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I: How are you?

R: I am good.

I: Now we will start our conversation, as I had told you we will have some conversation today. Our conversation will be about you as a parent or someone who stays with a child who has epilepsy, and as we talked, whatever we say here remains here, I just want to know the information you have, it's not a must that what you say to be right or wrong, what you know is what we talking about, so be free, talk and what we are talking about is confidential and remains here to be used for our study, I don't know if you are okay up to this point if we can start?

R: I am okay

I: Okay let's start, thanks.

Which names are used in this community to refer to epilepsy? The names you know are used.

R: What?

I: What names are used in this community to refer to epilepsy?

R: I see how a child does in the house, when he goes to school, when the teacher calls me, even how the child walks, there is a way he can walk then you are called a child has fallen, going to check he can sleep there for hours for him to wake up, he can fall at 7 and wake up at 4pm or 6.30pm in the evening.

I: So, for example like falling the way you said he can fall, which names can be used in this community to know that a child has epilepsy, maybe are there any other words used there?

R: I don't know, I am not aware of the names, depending on if I have a child and he falls I get called at school, when he walks with others, he falls you get called a certain child has fallen in the field he's asleep and it takes hours for him to wake up.

I: Okay, thank you. Which symptoms show someone has epilepsy? So, as you told us, you had mentioned the falling then you are told he has, so are there any other symptoms that show someone has epilepsy?

R: Other symptoms are, I see a child walking with others and you will hear someone has slept, going to check you see he is sweating and there is sweat.

I: So, you said sweat, as well that falling--

R: And then now you see he is not breathing normally--

I: As well breathing that is not like the normal, is there any other that shows a child has epilepsy?

R: No

I: Okay thank you.

In your opinion what do you think causes epilepsy as you understand yourself?

R: Something that causes this sickness is, a child can be born with it, a child can get while walking on the road and there are those people that pour on the road so when one passes by it's a must to get it.

I: So, you said being born with?

R: Yeah there is being born with it, but for this one it's not the one of being born with because right now he is older and it started while he was in class six, I tried the others, hospitals and herbal ones but they weren't successful.

I: You tried herbals as well?

R: It wasn't successful. That's when this one came, when he came, he told me we try again another way we see. Because even me I have tried as a parent when he was in class 6 because now he is in class 7 and next year he will be in class 8 he will do KCPE, and he is older he is not young and he usually falls, sometimes he doesn't do exams, when it gets worse the teacher calls me and he is taken to hospital.

I: You have mentioned to us that others are born with it, you mentioned herbs, you said which medicine?

R: Herbal medicines

I: Herbal medicines, now why do you think you have thoughts regarding herbal medicines and what it has to do with the causes of epilepsy?

R: There are those herbal medicines that are drunk and ones put in the nose when he has fallen so that he can regain consciousness, I have used all of them, but I know it goes away for a short moment then it comes back, even... happens due to... [*inaudible speech*]

I: So the main reason you have mentioned is being born with?

R: yes

I: Any other way, relating to where someone may get it from because you said yours wasn't born with it?

R: Mine wasn't born with.

I: So, what do you think caused it?

R: I don't know what caused his because you see I didn't give birth to him with it, he began from class six then the teacher started calling me to school that the child has fallen, when tested in hospital it was found to be it, even the hospital has tried those other medicines but it hasn't worked.

I: And any other causes you have heard of sociocultural or spiritual like, have you heard of causes that can bring the disease, which one have you heard?

R: I heard one person in their family had it

I: One person had it?

R: But you know the person who had it is a woman and has children but she still falls.

I: Have you heard of any Spiritual cause?

R: No

I: Thank you.

As we go on with our conversation, how does epilepsy affect those who have epilepsy. What effect does it have on someone who suffers from it?

R: The person suffering is weak and--

I: Is it weak?

R: Yes, he has that, unlike the others, and even when you see him standing alone, he suffers from memory loss.

I: His memory is lost and has lost consciousness?

R: Its lost

I: And what activities can't they do because of their sickness or what do you see they can do or what activity can't they do because of the sickness?

R: You see you can't ask him to cook, he can't even fetch water.

I: Why?

R: If he goes there you will be called he has fallen and he can fall in water, you know it's something that comes like a bad spirit and when it comes, he falls down.

I: And is there any other thing he can't do that this sickness prevents him from doing an activity?

R: When he goes to school, it's a challenge because when the others are on exams he suffers with the paper, you know when that thing comes and attacks him, then his paper falls.

I: So, at school he has a challenge?

Any other you see that can make these people with this sickness go through that makes them not able to do any activity?

R: There is nothing he can do, because it's something that comes, you know he can sit with you like this and when it comes, he is down.

I: So, you feel it prevents him from doing a lot of things?

R: Yes, a lot.

I: And how do ordinary people behave towards people with epilepsy in this community, in this our community where you come from, how do people who have no epilepsy behave towards people with epilepsy?

R: They look down upon them because they don't have the disease.

I: They don't have?

R: They look down upon them because they feel they are well.

I: So those who are well look down upon those who have it?

R: Yes, because even how they talk it's like they can't get sick.

I: Is there anything you see from them?

R: No

I: How do they behave towards those who have it?

R: It's them who look down upon others.

I: Looking down upon others is what you have seen?

R: Yes because they don't want their children to mix with those with it, they feel they will get the disease and you see I didn't give birth to this one with the disease he got it when he was grown and it's like a bad spirit pushed to him because I have tried everywhere for now a child to reach class 7 and do exams I have tried as a parent but I have been defeated and that one when he saw I had tried and I was tired, decided to come to me as he used to see me get called to school continuously after every few minutes. You know you can't be at peace and even if you sit you are worried because sometimes he is carried by a vehicle and

taken to Hospital X, he's treated and comes back, it goes away for a while then it comes back, like right now in the evening, he starts changing in the body then when the sun goes away he is okay, I know the moments.

I: You understand him? We appreciate it, so let's go on, so to ask again, how do you feel taking care of the person with the condition affects the lives of the other family members, how you live with him, how do you feel his sickness affects you and other family members you live with?

R: I was with another one, she couldn't even cook.

I: Was it your child as well?

R: No, it was my elder sisters' child, she also had the condition, she can't cook, fetch water or even wash clothes because when it came that was it, and it was a distance helping to take her there.

I: So how did you feel affected?

R: The one I was with, if you send her to get water you find she has fallen near the water where there is an ocean here and the bucket has fallen on the side, she would sleep there for hours until people came by, sprinkled water on her for her to wake up. So, she would only sit because she was unable to do any task and it wasn't her wish but due to the condition.

I: So, what are your hopes for your child or the one you said is your sister's child who is epileptic for the future life, what are your hopes for her?

R: With what I am seeing on this child and what I know is, when the condition attacks, I see he has lots of problems because he falls for hours, has issues with breathing before regaining consciousness and it makes others fear sitting with him because he takes hours.

I: It makes others fear sitting with him?

R: Yes.

I: And do you have any hopes for him in future or any plans you wish for him?

R: I don't know how the future will be, yes, because I have tried as a parent but I have been defeated.

I: Okay, where does your patient seek treatment for epilepsy? Because you mentioned sometimes you get called and he is taken to Hospital X.

R: Sometimes he is at school with his fellow pupils, a teacher sends another pupil to come and call me, even sometimes the teacher himself calls me because he has my number, I come to school, someone has slept down they are still giving him first aid so that he can wake up because when he sleeps he takes hours for him to wake up from there so they call the parent to come so that a call is made and he is taken to Hospital X.

I: So, you have mentioned Hospital X, is there any other place maybe you have ever tried to take him when he is sick?

R: Only there.

I: A while back you had mentioned you have tried everything but are defeated, what is that everything

R: I have tried even this herbal but there is no change, it goes away and then comes back, so you know he loses his memory, he gets confused and before he wakes up from there he doesn't know where he is going, he will be left there for hours for his memory to come back.

I: So those are two, is there any other you have tried due to the disease?

R: None

I: Okay. Do you think information on where to seek care and treatment for epilepsy is readily available in this community? Do you think it's readily available, people have information?

R: No.

I: You don't feel so?

R: Yes.

I: What are some of the challenges affecting availability of information and care for treatment in this community? What makes information not be available as you said you don't feel it's available?

R: The teacher calls me. That's how it goes, the teacher calls me and the time he calls me we go to the hospital.

I: So, it's only the teacher who explains to you?

R: Yeah.

I: And how is information for the people in your community, do you feel they don't have the information?

R: They don't have.

I: You don't think they have the information?

R: It's the teacher who spends most time with the children so he is the one who knows how the children are.

I: What might be causing the community to lack information about this epilepsy?

R: There is nothing this community people can assist you with, there is none, it's only the head master or class teacher, so when he falls the headmaster goes to the class teacher they lay him under a shade, he sleeps for hours until the time he will wakes up, they later send someone to call me after calling me we go to Hospital X accompanied with the class teacher or the headmaster, who leaves his work to take the child to hospital.

I: Okay. Our conversation is progressing well, so what challenges do people face in this community when seeking care and treatment for epilepsy? What do you think are the things that they go through for them to get the treatment for epilepsy?

R: They go through things because you can be there and get called by someone who is in this state and you take them to hospital then the patient is supposed to stay in the hospital to be treated but the issue is lack of money.

I: Now if you don't have money for inpatient treatment services--

R: It will force you to take the patient home due to lack of money and now the patient will not receive quality treatment due to lack of money.

I: He won't get quality services?

R: Yeah, he will get poor quality.

I: Have you seen any other issues people go through when seeking care and treatment for epilepsy?

R: I haven't seen it.

I: You talked about money and not getting quality services?

R: Yes, he gets poor quality service because you have less quantity which doesn't match the required level so he will be treated and the next day the sickness comes again.

I: Do people struggle on knowing where to access care and treatment? Is there any challenge in people knowing where to access the treatment?

R: If you go to a hospital you enter the gate, they will assess patients, those who are in bad state or condition will start to be treated, when I take him there he is treated with low quality services due to lack of money so when I go by 6.30am I will be back by 1pm because the treatment wasn't up to standard and the condition comes back the next day but

When you talk to him you will feel like he has a mental problem, you can talk to him and he stares at you but for me I understand him more than himself even the dad knows that, so he wants to be guided slowly for him to understand what you are saying even the teacher understands that.

I: Okay. What can be done to make the public more aware about epilepsy and its risk factors? A while back you said not many people know and understand him, so what can be done for more people to be able or to know what causes epilepsy and also to know about epilepsy?

R: For now, those who live around us can know because when he sits alone you can see how he is seated silently staring and when you watch him well you will know he has this condition that has affected his mental state and sometimes he's seated silently.

I: What can be done to those who have no information to at least be aware in the community because you said those who know are the ones who live next to you?

R: Those who don't know, can be told someone has this condition, doesn't like noise, the things he doesn't like and such.

I: Who will be telling them that?

R: A parent like me, his mother, I am the one who is with him and spends time with him in the house and at school, he is with the teacher but when he comes back you can never know what is going on with the child.

I: And other people outside, you know your child might be with it--

R: Other people out here know he has this condition, like the person who sent me here knows, there was a time he fell in the field and he saw him. That's when we called the herbalist who gave him medicine, slept for hours and woke up.

I: A while back you mentioned people look down upon others so much?

R: Yeah, there are those who look down upon others.

I: So, such people, you can find out it's because they don't understand the causes of such things. What can be done so that they stop disregarding others and be able to understand these things?

R: Such people are parents like me and it's because they don't understand this one has epilepsy so what I can do to make them understand; I will tell them my child has a certain condition so if you call him don't shout at him sometimes he stares and if you call him he will be shocked and when he is shaken he falls down

I: Okay so maybe a parent who has a child with such a condition can talk to them?

R: Yeah

I: Okay let's check out the last question in our conversation, please tell me how people who live with epilepsy can be supported towards care and living a quality life. What do you think people living with epilepsy can be supported with to help them live a quality life and care?

R: These people who have this condition can as well receive good quality treatment so that they get well and be like other ordinary people.

I: They get good treatment, is there any other--

R: No.

I: That you feel they can be supported with? Okay so we have come to the end of our conversation, I don't know if you have any question or anything to add to this conversation.

R: Now my question is this, so when he falls how he falls and takes hours until you think the child has died, how can we help him? You see, because he falls and takes hours, the child can fall at 7am in the morning and wakes up at 6.30pm so you see he has taken hours?

I: Yes

R: So how can he be helped?

I: What I can tell you is, when you take him to the hospital, you said you take him to Hospital X, yeah, so when you visit there, you inform the Doctor of such incidents that your child falls--

R: I even told the doctor.

I: What did he tell you?

R: I have asked this question, this is the second time, you see when he fell and we took him with the class teacher. I asked after he was being treated, the doctor said that he will patiently look into it to see how he can be helped. When he falls like that, I don't rush to

wake him up. I give him time for the memory to recover, so when he falls, I just let him be until he wakes up. I look at how confused he is.

I: This is a Doctor who had assessed and treated him so as he instructed you to, let him be for a while until he wakes up and you be patient with him due to that confusion you were told, okay?

R: Okay.

I: Do you have any other questions?

R: No, I don't.

I: We thank you so much for talking to us and we pray next time he will be okay and he will feel better.

I don't know if my colleague has anything to add on?

I2: There are two questions I would like you to answer as I was following on when you were talking, you said that you take the child to Hospital X and you also use herbal medicines, where do you get these herbal medicines?

R: I get these herbal medicines from my third sister in law who uses these herbal medicines, so when he sees the child fall, he comes with the herbs and uses it on this boy.

I2: And where does your sister in law get the herbs from?

R: She gets it from the village and comes with it to Nairobi and uses it. She has tried to use it so that the child can recover a little bit. This condition started when he was in class six. The condition has been rampant while in class seven it worsened.

I2: So, are the herbs drunk or applied or what are they for?

R: It's for drinking and the other one for pouring on the nose.

I2: Does she come with them ready-made?

R: Yeah, she comes with them ready made.

I2: Okay, also there is a time in our conversation when we asked what can be done or how can people be educated about epilepsy and you said you as a parent, you are the one person who tells neighbors that this child is not hearing well and if it's at school, if I got you well you said that the teacher usually tells other pupils that he has this condition, you also said that there is someone who told you to come here, who is that?

R: He is called. [*mentions a name*]

I2: Who is the person in the community?

R: I don't know he just told me his name and also visits those who have such a condition.

I2: He is someone who visits those people with this condition?

R: Yeah, it's him

I2: That's what I wanted know who he is or what he does,

R: He visits them as he writes these names.

I2: Okay, thank you. it's only that.

I: Okay, we appreciate talking to you, have a good day and we pray for you everything will be well. Bye

[End of audio]

