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I: **How are you again, as we start?**

R: I am fine thank you…and you?

I: **I am fine thank you too. Feel free to be part of this discussion, and say anything that you may be comfortable to share.**

R: Okay…

I: **In your opinion, what do you think causes epilepsy?**

R: Epilepsy can be caused at times by stress, too much stress, maybe because you don't have a job, staying idle…

I: **Apart from stress and staying idle, what else do you think causes epilepsy?**

R: I don't think there is.

I: **Where did you learn about those causes of epilepsy?**

R: Before I got the accident I didn't know anything about the illness, but after I went to hospital, it's when the doctors said the symptoms I have are for epilepsy. They advised I avoid stress, so I think this is what causes epilepsy

I: **I know you had explained to me before we started recording the discussion, how you were involved in an accident, but for someone hearing you talk about the accident, they don't know which accident you are referring to. Kindly if you don't mind, you can tell us how it was?**

R: Okay…it was in 2009, while I was still in high school Form 3 that I was shot. It was a stray bullet, no one knew where it came from, since I was in the house, revising. You know these villages, and the houses we live in are made of iron sheets, I didn't even know what had happened to me, I just fell and was unconscious, and people thought it was electric shock in the house, but when I was taken to

hospital, had an x-ray, it was when they realized I had a bullet in the head. They also said it cannot be removed, as it was in the memory place, and this is why I sometimes lose my memory, I cannot recall many things. I also get very angry, and I urinate on myself. They said I have epilepsy, and I should try not to stress myself, I be free, avoid anger. Be staying around other people to avoid feeling stressed up, or getting angry,
because I get headaches when I am angry.

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

R: I think medicine is the only solution, but also don't be alone, wherever you are, be surrounded by people to avoid stress, be friendly to all, eat your food well,
in the evening you go to rest. I have also noticed the illness will develop if you don't have a job, or you had an accident like me. I used to work, but now I lost my job due the attacks I would get and fall down, and I become unconscious.

I: **Is there anything else can that prevent people from developing the illness apart from the drugs and avoiding stress.**

R: I don't see any other.

I: **Please describe to me how you came to learn that you had epilepsy?**

R: Before I had the accident, I had never had any spell of falling down. Since the bullet hit me, there are times I just find myself down and even urinate on myself. I started going to Health Facility K for clinics
and again they told me that the bullet had moved inside

the head and I used to faint once in a month before now I started fainting more frequently.

I: **Is there anything else you might like to add, forgotten to Mention?**

R: I get a lot of headaches, vomiting a lot, and the doctors told me there is nothing they can do, but they said I can be taking painkillers from the shop when I have headache, so I get panadols when I get headaches.

I: **What are some of the names used in this community to refer to epilepsy?**

R: They use that epilepsy, most people just use that.

I: **Do you think the society understands the causes of epilepsy?**

R: Surely many didn’t know, but nowadays…like yesterday there is this child who has the condition, like in the morning he is okay, the next minute he falls down, so already people know that it's epilepsy. They have come to know due to the several cases we have in the community.

I: **Do you think they understand the causes?**

R: No… I think what they know is just like when I fall down they make sure I get enough air, through fanning, they say it’s just the normal fainting, that I will get up after a while, only that.

I: **What would you say about the awareness, knowledge of members of your community, regarding how to manage epilepsy? I know you have told me about them fanning and putting you in a cool place.**

R: On that, what I can ask to all those who are far, is that they know this illness, the only solution is that people, whoever is near should come together help each other and say that since this person has this condition, let’s help, stick together and see how we can help, they assist where and how they can on this problem.

I: While we are still there, on the awareness, what do you think about the level of support that the members of your community, given to people living with epilepsy?

R: They tell me to avoid staying under the sun, and it is good since sweating too much is not good, stay somewhere cool and don’t walk too much, be friendly to all people.

(noise in the background)

I: How is the level of support that they give?

R: It’s not bad because when they see that I have fallen down, immediately they pick me up, take me inside the house to cool me, they fan me. They even give me cold milk, to drink. They also give me advise that I should not go out, to stay in one place and rest. There are drugs that I take to prevent fainting and they are strong, so I have to eat first before I take them, since they are strong.

I: I have heard there are those who carry you when you fall, and even give you milk to drink, are there others who behaves differently towards you, due to your condition?

R: There are those who just say that the illness has no cure, they say I stay free of stress, but in this world there are a lot of problems. All I do is stay close to my family, because this illness can attack me anytime. Keep stress away from yourself.

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

R: Some say that I fall down because I don’t have a job, but that’s not possible, because everything is the will of God. But I feel it’s just because of the stress that causes all this.

I: Apart from the opinion of you not having a job because of this condition is there anything else they say that is not true about epilepsy?

R: Yes…there are some who abuse drugs, that there are bad drugs if abused like bhang, someone was normal then all over sudden they change…

I: You said which drugs?

R: These drugs that are not good, like bhang, other drugs that I see the youth using, and that’s why you don’t find me with them. The youths of this generation are now getting lost. Someone starts to eat miraa or abusing those small drugs, and that’s why you see they think you can reduce the stress with miraa or those drugs,within no time you lose network. There are very many in our community who have lost this way.

I: So they advise you to take the drugs to reduce the stress of your condition?

R: Yes, many say that but I don’t think it’s true.
There is no way when I am stressed about my condition, that if I take miraa I will reduce my stress, that’s not true.
The only solution is to avoid stress, and when stressed do not stay alone, that’s all.

I: Are there people who behave negatively towards you due to your condition?

R: No there aren't any, I have never seen anyone treating me badly.

I: And is there any other misconceptions, apart from that you abuse drugs to reduce the stress of your condition, or that you do not have a job because of the condition?

R: Yes, just like the way they say that if they use those drugs, they are not stressed…those are lies. I will not have stress, or that I will not have the condition if I take miraa, that I will be okay. Many people say that I should just eat miraa, to avoid stress, that's a lie. That's leading me astray so that I become worse than this or even go mad.

I: Is there any other?

R: No, only that on drug abuse, miraa, bhang. Someone you knew was normal starts to lose network, and even start collecting papers, while you think it's stress but its due to the drug abuse of bhang and others. They say that such a person has epilepsy, but I cannot believe this is due to the drugs he used that caused that effect.

I: What do you think can done to make the public more aware about epilepsy, and its factors?

R: In my opinion, that would be like giving education, sit down with people who are knowledgeable on the topic, its causes, how to assist any family member with the condition, not to leave them in the house, try to unite with others and see where we can assist each other. We help each other, we talk about our problem.

I: **And who is this that would be giving the education, on awareness?**

R: It can be one of the person that has the condition, and experienced it, maybe they went to school to learn more on the condition, then comes to the community where there are people with the condition, and bring them together to talk to them. Tell them this is not a disease, give them advice on what medication to use, if he hears there is a project where people need to be interviewed so that they can be helped like with medicine, or any other way people with the condition can be helped. Families in that area can come together and find out what the problem is, and when one of us is coming to educate us on the same we go and listen so that we understand.

I: **Apart from this person who has experienced the condition, is there anyone else that can give the education?**

R: I think it’s just that one, since there are those that experienced and still went ahead to learn more on the condition, went and did a course. He knows step by step about the condition, and he already knows all about it as he is among the people with condition or another one just experienced this for some years and knows the solutions, decides if he is to go back to the community he can create awareness.

I: **Why is it important we listen to that person who has experienced the condition? I know you might be mentioning it in your explanation, but please tell us…**

R: It's important because for someone who has experienced, like now me what I have gone through, I didn't learn from them, but since I began to fall ill, I am able to learn from others who have experienced the condition. My friends can come and tell me that their cousins were going through similar conditions. They tell me that the solution is to avoid stress, stay in a cool place. So my reprieve is what people tell me.

I: Is there any other thing, apart from us learning from those people who have experienced the conditions?

R: Its possible, because that person who creates awareness, and people learn from him, those people can also in turn help since they already know the signs, like fainting, falling down, losing consciousness, and if they are in the community, and they come across such signs in a person falling down, they can fan them, help them, take them in a cool place. So by that learning from a person who experienced it, we are able to help once we find a person who has the same condition.

I: Is there any other way?

R: I don't think there is, it's all that I have said.

I: Okay, thank you for that. Please tell me what has been your experience living with epilepsy?

R: I have lived with the condition, and it has been disturbing me.

I: How, can you please tell me more?

R: I lose consciousness, get headaches, and lose sense of taste. I ask myself what the problem is, no taste for water, food, and when I get these signs I don't leave the house. I can faint even while I am sleeping, and it happens most of the time. When I wake up, I have aches all over the body, all my veins are aching. That's when I take painkillers because of the pain in the body, and that's when I know I fainted while I was asleep. In a normal day, I sleep well, I am healthy. In the evening at times, when I eat and sleep I am not aware of myself. I just wake in the morning to find I urinated on myself while I was unconscious. So I got the attack in my sleep, when I wake up my hands, veins, body are aching, and I take painkillers.

I: **What effect does the condition have on your life now?**

R: This condition by the way, has affected me because like now I don't have a job, I used to work as a guard in one of the companies, and a colleague of mine in the workplace who was from another community did not know my condition. When I tried to tell him, he failed to understand me.

I used to do patrols away from the gates, and I would fall down only to wake up later to find my whole body is dusty, and that's when I would realize I got the attack. So I lost hope in my work, since the place was far, there are animals on the way, vehicles, motorbikes. I might fall on my way, since the attack can come at any time, unknown people would pick me in the morning from work, put me on a motorbike; people who just used to see me using that route, after I gain consciousness, and they ask where I live. That time I would have bitten my tongue, they fan me, I would tell them I live in Korogocho near the mosque and I am rushed home.

Its almost 1 year since I left my work place. I lost the job due to the attacks that had become many. I would lose network, I bite my tongue, so I was forced to stay in my village. I don’t go anywhere.

I Okay…

R: I need to take care of my child, he needs milk, if I need to work in a night shift in the company where I worked, I might get the attack on the way where there are vehicles this made me afraid and just quit. So I am just in the village, doing small jobs here and there, doing decorations in people’s houses, using sacks. In construction work I am a handyman, when I am doing fine and those other jobs that are not difficult.

I: Okay, thank you for that, I have heard that one of the difficult thing for you is going to work since you can fall on the road, what other activities has epilepsy made it difficult for you?

R: I have been advised not to do difficult work, like those in construction sites…

I: Why have you been told not to work in the construction site?

R: Because of the strength needed to do that work, it will affect you, don’t do difficult tasks, just engage in light tasks, since that difficult task will make your body ache, and it will trigger your condition. To me I got afraid, and that’s why I don’t do difficult jobs. I was told by my colleagues who I work with that it can affect me.

I: What other ways has it affected you? you told me that you cannot go to work, cannot do difficult jobs, any other

way?

R: I think that’s all.

I: **Thank you…and how does it affect your interaction with your family?**

R: In fact now with my family, I have remained in the family, they understand my situation, before I would sleep during the day, and leave for work at around 5 p.m., but now you see I am back home due to the illness. They understood that I can no longer work, it's not my fault that I am in this condition, so they cannot leave me alone. My wife left me because of the condition, I had one daughter, she took her from me but my aunty takes cares of my daughter since I lost both of my parents. My uncle and my aunt are now like my parents, they help me and even take care of my daughter. When I do the small jobs like I told you, doing decorations in people’s houses with sacks here in the village, and I get 300 or 400, that’s what I take to buy milk for my daughter.

I: **I Heard you mention a word that your wife, ‘‘*alikutoka*’’ Please explain what you mean?**

R: In this condition, my wife just decided to leave. We didn’t have any problem between us, it was just the mother who decided to take my wife away, because of the situation. My wife had never gone hungry while in my house, and since she left me, and also being idle, I have been more stressed. Taking care of my daughter needs like providing her milk, so all these problems are affecting me.

I: **She left because of your condition?**

R: Yes.

I: What about your friends? How have you been interacting with them?

R: With my friends, the ones I stay close to, and they come to my house at times and they know my condition, they guard me…

I: You said they guard you?

R They keep me busy in the house so that I don't get stressed. We sometimes just stay in the house, resting, when it's time for me to sleep, they ask if I am alright, and they too go to sleep, and they leave me to rest. Instead of staying alone, when I am idle I can also go to their place to visit them, spend the day there and in the evening I go back to my place to sleep. So you see the advice my friends give me like not staying alone, going to stay with them, reduces the stress that I might have so that when I go back, I just go to sleep. This is one way I manage my condition.

I: Those are family and friends, what of other people now in the community?

R: Even for them it's like for family and friends, no difference.

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

R: Changes?

I: I mean, how your condition will affect your life in the future?

R: In education or?

I: Just in life, how the condition will affect you in the future?

R: I am hopeful because I have gone through a lot, and with Gods will I can achieve. Since after all that I have gone through, in the future the condition will go away and I will have a new life, and its because of what I have gone through. And if today I am getting friendly advice, I know I will have a change even in my body, I go back to work, and I also plan for the future.

I: **What hope do you have with your family in the future?**

R: I am hopeful that I will get well, the condition will leave me, and God will help me. The condition is just a challenge we are going through in this world, but in the coming years I know I will have changes, even in the family.

I: **What changes will there be in the family?**

R: Even in the family, they told me to be hopeful. They mostly give me advice. They say that I will get well, and also my friends tell me the same. They say even if I face the problems, at least I have friends and family, that whatever I want I will get, and even go back to working, and that I will start my life again. That’s how I get hope from family and friends.

I: **What effect does this have on family and friends?**

R: In fact this time, I have remained with my family, despite some people saying that I don’t have anywhere to go, but my family is there for me. They understand my condition, and are hopeful that a day will come when I will go back to working again, and that’s why they are with me. My aunties and uncles, and cousins, I live with them.

I: **And what about to your friends, what effect will it have**

on them?

R: In the future if I succeed, for all that I have gone through I can help others, who may be going through what I have gone through. In the future I can help the coming generation, on my own will.

I: What effects on personal life, career in the future?

R: Because of what I have gone through, if I get well and my life goes back to normal, the community I live in, if a person gets that condition, I will sit with them advice them accordingly, and explain to them on how they can be helped.

I: Which is the most pressing concern you have as a person living with epilepsy?

R: Can you make me understand this?

I: What would you say is your concern as a person living with epilepsy?

I2: Your fears…or anything that makes you worry…

R: For me, my worries, when Iam just bored in the house just, I start seeing things, and I run away.

I: What things do you see?

R: I just see things, and you wonder what's wrong today with me, I start imagining things, in my mind, as if someone is after me, or as if I want to go mad, someone wants to kill me, you just see things that I don't know what to call them. At times I see things…like the other day while I was in the house, I was almost fainting, I felt sleepy and suddenly I ran out of the house, and went and spent the night in my aunt’s place. Luckily where I stay and my aunt’s place…it used to be a bit far, but I had to move nearer to them, because of my condition.

Therefore, most times when I sleep, they are ready to watch over me or even the neighbors when they know I am asleep; they listen since I make noise when I bite my tongue, they go and wake my uncle and aunt, they tell them "it seems today he has an attack". They break the door, remove me from the bed and they fan me for fresh air, and there I regain my consciousness. So that's how it's been.

I: Apart from the concern of seeing things, is there any other?

R: No it's only that, the thoughts that make me run away.

I: As we finalize, we are almost finished now, so don't worry. What would you say about care and treatment for epilepsy in this community?

R: That one, is just like I had said, you stay in a cool place, you don't walk in the sun too much, because of the fainting, if the attack comes, drink milk to cool a bit for the mind to open.

I: And how are the care and treatment? Or if I may ask, where Do you seek care and treatment for epilepsy?

R: I am using drugs for epilepsy, and I got them from another place in Jonsaga, a hospital that I had been recommended by a friend who is a neighbor.

I: Is it a government hospital or private?

R: It's a private facility.

I: Do you know the name?

R: The hospital is called…I cannot really recall the name.

I: It's okay then.

R: I have an appointment after every 2 months at the facility. I get drugs, and there is a card that they gave me, so they monitor to find out what how frequent the attacks are because I can just faint once in a month.

I: Are they the ones that gave you the card?

R: Yes.

I: And what is it for?

R: It is for my condition, that I am epileptic. So they give me the medicine that I will be using, and after every 2 months I go back, and they enquire how many times I had attacks. At times, I go on date 1 or 8th,15th, and 20th.So you see at times it is 4 times in a month, so that they check if they will change the medication for me or they add the dosage. For this time the only thing I have is the medicine, and they have given me a lot. It will last up to February of next year, God will. They gave me almost 180-200tablets. They also advised I don't take drugs without eating first, and the good thing is I don't take it day and night. I just take it at night when going to sleep. I must therefore have supper, look for milk and drink then I take the medicine.

I: You said someone took you to the facility or they recommended it to you?

R: Yes it's just another lady who is a neighbor.

I: Is she involved in any health services or?

R: No she is not. It's only that her nephew had a similar condition, but he followed up with the medication and all that until he went back to work. Even for him its just like epilepsy, he had an accident while going to work one day. He met thugs and they beat him in the head with wooden bars. So he also falls down at times when he is just walking, it's the effect of the beating he received. But for him, he is better now, he has gone back to normal.

I: Is there any other place, apart from Jonsaga, that you go for treatment?

R: No I only go to that one. It’s where I go when I have the appointment, they check the card, all those times I had the appointment for the months, if I am supposed to get change of medication or its adding the dose, and they give back the card.

I: What is your opinion regarding the drugs and tests for epilepsy? Availability and costs?

R: For the drugs, if I was to say like where I get mine the medicines are okay, even the price is fair, it’s like 400 to 500 shillings, you pay via Mpesa, and once they test you and know what the problem is, they will advise to you to continue with those drugs, and when it’s time for my appointment they collect my history of several months, and check to see whether they will change the medication, and for the medicine price it’s also fair, they consider our condition.

I: And are the medicines available?

R: Yes they are there, no problem.

I: Apart from the drugs, what about the equipments for testing?

R: They have them, before they give you any drugs… like now for me, when I went there they investigated to see whether what I was saying is true about my accident. They checked all my documents, and confirmed that it was true, that it was a bullet in my head, which was due to an accident and that I had even been taken to Health facility K and I also did not lie to them. They said

I should not be stressed and even reminded me what the doctor at Health facility K had said that I should not be stressed. They also advised me not to watch too much television, avoid using cell phone too much, because the brain of a person is everything, so if you watch too much television, and use cell phone it shocks the memory, yet you have that condition, then you will faint, and fall down. So don't get stressed and don't watch too much television or use cell phones mostly. That's the advice they gave me, and also for the drugs I should not miss. I eat properly, drink milk, and when my my stomach is full, so I can now take the medicine. So that's what I am following to take care of myself.

I: You said they have drugs, and cost is fair, what about the equipment for testing?

R: I think they have them, because the hospital is for the students of university, I don't know the name, but it's in Jonsaga, on that road, you just walk straight there is a big hospital, near those umbrellas, it's a big hospital. And there are those umbrellas for people to sit under.

I: So do they have equipment for testing?

R: Yes they have.

I: I don't know if you have anything you would like to add, regarding all that we have discussed about epilepsy?

R: On this I all can say or ask is we get assistance, we should not be forgotten, the people with this condition, all those who have it wherever they may be, They look after and help each other.

I: Any question, comments?

R: No

I: I don't know if my colleague has any question or clarification?

I2: I would like to ask; I did not get how you learnt you had epilepsy when you were at home? or after you had gone to, Health Facility K mentioned, they told you after the x-ray, or? I did not get that clearly?

R: Now, when I got the accident, and I went to Health Facility K, I stayed and the only report they gave me is to avoid being stressed, so I stayed. After being discharged, I was okay, so one day while Iam just in the village, I started feeling something with me tongue, lost sense of taste, water had no taste, tea was tasting differently, when I went to sleep, in the morning I found I had urinated on myself, then I also bite my tongue. That's when I wondered what's this, and it's when I was told it's the fainting that comes with epilepsy.

I2: Who told you that?

R: It was another girl, she is part of my family, and she also has the same condition. Even the other day, she fell in the house. She is a daughter to my aunty, the mother died, so she lives with a step dad.

I2: That's all I wanted to know, thank you.

I: Okay thank you for your time.

[End of audio]