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**I: This is an IDI for a caregiver for persons living with epilepsy, thank you very much. How do people in this community refer to epilepsy?**

R: People in this community refer epilepsy as people who fall down or people who have been possessed by demons

**I: Mostly which group uses these names?**

R: Youths, and the men.

**I: Are you aware of the reasons why they use these names and what does this name refers to**

R: The reason as to why they use these names to refer to epilepsy is because of what they observe when people fall down due to epilepsy and how they behave. this is the reason why they say that you are possessed with demons

**I: Okay; How do you understand epilepsy?**

R: I understand epilepsy since my sister is epileptic and therefore, I know that epilepsy is there. I also suspect that my husband is epileptic and also my other sister used to fall sometimes. I know a number of people in my family that are epileptic.

**I: How would you know that someone is epileptic?**

R: There are different types of epilepsy, I used to think that to be epileptic one must fall down and urinate on themselves, vomit or bite their tongue but now I know there is epilepsy that sometimes I observe in my house where one might just be staring at one place for a long time before they get back to normal again. My son used to fall down and stay for a long time before he gets back to normal. Also my younger daughter has not yet been tested but sometimes she stares at one place and when sick she will be having

abnormal hands movements, she shakes one hand for long the first time she did that, I did not understand what was happening and when I gave her the medication it just came out and people would think she is dying and after some time she comes back to normal. Therefore, I know there are different types of epilepsy but I cannot specify that this is epilepsy before they are able to do tests in the hospital and confirm.

**I: What are the signs and symptoms of epilepsy?**

R: You must first go to the hospital for confirmation since you can't look at someone and conclude that they are epileptic.

**I: You said that you know a number of people living with epilepsy and have lived with them most of which you said are your family members, mostly what indicates that someone is having an epileptic moment?**

R: Most of them faint, takes some time and also will have characters such as staring at a place, falling down and rolling and sometime will have saliva gushing from the mouth but later will be okay after sometime. When you ask them, they just tell you that they are okay. So probably they are suffering from epilepsy and it is only that they have not gone for a test.

**I: You mentioned that you know different types of epilepsy, kindly tell me and if you have a different name that you use to refer to them.**

R: I just know two: one is called seizures and the other one is called epileptic. Those are the ones that I know.

**I: And do you know the characters that are usually related to that specific disease like the one you mentioned**

R: The difference is that some will just stare at a specific place and some will be having abnormal movements of hands like throwing hands. Some of them, you will realize from the eyes because they look like they are not able to see well or they look sick. Sometimes, some of them will tell you that they feel like one side of their body is dead and that they cannot move it.

**I: According to you what causes epilepsy**

R: According to me, I understand that epilepsy is caused by genetics meaning that it is in your blood and it is transferred from one generation to the other. Also, some of them are caused by the time one is born, if they did not cry on time when they were born it might cause an air block in their brain and they have epilepsy. Also, when people keep on fainting it can cause epilepsy since it will block the veins in the brain and prevent blood from flowing.

**I: Are there any other causes of epilepsy**

R: The other one is when you're given medication that do not help your body, or an injection that will not go well with your system.

**I: Are there any psychosocial factors that causes epilepsy be it religious or traditional?**

R: People believe that it's contagious but I do not believe in that. Some say that when someone is epileptic and then you get to touch their urine it is believed that you will also be infected with epilepsy. Also, if you are trying to help them not to bite their tongue and you get to touch their saliva, you are likely to have epilepsy

**I: Okay; so, people believe that you can get epilepsy from helping an epileptic patient?**

R: Yes, that when you're helping them and get to be in touch with the fluids that they're producing, you're likely to get epilepsy.

**I: Do you know any other beliefs that people talk about relating to causes of epilepsy?**

R: Some people also say that you have been bewitched and then someone has pushed epilepsy to you, or that you stole someone's items and they caused you to have epilepsy. Also, if you are given a name that belongs to someone who had epilepsy, it is believed that you will also be epileptic. Also, if you did not follow some traditional guidelines you are also believed to have epilepsy and until you fulfil the traditional requirements, that is when epilepsy will leave.

**I: Especially which kind of tradition do they believe that if you don't fulfil them you will be epileptic?**

R: Mostly if you're married somewhere and you do not take the children to be shaved in their traditional home, that will cause epilepsy.

**I: Okay, personally what do you believe about epilepsy**

R: The ones that I personally believe causes epilepsy is, as I told you genetic factors as well as when someone is born and they are not able to cry at the first few minutes, it will affect their brain and will have epilepsy. Also, I believe when you receive an injection that is not supposed to be in your body you will have epilepsy. There are also other diseases like malaria and meningitis which might cause someone to have epilepsy.

**I: I would like you to tell me how epilepsy affects the life of a person living with epilepsy**

R: Epilepsy affects the individuals in different ways for example when one falls near people, individuals who do not want to be related to that person or sit together because they think that the individual will infect them with epilepsy, their self-esteem will also go down and if they are employed, they are likely to lose their jobs. Therefore, it depends with the environment you're living in and if you are living in an environment where people do not know how epilepsy is caused and you have a child your neighbors would not want their children to play with your child and they advise them to stay away to avoid being infected with epilepsy. Even when they are adults, people will not want to hire them and even after the employer realizes that they are epileptic, they will be fired. Also, for the ladies if you're married and you did not reveal it to your husband that you are epileptic, when your husband realizes that you are epileptic, they are most likely to leave you. Therefore, epilepsy affects the lives of the individuals a lot.

**I: Now that you have told me the effects of epilepsy on a person, having lived with a child who is epileptic, what are some of the effects of epilepsy to that child?**

R: First of all, most people do not understand him they sideline him and some that want to be with him are the ones that are just showing me because I'm there, but when I am away, they will keep on sidelining him and also advise their children to keep away from my child to avoid them being infected. Another challenge that my child faces is that he lacks fatherly love because when the father realized that he was epileptic, he said that it came from my family. Therefore, they are not able to find someone who will love them unless

I decide to get married as well and find someone who will be able to appreciate the child after I explain the situation. His real father refused him due to his condition.

**I: Okay; So, for now he does not live with his father?**

R: Yes.

**I: What about in school how does epilepsy affect him?**

R: It has affected him in school because he used to fall down for a very long time and this affected his brain, and he does not understand anything in class since it's just that we have been pushing that he continues to school with other students but even if you were to tell him to write his name he will not be capable, therefore they are not able to process a lot of information. Also, when he is having an epileptic moment, he usually urinates on himself and therefore you find that other children will be laughing at him. They will even call him names and relate it to how he urinates on himself. But I understand too this is not normal to him because most times if he wants to urinate he will tell me but when he is in school and he has this epileptic moment he will not be able to control himself. It has affected him since his self-esteem has dropped a lot, also other children will not want to stay near him because he will be smelling urine. I am not able to tell the teacher that when he has urinated on himself to be changed and therefore every child will not want to be near him due to the fact that he is smelling.

**I: Okay so those are the factors that affect a child from suffering from epilepsy?**

R: Yes.

**I: As a parent who has a child who is epileptic how does it affect you?**

R: For me as a parent, number one to manage epilepsy is not easy and I have not found anywhere medication that can cure epilepsy, if I could find a place that I can get a medication that will cure him I would. This is something that drains you, since he needs medication all the time which you have to buy from the few monies you get. Sometimes you get to question yourself if you should buy medication or food. Sometimes you even have the medications and you forget to give him and he cannot give himself medication he cannot remember. Also, the more you don't follow medication, when you go back to the clinic you realize that this has affected the child. Also, as a mother your self-esteem will go down because sometimes you feel exhausted like for example my child is thirteen years but I still take care of him like a little child.

**I: You told me that you buy medication, so does he have a regular clinic day?**

R: He usually goes to the clinic after every month, before he was diagnosed with epilepsy, I did not know that this was epilepsy I used to buy medication where I want and did not know that it was supposed to be a follow-up medication. I used to take him to hospital all the time when he had an epileptic moment and they will just treat him and after sometimes he will be back to normal and I will have spent a lot since the hospital they will still charge you. Also, the fact that they usually give him one-month medication will also drain you because it's not like one year where you don't have to go all the time. Also, when you are working it is not possible to seek permission every month that you are going to hospital and people will not understand you.

**I: You told me that people in your community will sideline you because of being epileptic would you tell me why?**

R: The reason why people will sideline you it is because of the fear that they will be infected with epilepsy.

**I: How do you usually feel as a parent taking care of your child who is epileptic**

R: This will also affect you because you get to be aware that this child will depend on you forever and that you have to be there. When they are having an epileptic moment, you have to be there and be very careful because they might fall on fire, oil or water. Therefore, whenever you are, you are never settled because you wonder where they are and if they will fall in a dangerous place because it does not have schedules and therefore it needs 24 hours' care.

**I: Apart from you as a parent who has epilepsy affected other family members**

R: The ones I'm living with I don't think they are affected because they do understand him, my family members too understand him but the problem is the neighbors and where he goes to school but so far, the people we are leaving with in the house understand his situation and condition.

**I: How about issues like stress or any emotional problems?**

R: It has affected his brother because he has dropped his scores at school. Most of the time, I tell him that instead of going to study he observes his brother even when his brother steps out of the house, he has to follow him so that he keeps an eye on him, but since I took him to boarding school, he is no longer being affected. Others are not highly affected but sometimes they feel bad washing his clothes.

**I: Okay for now do you live with other family members apart from your children?**

R: I also live with my sister, apart from my children.

**I: And have they been affected in any way?**

R: No, she has not been affected.

**I: Where does your child go for medication or clinics?**

R: Health Facility K.

**I: Does he has specific medication that he uses?**

R: Yes, he has his own medications that he has been prescribed.

**I: Are you usually satisfied with the services that you get from the hospital?**

R: At least nowadays I'm able to get satisfied because before, I used to go to a different hospital and I realized that there was no change and that is when I changed to different hospital where I was also not satisfied because they started taking me to the mental hospital and that is when I went to Health Facility K. For Health Facility K, you're able to get the services you want but the problem that they have is that before you get the service it is very hectic.

**I: In what manner is it hectic?**

R: When you arrive, you are told that by six o'clock (6:00 am) you are supposed to be at the hospital so that you are given a number which allows you to see the doctor for treatment. When you try and get there by Six O'clock (6:00 am) so that you are among the first people to see the doctor; you get to see him at Twelve O'clock (12:00 noon). This becomes an inconvenience because if you had sought permission from your workplace, thinking that

you will be at the hospital by Five O'clock (5:00 am); get the service and be able to get to work on time, you are unable to...Also, when you go for monthly visit's consultations, there are charges. It is not that you get there, see the doctor and a prescription is issued. There is a fee charged... When you pay the amount KES. 650.00 (Six hundred and fifty Kenya shillings), thinking that it also covers drugs, no medication is issued. Instead you are given the prescription and you get them from the hospital pharmacy at a cost. It would be best if drugs were covered in the KES. 650.00 (Six hundred and fifty Kenya shillings).

**I: Okay. So, in your opinion, epilepsy treatment is too costly.**

R: Yeah. It is too expensive.

**I: In the community, at home or in the village, are people aware of a place where they can take a child in case of a condition such as yours or a family member who is epileptic to seek treatment?**

R: They don't...There is a friend of mine with a child who is epileptic and has CP. She keeps on taking her child to a hospital back in the village because the first medication was issued there therefore, she believes in their services. Recently I tried to talk her into taking the child to Health Facility K but she objected, her reason was that she has to take the child back to the village hospital. I don't even know which hospital it is.

**I: Which reasons did she give as to why she has to go back in the village and not here?**

R: First of all, she is not aware that the child is epileptic she keeps on persisting that the child has CP. By looking at the child; 50 - 90 percent of the symptoms are for an epileptic person. Because the mother does not want to acknowledge that. She says the child only suffers from CP.

**I: You already mentioned several challenges you go through when seeking treatment for your child. Do you know of other challenges epileptic people go through when seeking medical services?**

R: Apart from the one in hospitals. It would be better if there was a clear classification in the hospitals. Specifying that these doctors are for epileptic person and not having to combine patients for example you get people suffering from epilepsy and so on seeing one doctor.

In Health Facility K, it is only labelled as mental health therefore, when I ask for example you to take me there and you see that I'm taking my child to mental; your conclusion will be that my child is mentally unwell. Another challenge is that people are unaware of epilepsy. For example; if a child is epileptic and you begin to tell them that they have an epileptic condition, they don't even know what it is. Beginning to narrate to people that a child has a certain condition; you find that it is hard because the disabilities they are familiar with are the physical ones (one being lame or without a hand). You find that they are unaware that being epileptic makes one disabled in one way or the other...

**I: That's true...**

R: Many people are not aware and this becomes a challenge because you are not in a position to go telling everyone that your child is epileptic and therefore, they are supposed to help them in this or that manner when they fall. I come across crowds on the side of roads, surrounding a person who has fallen down, the crowd keeps on getting bigger and limiting the person of the oxygen they need. You see...If everyone was well informed about epileptic condition and how to deal with persons suffering from it, they

wouldn't be surrounding the person and instead would be giving them the first aid they need.

There are instances where people give epileptic persons the first aid they require, when they get up and see that the progress is well, they assume that these people were faking it.

Others even begin to converse that bad omen has befallen over these people. Many people have never understood epilepsy and therefore, it becomes very hard for an epileptic person to inform them of the condition.

**I: Earlier you had mentioned that people are unaware of the places to seek treatment for epilepsy. What are the challenges that make people unaware?**

**Why are people unaware of places to seek treatment?**

R: Because it has never been advertised. No posters are made to inform people. Corona posters were placed everywhere. When there is treatment for example in Mareba, posters indicating Corona-Mareba is enough for people to understand. Epilepsy has never been given such a thing. Yes...

**I: So, you are saying that lack of publicized materials is one of the factors affecting it?**

R: Yes.

**I: The government don't inform people?**

R: Yeah. They don't inform people. They are to make people aware of the epilepsy condition, when people have the information, there is no way that they...

When people are educated that epilepsy is not transmitted through air or coming into contact with a person suffering from the condition and one gets an epileptic person

having tumbled on a stone, they are in a position to help them. Due to lack of education, people are fearful and hence don't help these people.

**I: Okay. What are other challenges that make people unaware?**

R: Apart from advertisements, many people like keeping it a secret. People don't want to be exposed. Some people are courageous- and you find that a person suffering from HIV/AIDS may tell another that they have been suffering from the disease for a certain period of years. An epileptic person may not tell because unless you see them fall down it is hard for one to tell if they have the condition. This becomes a challenge because they are not able to educate others on the condition and its effects.

**I: Apart from the hospital being far and being too expensive. What other challenges affect people when seeking treatment for epilepsy?**

R: Epilepsy drugs are misused. People say that the drug is used to treat other conditions or manufacture of some things therefore, nowadays when your dose is over and you go seeking another one in a pharmacy despite you being sure of the name, they can't issue you with one unless you have the doctor's prescription. And maybe your medication ended today and you have not been able to get others or when you went to the clinic and you got a prescription for 30 days' medication and you are able to buy only medication maybe for a week the person at the pharmacy will indicate that you have received the medication and therefore when you go back to get other medication you will not be able to purchase because you will be told you need another prescription. When you go to the hospital, they cannot give you another prescription because they still believe that you

have a 1-month drug. This is because people use it to treat other things and also miss use it in a lot of ways and therefore it is hard to get the medication

**I: What are some of the things all drugs that are made with this medication oil used to treat?**

R: They say that the epileptic medications are used to make this alcoholic brew that we have and also it is used as a drug to sensitize the mind.

**I: Okay, what are some of the other challenges that one will experience when trying to get epileptic medications?**

R: Another problem is that the medications are usually hard to get especially here in the local facilities or in the village, therefore you might have the money but you have to go very far to get the medications which will cost you in terms of transport.

**I: And do other people know these medications can be found in this chemist?**

R: You cannot know where to buy these medications, like for me, when I'm looking for the medications I usually go looking at the local facilities but the problem is that I am usually sure that I will not find them, also there are others who have the medications but will refuse to sell them to you.

**I: Okay, how about financially?**

R: Epileptic medications are very expensive like for example one medication for 500 grams is 50 shillings and the price has gone up to 75 shillings, so if you're a hustler like me you

get the money and then wonder if you should buy medication or food and when you decide for food the child will miss his dose.

**I: You had told me about the number of things that can be done to publicize epilepsy to the common people in the village like advertisements as it is being done for Corona and HIV what are some of the things that can be done on epilepsy?**

R: People should be educated for example the way they have done it to publicize coronavirus. They have included it in the syllabus. It is available everywhere like posters even as you're walking along the road. We also have it in the radios. Also, near the hospitals they have posters to publicize the disease.

**I: In this community have you ever seen like a medical camp focused on epilepsy or a home visit like from the CHVS who wanted to talk about epilepsy to you?**

R: I have never seen a medical camp on epilepsy, the CHVS usually come to the homes just to ask questions but when you even ask them how it will help you, they tell you it will be used to make policies.

**I: So, you have not received any epileptic service anywhere else**

R: yes

**I: How can people living with epilepsy be supported?**

R: I would say that for those who are using the medications, they can actually pay for their medication if possible, which will be very good. Also, they can make it easy to access the medication since you might have money but accessing the medication is a problem. We

also educate them so that they are able to accept themselves and know that they have epilepsy. For example, my son is taking the medication because he does not know what they are for. I'm afraid that when he gets older and notices what they are for he might refuse to take the medication. Therefore, they should be educated and also get to know the sources of epilepsy and also get to know individual cases where they got the epilepsy from therefore counselling will be important so that they can get an explanation if this is a disease that they are going to cure or how they will manage for example for me I always say if I was to get a medication that I can give to my son even if it was to cost a million, I would pay just to see him well. All they say is that they are managing, you will be getting his medication but not cure. If they can also come up with a vaccine that one can be given to avoid getting epilepsy like we have for some other diseases. Also, if it can be detected early enough and if possible treat it at this first stage. They should be able to sensitize the public because this is a disease that is there and we have to live with it. They can also try to make the medication simple to take the way we have one for malaria where you just take one medication, even if it was to be expensive and you swallow it once it will be better but for this one it is expensive and you keep on taking daily. The lifetime medication should be cheap because these are things you have to buy every day.

**I: Thank you very much I don't know if my partner here has something to add**

**I2: You have told us the problems that your son goes through because of having epilepsy, what are some of the things your son cannot do because of having epilepsy?**

R: Apart from epilepsy my son also has a different problem because I think when he was born that is when he had epilepsy. For example, he has delayed milestones, therefore

most of the things he cannot do them for himself and I have to keep on doing simple things like washing him and changing his clothes. Sometimes he can dress but I have to choose the clothes he will wear and monitor how he's wearing them. If it is school, I have to prepare him and have to tell him that he's going to school. Therefore, almost everything he depends on me the only thing he can do is be able to sit and eat by himself but if you ask him to prepare maybe a cup of tea, he will not be able to do it because he does not know even a simple thing like opening a door, he does not know what it is.

**I: Okay thank you very much we have come to an end of our interview. Thank you so much.**

.....*The End*.....