

DATE OF INTERVIEW	23/11/2021
ORGANISATION	APHRC
NAME OF THE PROJECT	EPInA
TYPE OF INTERVIEW	IN DEPTH INTERVIEW WITH A MINOR, MALE EPILEPTIC PATIENT
FILE NUMBER	211123_002
DURATION	00:23:03

Idi with A male minor patient

I: Please describe to me how you came to know that you had Epilepsy?

R: I knew that name...

I: Which name?

R: The one for epilepsy...

I: And how did you come to know that you had the illness?

R: I knew of the illness when I was in school seated outside, I mentioned that name...

I: So how did you know by mentioning it?

R: That day I had not fallen down, but the next day I fell down...

I: What made you mention the illness?

R: I remembered the name...

I: And before you remembered and mentioned the illness, where or who had you heard mentioning it?

R: I just remembered on my own...

I: What made you remember or mention the name?

R: Because I knew the disease would attack me and it would be severe.

I: Where did you learn about epilepsy, its causes?

R: I knew it by myself, and I decided to mention it.

I: What can be done to prevent epilepsy?

R: The only thing that can prevent it is taking drugs..

I: When you say drugs...which drugs?

R: The big ones and small ones...they are the ones I take.

I: Where do you get them?

R: I get them from Health Facility N.

I: What do you think causes epilepsy?

R: It's caused by that illness...

I: Do you know what brings the illness?

R: No I don't know...

I: You have told me that it's taking drugs that can prevent epilepsy...apart from drugs is there anything else that can be done to prevent the illness?

R: Yes, the disease can be prevented by taking drugs.

I: What has been your experience living with epilepsy?

R: It has been very bad...

I: Why would you say it has been very bad...please tell me More on that.

R: When it started, I fell and injured myself below the chin.

I: What else...

R: Another thing is... (He keeps quiet for some minutes, and is shaking one hand)

I: Are there activities that are difficult, for you to do

Because of your illness?

R: The only thing I do is sit for my exams...

I: **Apart from doing exams at school, what activities are you not able to do, because of your condition?**

R: I can fetch water just near our house, by the road side...there is a tap.

I: **Do you play any games at school or at home?**

R: I don't play with kids who are not my age mates...

I: **What about your age mates do you play with them?**

R: yes I do play with them...I play soccer with them.

I: **At home do you do any other household chores apart from Fetching water?**

R: The teacher says I do school work when I reach home from school...I write my homework.

I: **And while you are at school, are there activities that The other kids do but for you, you don't?**

R: Yes...

I: **Tell me more... what they do, but you don't do.**

R: They play with the toy cars that they put on the table that looks like this one.

I: **And are there games that maybe the other kids play in school but you don't, apart from the toys cars, and soccer?**

R: For me what I do is do beadwork...

I: **What other games/activities are there for the other kids?**

R: They skip rope...but I don't, because it girls who skip rope.

I: **Any other thing that you do or don't do?**

R: I also run...like running games.

I: What is the most pressing concern that you have as a child living with epilepsy?

R: When I am eating I fall down with my food..

I: Is there any other concern you have, as a patient with epilepsy?

R: No.

I: Where do you seek care and treatment for epilepsy?

R: I go to Health Facility N

I: Any other place?

R: Before that I used to be taken in another hospital in our upcountry..

I: Where is your upcountry?

R: Maragua...in Muranga.

I: And were you still living here in Korogocho, or you used to stay there?

R: We use to live there, with my grandmother.

I: And is there any place you seek treatment, apart from Health Facility N and Health Facility G

R: Yes...Health Facility N.

I: Okay..And what is your opinion regarding the place you seek care for Epilepsy?

R: It is good..

I: What makes you say that it's good? What do they do to You?

R: I mean they do or try how the illness will end.

I: How?

R: They do surgery.

I: Which surgery?

R: Of this place... (child points to his chest)

I: You mean the chest... What do they do?

R: They put something on my chest, and when they press it, it produces some noise.

I: And then...what happens next?

R: Once it produces the sound, it's kept back on the table.

I: Does the doctor tell you what he tests with this gadget?

R: It is for testing the illness that I have.

I: Which illness, another one or epilepsy?

R: Epilepsy.

I: And in Health Facility G when you were there, were they doing

any test on you?

R: Yes...they would also check my chest, using a similar gadget that produces sounds.

I: Are there any other tests they do on you except the chest one?

R: No.

I: And now what about drugs...?

R: They used to give me drugs, in Health Facility G and even at

Health Facility N. (Interviewer pauses for a few seconds as he notices the shaking of one hand getting more and more...then it

stops)

I: What do you wish changed in both Health Facility G and Health Facility N in respect the care and treatment that you get?

R: What I would like to see is the disease gone. I don't have it anymore.

I: And is there anything that the doctors do that you would like to see changed? The doctors at Health Facility N and Health Facility G?

R: Yes... they should change, remove that illness so that I don't have it.

I: **Is there anything else you would wish they changed?**

R: Yes... they bring me more drugs.

I: **More as in? How much drugs do they give you now?**

R: They give me just 3 drugs and say I take one and when I finish, I take the other one.

I: **And when they give those drugs how long do they last? are they for a month, week or? Are you able to tell?**

R: No...

(The interviewer notices some discomfort with the child again, his hand and face, and she ask if it's okay to continue)

I: **What effects does the condition have on your life? How does it affect you?**

R: No it doesn't affect me...

I: **Are there things that other kids do, but you don't do due to the condition?**

R: Yes they play their games, but I just sit alone. At times when am tired, I sit in the class.

I: **Apart from sitting in the class, what else?**

R: That's all that I know.

I: **And from apart from staying alone from other kids, what about family? at home?**

R: At school even my desk is far from the rest...

I: **Why is it that way?**

R: When I went to that school, it was there, next to the window.

I: **Is there any desk near yours, or that window?**

R: Yes...another girl sits there.

I: **How do you think the illness will affect your future?**

R: It can make me have a very bad life.

I: **Please tell me more... what do you mean when you say bad life?**

R: It makes your life bad...you fall down every day.

I: **Another bad thing...**

R: No it's just that... It will make me fall down.

I: **I remember you had said the teacher has placed your desk far from the rest, what makes him/her do that?**

R: He just tells me to sit there.

I: **How do you relate with other kids at school?**

R: I have a good relation with them...some other girls they sit far from me.

I: **Why do they sit far from you?**

R: It's the teacher who put their desk far...

I: **Did they say why they put the desk that way?**

R: No he did not... I saw him put the desks on one side and another near the door.

I: **At home how do you interact with other kids?**

R: I don't play with them...I can only play with my age mates.

I: **Do you have any questions; comment you would like to ask or suggest to us now that we have come to the end of our Discussion?**

R: No.

I: **Okay, now let me give my colleague an opportunity to seek any clarification she might have.**

I2: **How are you...I heard you said your upcountry is Maragua, were you being taken to a hospital there or where were you seeking treatment?**

R: Yes, I was taken to a hospital.

I2: Okay, thank you.

[End of audio]