not true?

R: The first one is when they say the disease is contagious, but it is not true.

I: Any other reason?

R: You cannot get epilepsy just because you're sitting next to me or sharing a meal with me.

I: That's also another reason. Another one?

R: When we share items, I cannot infect you with epilepsy.

I: Okay. Those are some of the reasons people in Viwandani give why they don't want to get associated with people with epilepsy, but they are not true?

R: Yes.

I: Why do you think they have this mentality?

R: I think it is because they don't have good information about epilepsy.

I: Lack of information. Any other reason?

R: No.

I: What are the dangers of having epilepsy that the community talks about, which are not true?

R: Pardon me?

I: What are the effects of epilepsy?

R: Effects that affect me?

I: Yes.

R: Avoiding fire, not spending too much time in sunlight, not walking long distances, not overthinking, and not getting over excited.

I: What I would like to know is, are there any effects regarding epilepsy that people talk about out there which are not true?

R: Effects which are not true?

I: Yes.

R: Effects are not many.

I: Which are the few they talk about?

R: You can't sit near a person because it is contagious. You can't work as a tailor, and I usually see people with epilepsy working in tailoring factories, they get dizzy, and they still survive.

I: Are there any other effects they talk about which are not true?

R: Those are the only ones I have heard.

I: What do you think can be done to enlighten the community about epilepsy?

R: The only way is to educate the community.

I: What else do you think can be done so that they can understand more about epilepsy and take care of people with epilepsy, apart from educating them?

R: You can use posters for more information on epilepsy.

I: Posters, what else?

R: It can also be done through drama and arts. We have young people who draw arts on walls. It can be used to pass information on epilepsy.

I: Why do you think it is important to educate the community about epilepsy?

R: It is important because not so many people have an understanding of this illness, most of them don't know it, in case you faint in the company of people who are not aware of it they say you're not a person they can live with.

I: Another reason you might have why the community should be sensitized about epilepsy?

R: We have patients with epilepsy who keep hiding because they don't want the community to know about their condition.

I: Do you think with enough information on epilepsy the community will learn, and it will help some of those patients who hide their condition not to hide it anymore?

R: Yes. We would also appreciate it if the testing facilities were brought closer to the community, because the only one offering scans to epilepsy patients is Health Facility N. In that manner, people will learn epilepsy is a normal disease.

I: Okay. Could you please explain to us how your experience has been living with epilepsy?

R: First is to accept that you are epileptic. Secondly, don't listen to what people are saying regarding your condition, accept and take your medication as instructed by your doctor, whether people talk about your condition or not life must go on.

I: How has epilepsy affected your normal life?

R: Sometimes I lack basic needs, like food, rent, because the medicine I am taking lasts up to 12hours in the body and I am supposed to rest for all that time, I won't be working.

I**: It affects you mostly on food and rent?**

R: Yes.

I: When you talk of food, what exactly do you mean?

R: For example, when I sleep for all those hours, I depend on my tailoring job, by the time I'm getting out to look for jobs, they will all be grabbed by those who got there on time.

I: Does epilepsy prevent you from performing certain duties or activities?

R: Sometimes it depends on the weather. With certain weather, I can't do tailoring, it triggers epilepsy, and the sewing machine can harm me if the seizures happen while I am working.

I: What kind of weather?

R: When it is very cold and when I'm so tired.

I: The weather prevents you from doing your tailoring work?

R: Yes.

I: Other than that, are there any other activities epilepsy prevents you from doing?

R: If the weather is favorable, I can do my tailoring

job from morning to evening. But once it starts getting cold, I close and go home.

I: Which other activities does epilepsy prevent you from doing at home?

R: I can't cook, I must look for someone to help me with cooking, or rather a person we can cook together. In case I don't get, I must look for someone the following day.

I: Other than to avoid cooking, what else?

R: I can do my laundry; I can do all the cleaning around the house.

I: When it comes to cleaning you can do it?

R: Yes.

I: Cooking is the problem? And tailoring when the weather is very cold? Or when you're too tired?

R: Yes.

I: Does having epilepsy affect your relationship with your family members?

R: No. I went with a certain lady who explained to them what epilepsy is, and how to take care of an epileptic family member. They're okay with me.

I: Has it affected your relationship with friends?

R: No. After educating them about epilepsy, they are okay with me. Although I still have some friends who are not okay with it, and they don't want to spend too much time with me.

I: What about people generally who are not close to you?

R: Most of them we are friends.

I: How do you think epilepsy will affect your future life?

R: Kindly repeat the question.

I: How do you think epilepsy will affect your future?

R: I might not get my own home, because whenever I get a suitor and mention my condition, most of them become afraid and run away. They won't tell me directly, but they will cut communication with me immediately.

I: When you talk of not getting your own home, what do you mean by that?

R: Getting married.

I: Why do you think epilepsy will affect you from getting married?

R: I have tried dating someone and we almost got married, but when I fainted in his presence and he learned about my condition, he ran away and left me unconscious. I decided to tell the second man I dated about my condition, and I told him in case I get seizures in his presence, he should not get worried. A month before our wedding, his family changed his mind and said that epilepsy is not a good illness, he ran away too. I explained to the third man I dated, but I'm not sure of the decision he has made about our relationship.

I: This means the third man you are still together with?

R: Yes, but I'm not sure if he's here to stay. He looks indecisive.

I: Okay. Apart from how you think it will affect your marriage life, what about your friends?

R: My friends don't have a problem with me.

I: What about your personal life? Do you think it will affect you in future?

R: I'll pray to God. If He heals my condition, I will be grateful.

I: What about your work?

R: I can't get employed anywhere, unless I just do small businesses which are not reliable.

I: What do you mean they are not reliable?

R: I work very few hours in a day. In case I get seizures, I can only work for a few hours or sometimes not work at all.

I: Does it affect your work because you can only be self-employed?

R: Yes, I can't get employed anywhere.

I: Any other reason that it might affect your future?

R: I don't have any other reason.

I: What are your concerns with epilepsy?

R: It worries me that sometimes when I'm alone in the house, my stove might be on, and I get seizures.

I: The stove being on is one of your fears?

R: Yes. When I imagine the damage it can cause if the house catches fire.

I: Which other concerns do you have?

R: Fire is my biggest fear.

I: You mentioned earlier about going for your clinic in Health Facility N, is it the only facility you visit?

R: I was sponsored to go to Kibera. That is where I get my medications.

I: Kibera hospital?

R: I don't know the exact name.

I: Is it the Association for the welfare of People with Epilepsy?

R: Yes.

I: That's where you got your sponsor?

R: Yes.

I: Before you started visiting the Kibera facility, you used to visit Health Facility N?

R: Yes, I used to visit Health Facility N for my clinic, but I used to buy my own medication.

I: Now, you go to Kibera?

R: Yes.

I: What would you say about the community support for people with epilepsy here in Viwandani?

R: The biggest problem we have for people with epilepsy is lack of medication. Most people might lack money to buy the medication required. You find a parent who has kids in secondary school, they cannot afford to buy medication, food, and pay for education at the same time. It means that if they don't have enough money, they go without the medication. If such a parent can get support, it can help a lot.

I: Are there any facilities here in Viwandani that offer support on epilepsy?

R: No.

I: In case you need help with epilepsy, where do you go?

R: We go to Health Facility N; it is difficult to access Facility Y because it is a very busy hospital. The easiest to access is Health Facility N.

I: Okay. What made you visit Health Facility N? What kind of help were you looking for?

R: When I was young, my dad was advised to take me to Facility N for a scan to determine what exactly was ailing me. And after the scan it was confirmed, I had epilepsy.

I: You have been going to your clinic in Health Facility N because that is where you first visited with your dad?

R: Yes. They also have specialists on epilepsy.

I: When did you think of changing the facility and starting visiting Kibera?

R: That is because of the sponsorship on getting my medication.

I: Okay.

R: For the clinic I still go to Health Facility N. Kibera is just for medication.

I: Okay. What is your opinion about medication and testing for epilepsy? You had mentioned earlier medication is the challenge.

R: Medication is available; the problem is they are very costly. You might find one tablet costs about Ksh.5, the small ones are Ksh 1. You can find a patient who has been prescribed two, three, or four tablets in a day, they can only afford to buy for one day only. Sometimes they don't have cash to buy the medication, they end up borrowing the cash to buy.

I: According to you the medication is readily available, the challenge is the cost being high?

R: Yes.

I: What about the testing of epilepsy?

R: You decide as a person to go for the tests because it affects you personally.

I: What's your opinion regarding the support offered to people with epilepsy by these facilities?

R: The support is good, but we would appreciate it if you can bring the facilities near us, so that we can also bring out the other patients who are hiding and educate them that epilepsy is a normal illness. We can be very grateful if you can bring the facilities near us, and we avoid going very far to access the same facilities.

I: You don't have any facilities available here in this village?

R: No. We don't have any, but the medication is available in the chemists around.

I: At Health Facility R, they have medication available?

R: No.

I: In the chemists the medication is available?

R: Yes.

I: You have said in the chemists the drugs are expensive?

R: Yes.

I: I don’t know whether you have any recommendations you would give regarding epilepsy. Any suggestions you might need to give in general regarding epilepsy.

R: I don’t have any recommendations.

I: We have come to the end of our discussion. I don’t know if my colleagues have any additions.

I2: I don’t have anything to add.

I3: You have mentioned medication is available here at the village, but it’s costly?

R: Yes.

I3: What about testing facilities for epilepsy, are they available here in the village?

R: No, they are not available. When you go to the chemist to buy the medicine, you must produce the prescription receipt.

I3: If someone needs to be tested for epilepsy, the services are not available here in the village?

R: No, they are not available. The patient must go to Health Facility Y.

I3: To get the testing?

R: Yes. Then you come with the results and prescription for you to get the medication from the chemist.

I3: Okay.

R: Without prescription receipt, you cannot be sold the medication.

I3: What are the causes of epilepsy according to the community?

R: They don’t know anything, they only make comments like, this one has started with seizures, it can be contagious.

I3: They talk about--

R: They don’t know the causes.

I3: That’s all from me.

I: Okay. We have come to the end of our discussion. We really appreciate you creating time to talk to us, thank you.

R: You are welcome.

[End of audio]