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CONTACT TYPE OF INTERVIEW	IN DEPTH INTERVIEW WITH FEMALE PATIENT
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**I: Thank (name mentioned) for giving us your time for the
to have this discussion with you. In your opinion what do
You think causes epilepsy?**

R: For me you know I fall down.

I: Tell us more...what causes epilepsy?

R: First I get shocked, and then I stay for some time, after
which then I get shocked for a second time, and during
this second time I fall down, just like that. Now I
just fall like that.

I: What do you think causes that illness?

R: I don't know what causes it, because it just happens like
that to me, so I don't know.

**I: Is there anything that can be done to prevent people from
Developing epilepsy?**

R: To the other people?

**I: What can be done to prevent people from getting that
condition?**

R: I do not understand you.

**I: Okay, I am asking what can be done to prevent people from
getting that epileptic disease? Have you understood me
now?**

R: For me, it cannot be prevented since I do not sit near
people, because of a lot of stress, I have a lot of
stress, and when I am stressed, I then fold myself as if
someone has died, and I must be strong for myself, and
take care of myself, and if I fall down, that's all.

I: What is causing that stress?

R: You know, even me I have my own problems. I have 2
children and feeding 2 children is difficult. And also

like now the younger one has overgrown her clothes, and I do not have money to buy more clothes. I do not have money to take child to hospital; I do not have money to take care of myself, buying food, that's difficult. I must help myself and I also don't have a job. Looking for work at the hotel is difficult because this illness if you go near fire it attacks you very fast

I: So even fire causes the illness?

R: Yes, I have even fallen in the fire, while I was stressed, now me, I am just like that.

I: If I got you correctly, you said when you are stressed you get epileptic attacks, if you go near the fire, you also get the attacks, what else causes the illness?

R: Also being absent minded for long periods.

I: What makes you absent minded?

R: Absent mindedness is brought by getting shocked, I get the disease myself, it just came like that at once, and I do not know where it came from. I just found it like that.

I: Going back to our previous discussion, is there anything that can be done to prevent people from developing epilepsy?

(...Respondent shaking her head, from side to side)

I: When you shake your head, I do not know what you mean, and also for someone listening, they would not know what you mean, or see that.

R: Nothing can be done.

I: Okay, and as we continue, can you tell me how you came to learn that you have epilepsy?

R: The way I came to know is that it just attacked me and I

fell on the ground at once.

I: When did this happen? Where were you?

R: It was in 2019...but I cannot remember the date.

I: It is okay, tell me how it was.

R: The way I came to know that I had epilepsy, first, I just started feeling dizzy...

I: Where were you by then, at home, on the road or where?

R: I was at home, the dizziness was very severe and it would come, disappear then come again, I fell down that's when I realized I had epilepsy.

I: So you felt dizzy and you fell down? And then?

R: I realized I had epilepsy.

I: You fell down for the first time and you knew you had epilepsy?

R: It made me fall down that very first day.

I: How did you know it was epilepsy? Did you go to hospital or who told you that it was epilepsy?

R: I was taken to hospital.

I: Which hospital were you taken to?

R: I was taken to Kariobangi, and they said they cannot treat this illness, because it's a difficult illness to treat, that I should go look for another hospital.

I: You are saying they told you to go to another hospital?

R: Yes, for the treatment of this illness.

I: And did they tell which hospital you were to go to?

R: No they did not tell me, they just said I look for another hospital that will help me, so from there I went for spiritual prayers.

I: Where did you go for prayers, can you tell me more?

R: I went to ACK in Korogocho...

I: And what is ACK, is it a church or what?

R: It's a church.

I: Who prayed for you there?

R: I did not find anyone there, and so I decided to go Legion of Mary.

I: And before you went to ACK, was it somebody who had recommended, you to go?

R: No I had just gone on my own, to find where I can get help. There again I was told there is no one...and I don't like those churches of legion.

I: And who had told you to go there, at legion of Mary church, or who took you?

R: I went on my own, because I already had the disease.

I: What had made you think of going for prayers at the Legion of Mary, was it someone who told you or?

R: Thought of going there because the illness makes me fall down every time, if I eat kales, I fall down.

I: And for someone listening here, when you say legion, what do you mean?

R: Legion is in Korogocho.

I: What is it, a hospital or?

R: It is a church.

I: What do they do for people there?

R: They pray for you.

I: They pray for which people?

R: Like now for my illness, I go there and say I want to be prayed for as I have tried everything. When I go there, they tell me to kneel down, and also close my eyes, and whoever is praying for me holds on my head and back, he

prays for you and tells you that the illness is gone. When we finish praying he says I can go home, and I just left it there, but now I don't fall more often. I fall once in a while, one day I fall the next time I don't, but it can take like a week. And when it comes again I have to sit and think what I will do, because when it comes I fall down completely.

I: What are some of the names used to refer to epilepsy?

R: In Kiswahili?

I: In any language that is used in this community.

R: For me I use Kiswahili...

I: Which is...?

R: Fainting.

I: Fainting, so that's one name, is there any other name you have heard people use?

R: No.

I: What is the meaning of that name, fainting?

R: It means falling down.

I: Do you think people in this community understand the causes of epilepsy?

R: No, because when I fall down I don't look, so I don't know what is happening?

I: What about the people you live with, people around you? Do you think they understand the causes of epilepsy? not just when you have fallen down.

R: For that I think everyone has to understand her condition, I've been told I have to know my condition, because when the attacks come, it comes in a forceful way, and its a must you bite your mouth.

I: What about for those that do not have the condition, do they understand the cause of the illness?

R: They don't even bother.

I: What makes you say that they don't bother?

R: Now if they don't bother, why should I not say?

I: What is it that they do that makes you say they don't bother, can you give me examples?

R: They treat me with contempt, look with bad eyes, they can even catch you while you are walking and slap you.

I: So they slap you because of your condition or?

R: Yes.

I: Is there any other way they treat you with contempt?

R: I cannot say anything; I just see them look at me with bad eyes.

I: Is this why you also say that they don't understand the cause of epilepsy? by treating with contempt, and looking at you with bad eyes?

R: Yes.

I: Anything else?

R: When they look at me with bad eyes they also use abusive words.

I: What abusive words do they use?

R: They tell me I am manner less, and even that I am mentally ill, and that I should use my brain properly to look at those who have a brain, and that I should use the brain for adults. That I should have manners towards adults.

I: Is there anything else that they do to you, due to your condition?

R: No.

I: **What would you say about the awareness and knowledge of members of your community regarding how to manage epilepsy?**

R: My mother?

I: **The people who live around you, like neighbors, all those who are around you?**

R: If I was to talk about neighbors, there is one lady who is our neighbor, who helps me, when I fall down she helps me, like removing clothing from my eyes...

I: **What does she remove from your eyes?**

R: Things, for example this mask, she applies Robb on my head, face...

I: **How does Robb help you?**

R: It helps with injuries, like here...I fell and injured myself just like that, but when she applies the Robb, it the relieves the pain and I am fine.

I: **So can you say that, those people around you, the community you live in, has awareness regarding how to manage epilepsy? For example, the lady you said helps you when you fall?**

R: Her I can say she is a friend and you can even cooperate with her in things that she is doing, in things that she has, for example when I don't have food, she gives me.

I: **Is there anything else she does for you?**

R: No.

I: **What about the other people? Do you think they are aware of managing the condition, like your neighbor lady?**

R: Them they cannot do that.

I: **Why do you say that they cannot do that?**

R: Because they come and say they do not understand my

condition...

I: They say they do not understand your condition, what else?

R: If they tell me that, I just take care of myself and think how the condition will leave me.

I: Coming back to your lady friend you talked about, the one that helps you, what do you think about the level of support that members of your community give to people with epilepsy?

R: I don't understand...

I: What do you think, about the level of support, that members of your community give to people with epilepsy? *(Respondent displays some discomfort by a facial expression, breathing difficulty for a moment, then sighs.)*

Hope you are okay? Sorry for that.

R: There is no support from other people apart from the neighbor friend. I can see some support, since she helps me a lot.

I: And you said she is your friend or who is she to you?

R: She is a neighbor.

I: Okay, thank you for that. And how do people in this community behaves towards you? and why do they behave that way? I know before you had mentioned they treat you with contempt?

R: Where I go to take medicine, at Health Facility R, someone

holds my baby for me...

I: Who does that?

R: My sister...because if I fall, I can fall with the baby, what I can say is that it's difficult...that part of falling down is difficult and I have to control those who are there to help me.

I: Why and how do you have to control them?

R: I have to control them because I can fall down and maybe I hadn't eaten anything, and so I can't just go like that.

I: What do you mean when you say you cannot go just like that?

R I mean I cannot just go somewhere and say that I have epilepsy, and also cannot stay with someone due to a lot of vomiting, and falling down. If I start vomiting I cannot stay with anyone, even my neighbor friend, because that place I vomit becomes very messy. I vomit a lot, and it comes out at once. So I have to be aware of myself, and how I go.

I: Is it them that decide not sit near you or it you who tell them to sit far?

R: I tell them because I'm the one who vomits, falls.

I: Apart from your sister who holds your baby, and the neighbor who helps you, how do other people behave towards you due to your condition?

R: To others, when I fall down they just start laughing, due to contempt. They cannot even help you when you are in need, they just laugh at you.

I: Is there anything else?

R: No.

I: What misconception do members of the community have regarding epilepsy?

R: They say I go to hospital, and at the hospital I am warned not to eat certain foods, like for me I don't eat

kales.

I: That you were told at the hospital, what about here outside in the community, what do you think is said and is not true about epilepsy?

R: It's only kales that I don't eat, and I was told there at Health Facility R mentioned.

I: And do you think that's a misconception or?

R: Those are the vegetables that would make me fall most times.

I: Is there anything else you were told not to do or eat?

R: No.

I: And did they tell you the reason why you should not eat kales?

R: But even me there are things I don't like.

I: Please tell me, like what?

R: Meat from a goat, I don't like, it makes me feel like throwing up, and makes me feel tired all over the body when I walk, and also my neck gets tired, and it aches everywhere, sitting down and eating becomes difficult.

I: Is there any other misconceptions people have apart from not eating kales?

R: No.

I: What are the effects of epilepsy?

R: It makes me to be shocked when I'm walking, because I can fall on the road when walking.

I: What else?

R: When I am bending, my back aches, head also aches a lot, and biting my tongue... and also in this place...

(respondent touches her chin to indicate where she gets

pain due to falling and hitting on the ground)

I: Is there any other opinion?

R: No.

I: And what can be done to make the public more aware about Epilepsy, and how to support people with epilepsy? and do you think it's important?

R: Yes it is important, because those that are in this condition, they fall down, they should be helped, and be given something small...

I: When you say something small, what do you mean? Please tell us more? And don't be afraid to speak your mind, today we are here to talk.

R: Something small is like for someone, when I fall down I have to eat a lot, because of my baby, and when I fall down, I don't have anything.

I: You are saying that you have to eat a lot because of the baby, what do you mean by that?

R: You know she is still young and she is breastfeeding, and I might lack food to eat, and also money for buying the baby's clothing, so that is where the problem is.

I: What should we do to make the public aware of epilepsy and how to support the people living with epilepsy?

R: Now what I can say is that, we just talk to them. We should sit them down, talk to them just like people who are falling down and also take them to hospital, seeks treatment, and find out if they can be medicine for falling down

I: So you are talking about the epileptic patients, they be taken to hospital?

R: Yes.

I: What of these other people that do not live with this condition, what can be done for them to be more aware on how to support those that are living with the condition? And you even said that they should be talked to. Who is going to talk to them?

R: The doctor is there, to talk to them...

I: What will he be telling them?

R: He should tell them what is happening, because they can also say that they are not able to do this or that, or that they don't have anything to say, that's all.

I: Apart from the doctors, who else can talk to them?

R: Even my mother can talk to them.

I: Anyone else apart from the doctor, or a parent like your mother, anyone else?

R: No.

I: What has been your experience living with epilepsy?

R: The experience I have for epilepsy is falling down, even yesterday I fell down, and when I fall I become absent minded for a while, I get shocked, the whole attack comes, and I fall on the ground...Now what can I say?

I: What activities are difficult for you to do due to the condition? And sorry to say this, I can even see a wound on your face, tell me what happened?

R: I don't understand you very well.

I: Are there activities that you cannot do because of your condition? Like the way you said your sister holds the baby for you at the hospital, in case you fall?

R: You know like the jobs people do along the river to wash paper bags, those I cannot do.

I: Okay, washing paper bags in the river... why?

R: Because of this condition, it can come at any time, so I need to control myself if I am to go there...

I: Why? What will happen, or so what doesn't happen? for someone listening tell them more why you cannot do jobs near the river?

R: I cannot do those jobs because; I can fall at any time, when my back gets tired.

I: So one is that working along the river is difficult, you might fall...what other activity is difficult for you?

R: Even cooking...

I: Okay, cooking, how and why is it difficult, tell us more?

R: I cannot cook because I get shocked, and also because of the noise...

I: Noise...from where?

R: From people, this condition does not like noises, when it comes you have to control how the noise will stop..

I: What does the noise do to you?

R: That noise makes me fall immediately.

I: So apart from working in the river, cooking and being in a noisy place what else cant you do?

(...shakes her head)

When you shake your head, be saying what you mean, like nothing or that's all, because for someone listening they won't see

I: How does your condition affect your interaction with your family?

R: In my family, I need to help them...

I: And does it affect your interaction?

R: No it doesn't, I get on well with my mother, I stay with

and my father.

I: How do you relate with them? Does your condition affect how you relate with them?

R: When I am about to fall down they hold me, from behind, and also my head, I have to look how I am falling down, not to hit my head, because this is a problem, I will get wounds.

I: Has how you interact with them, been affected by your condition?

R: No it hasn't.

I: So for them they just help you?

R: Yes.

I: What about your friends now?

R: I do not have any friends

I: Not even a single friend? why?

R: I don't like having friends.

I: Are you the one who doesn't like or?

R: Do you know friends are enemies?

I: Why do you say that friends are enemies?

R: Now you know even if you have those friends and you tell them to help you with something to eat, if maybe you don't have, they will ask you if they are the ones who brought you to this world... they also ask if they gave birth to you.

I: And do they ask you that because of your condition or what?

R: Yes, they ask me that because I fall down, so I cannot control them. That is why I am telling you I don't like friends.

I: Is there anything else... What of other people now, apart

from family, your mother, father, friends, how you interact with them?

R: No.

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

R: The condition might go away, I might become better, if I take my medicine properly, it might go away, and also I might get help.

I: You are saying if you take medicine properly, you might get well soon, then after that, how will your future be affected by that?

R: I think I don't get your question?

I: Even what you had started saying is okay.

R: I still don't get you.

I2: She is asking...you had said that if you continue taking your medicine properly, that the condition will go away, now after it has gone away, how will your life be?

R: I can have a life, to look for work by myself, take care of the kids, take care of myself, and see how to feed my children.

I: What about with friends? family?

R: Now you know even my mother has her own family I cannot take care of other people's family.

I: What is most pressing concern as a person living with epilepsy?

R: I tell myself that since I am not the one who brought the condition upon me, it came on its own, I don't even know where it came from, so the pressing concern I have now is about my babies, how they can clothe, feed, and

also their school fees, how they will go to school.

I: Okay thank you for that.

What can you say about care and treatment for epileptic people in this community?

(respondent is stretching her baby by holding him upright, on her chest)

R: I have never bothered with people's business...

I: I mean even the services that you get, you had mentioned that you do go to the hospital? How are the services for the epileptic people there?

R: I go there for help...

I: What kind of help?

R: I must go there and speak for myself, as a woman...

I: Where is this? Because initially you had told me you go to Health Facility R?

R: I go to Health Facility R...

I: And is there anywhere else that you go apart from Health Facility R?

R: I just go to Health Facility R only, my mother advised me to

follow up on there, even for my baby ante care I just go there.

I: I want to talk about where you go because of your epileptic condition...

R: I don't go to the hospital.

I: Even at Health Facility R?

R: I take my baby for clinic there,

I: If you don't go to hospital, for your condition, where do you seek services and treatment for your condition? and I remember you had told me that you do go for spiritual

prayers?

R: Yes, for those prayers I had gone and the illness did not go away, so what could I have done?

I: **So you do not go to the hospital because of the condition that you have?**

I2: **Earlier you had said that you had gone to Health Facility R, the first time you fell down, do you remember? you were taken to Health Facility R, and they looked at you and said that this illness cannot be treated, or you go to another hospital? That time you had not gone because of your condition?**

R: That was the first time I went.

I2: **You had also mentioned that you do get medicine at Health Facility R. What is the medicine for?**

R: They are for fainting.

I2: **And it's at Health Facility R? same where you take your child?**

R: Yes for clinic.

I2: **So the same Health facility you take child for clinic you also**

get your medicine?

R: No, the child has other medicine.

I2: **I meant your drugs**

R: Mine? There at Health facility R, I also get my medicine for

fainting.

I: **So apart from Health facility R, there isn't any other place**

you go for treatment?

R: No

I: **Okay, what is your opinion regarding the drugs maybe for epileptic...do you use any drugs for epilepsy? And those**

drugs you get from Health Facility R? when you are also taking your child to the clinic?

R: I go alone.

I: What can you say about the availability of those drugs, at Health Facility R? Are they available?

R: Yes.

I: What about the cost?

R: I am just given like that.

I: You don't buy?

R: No.

I: Okay, thank you, but first I don't know if my colleague has something she would like to enquire, something that was not clear?

I2: I have only one question, when you said about doing work at the river, what kind of work was that?

I: She said washing paper bags?

R: Okay, thank you.

I: (Name mentioned) we don't know if you have anything to say, question you can ask us?

R: I am fine?

I: Okay, we thank you for your time.

[End of audio]