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I: Thank you for your time and agreeing to be part of this discussion. As we start, could you please tell me some of the names that you know are used in this community to refer to epilepsy?

R: The way this illness started, he got infected with malaria and pneumonia. And so I went to Health facility B...you know Health Facility B? I went there but was referred to Health Facility M. They did a full body checkup and nothing was found. After I started going to the clinic, that's when they said it was epilepsy, and it's just starting.

I: And now, can you tell me the names that are used to refer to epilepsy in this community?

R: For me, they said it was epilepsy. When I went there, I wanted to know which drugs I would use: but in our tradition we do not have epilepsy: but

I heard that when her mother went to give birth, she gave birth on her way to hospital, she fell down, hit her head, and since we didn't follow up, on that incident that's where the problem started.

I: **Okay and now are there any names you know that are used to refer to this illness of epilepsy, in this community?**

R: You know people in korogocho just like to say, 'that person who falls down' or 'an epileptic person'

I: **Is there any other name that they use to refer to people with epilepsy?**

R: 'This is the person with epilepsy, or the one that falls down'

I: **Any other that they use?**

R: I haven't heard any other.

I: **And what is the reason behind the meaning of those names that they use, like the one who falls?**

R: According to them they use those names, to scare others off, so that you don't sit with them or else they will transmit the disease to you...or I am saying something that is bad?

I: **No you haven't said anything bad..**

R: Because that's what they say...

I: **As we continue, what are some of the symptoms that show one does have epilepsy?**

R: They say that they have a headache, starts behaving as if they are mad, speaking to themselves, shaking a lot, screaming, and falling on the ground.

When they fall facing down, you should turn them.

I: When you say you turn them, what do you mean? And why do you do that?

R: If their face is down...I turn them to make the face look up, put a spoon in his mouth, so that he doesn't have difficulty breathing, to give him more air, and to prevent death due to shortness of breath. And also that disease is not good when near water or fire. So when it rains; don't allow them to go outside, or when cooking with firewood, they should not be near the fire place as the attack may happen anytime. But I am thankful there are drugs we are given to prevent quick attacks as it used to be.

I: And when you say during rains, you don't allow them to go outside? What do you mean?

R: You know this illness is just like for a mad person, they will go, walk aimlessly and get an attack, seizure or fall in a pool of water, and before gaining consciousness, they might drown.

I: Apart from the headaches, shaking, screaming and falling down, are there any other symptoms?

R: No.

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

R: When pneumonia gets into the body, and malaria. Also, when that blood is taken to the brain, and it

mixes with water, that's when things become bad, and that's when you see someone has that epilepsy.

I: And apart from that pneumonia and malaria combining with water in the brain, what else causes epilepsy?

R: There are those that are cultural...traditionally, there are people with epilepsy.

I: Tell more about that...tradition or culturally? What you mean?

R: If you have a grandfather, who used to fall down due to epilepsy, then it's automatically that in your lineage there will be a person who gets the disease, or if a person died of the same illness, then it passes trickles down to other generations that follow, but people of long ago didn't know it was epilepsy. But if you pray and confess you can get free from the spirits of epilepsy.

I: You are saying you pray...?

R: Yes, you pray and send away those demons of the illness.

I: Is there any other cause of epilepsy?

R: Yes, if you don't take care of a newborn child when they are still young, and they get exposed to cold, leaving them to play in water, this is a must they get epilepsy.

I: Is there any other cause...maybe spiritual?

R: Yes...people in the old days would say it can be thrown to you from one person to another. Nowadays people are saved, but previously people would believe in witchcraft and claim that there were people who can go to

a witchdoctor for charms, and throw them to others, charms like for epilepsy: are placed on your way, and if you cross the charms, you get epilepsy.

**I: Who are the people that place charms on the way? or
What do You mean?**

R: When they go to a witchdoctor, for treatment of the same, it leaves them and transfers to the person they throw it to, the one who crosses where they placed.

Let me give you a small story...the father of the sick child I take care of, killed someone...the person who was killed used to stay in Ngomogo, this was when the business of bodaboda had just started. They stole the deceased man's motorbike and killed him. During the burial of this guy, it's when they threw those spirits to whoever was involved in the death, and so it fell on this child, he started experiencing the attacks after this incident.

**I: What are some of the effects of epilepsy to those living?
with it?**

R: Epilepsy, if it's from a traditional cause, the one that passes from generation to generation it can be transmitted to other people; but if it's not that one, it cannot be transmitted to other people, in the family. My other son, sleeps on the same bed with the sick boy, yet he hasn't contracted it, because it's not from our ancestors, otherwise he too could have contracted it.

**I: So you mean it can be transmitted from one person to the
other if they share a bed?**

R: Yes... if the sick person starts to throw their legs while he is asleep, and then he urinates, and you are sleeping on the same bed, you also become epileptic.

I: **And now how does epilepsy affect the life of the person living with the condition? What effects does it have on his life?**

R: For this illness you cannot tell how it will be, or what God's plans are, because even the bible tells us that there shall be a time when all kind of illnesses will come and there will be no treatment, and so for me the way I am, I will just ask God to remove this illness from my child.

I: **What are some of the activities that he cannot do, due to this illness?**

R: If you are taking medicine, you can do some work, but if you don't take medicine you cannot do any work. It will prevent you from going to look for a job.

I: **Which activities are these that he is able to do if he takes medicines?**

R: If it's a student, he can go to school if he takes medicine, but if you haven't known about the medicine, you may go out and fall down on the road.

I: **And what are the activities that he cannot do?**

R: He cannot go to school, because if he goes, there is a lot of discrimination from other children.

I: **Why do they say they will discriminate against him?**

R: Because he is sick, they think he will give them the disease.

I: **Is there anything else that he cannot do?**

R: This disease at times attacks him in two ways, you know if it was to come at night he could go to school and learn and complete. During the day, it comes like this time, or during the night it starts at 4pm or 5pm in the evening.

I: **Can you tell me more on that...like what is the difference?**

R: At times like this, it can attack him during the day, any time, but the one for the night start from 4 pm/5 pm onwards.

I: **And what activities does the one for day or night prevent, or hinder him from doing?**

R: During the rainy season and its cold, the disease affects him mostly during the day, it doesn't like cold season, and at night when he is sleeping, although not every day that it attacks him at night, like now when he takes drugs, he gets the attacks once a month. I prefer at night because I am near, and if he was sleeping on his back, I turn him face upwards.

I: **If I got that correctly you say that during the rainy season affects him during the day...? Why is that?**

R: Yes... it does, but there is no reason for that, it's just that I have observed that he has to get a seizure one day at night in a month: and also he gets attacks during day

time in rainy season...so we give him medicine during the day, in the morning, but we don't give him at night because the drugs have become very expensive, one tablet is 5 shillings. There are days I don't get anything, I come back home empty handed, so he misses the drug, and when he does it's a must he will get the attack.

I: Are there any other activities that he cannot do, apart from not going to school?

R: Yes, if it's an older person they can go to work, but now since he is young that why it's like this and again if you find I am with him at home he hasn't gone to school, I don't have school fees, and then the drugs are very expensive. I just pray that if I get someone to help me with drugs only, he can go to school. Also he cannot share a bed with others. The Doctor told me he cannot infect others by sharing a bed. Now for me, there is one blanket and one mattress for the children, how can they not share, they have to, since even these houses in korogocho you don't have space to separate them: if it was in a rich man's house you can separate them. I don't separate them, they sleep together. If I got someone to provide medicine for him, I would even take him to school.

I: Is there any other activity you think the illness prevent him from doing?

R: No.

I: For the ordinary people, how do they look or behave towards people living with epilepsy, how do they treat them?

R: They look down on them.

I: **Why do you say they look down?**

R: They look down on the sick child, they will even refuse their children to sit, walk, or associate with them, since they have the condition. Even when he goes to school, in the classroom he sits aside, alone far from the rest, his desk is kept aside.

I: **And why do they put him aside, there at the school?**

R: The teacher says that the other parents don't want him to be put near their children even in class.

I: **And why don't they want him to be near their children, reason?**

R: They say he is not well.

I: **What about at home? You had said they refuse their children to sit, walk with them, what else do the people of this community say or treat people living with epilepsy?**

R: Also, they hate him...

I: **What do you mean when you say hate him? Why?**

R: They give him names, like if they see him coming they say... 'The one with epilepsy is coming'.

I: **Any other way?**

R: No...they just hate him because of the illness; if he didn't have it, they would not treat him the way they do. And for me I cannot abandon him, while he is still alive, I will wait until the day God decides to take him.

**I: How is the life of your family members affected by you?
taking care of the person living with the condition?**

R: You know, the sick child is my grandchild, he is the son to my daughter, she left him under my care, since she had to go back to school, and so when the child started falling sick, he was under my care since the mother didn't even want to see the child, and also the paternal grandmother said she doesn't want anything to do with such a child. This attitude was painful and it affected me, but I told God if this is my burden, let me deal with it. I have taken care of the child and it's now years.

I: I heard you said it has stressed you, you think lot, what other way has it affected you?

R: It has also affected me since I cannot afford to get medicine or drugs for the ill child, also at times I am not able to go out, hustle for the family, since the child has an attack. At times I want go look for work at Eastleigh, Kariobangi south or Buru Buru, but then I ask myself who do I leave the sick child with. I cannot even make fire when he is near, or else he might fall in the fire, so you can't and you get a lot of thoughts, but I pray to God, if I could get medicine he cannot fall.

I: You said you cannot go look for work, you have a lot of stress, any other way you or your family has been affected?

R: The moment I don't go to look for work, we will sleep hungry, including him.

I: Any other way?

R: No...for me I don't mind, even at times I come from looking for work, I find him dirty, full of dry blood from injuries he sustains when he falls, I clean him, clean the wounds, and tell God he is the one who knows why he gave me that child, and also ask him to reduce my stress. so I am now used to it.

**I: Now you have told me how taking care of him affects
 You, what about the effect on other family members?**

R: Most of my other family members are in upcountry, but I have my daughters with me, and what can we do now? We have gotten used to it. When I am here if he falls down, they will take care of him; after all he is our blood. They are saved and know this is God's creature, even my youngest son, knows if he finds him fallen, he will take care of him, clean him, change his clothes, and even feed him.

**I: What are your hopes and those of your family for the
 future of the patient?**

R: I can only say that he can suffer if God decides to take me from this world, since the rest of the family cannot look after him how I do. But I pray that God helps him to become an adult. I can also want for him to learn how to read and write, even if it's just his name, I will take him to college.

I: After College, what next?

R: If he passes college exams and gets a job, I will have no worries from there. I will tell him to buy drugs and keep in the house: and do one or two things in the house,

if God helps him.

I: Where do you seek treatment for the patient?

R: I started at Health facility B, from there I was referred to the Health Facility M, where we continued with the clinics

until they diagnosed that it was epilepsy. They told me I will have to be buying drugs for the patient, and the drugs were very expensive, so I decided since they have already prescribed the drugs, there was no need of going back to Health Facility M, rather, I will be going to the chemist to buy them when I get money. When I get money I buy drugs for 1 month. There is a shop in town where I source the drugs

I: Where in town?

R: There is a chemist near OTC...

I: Is it in a hospital or?

R: No it's just a shop for drugs, not a hospital. If I go with like 5 thousand, I buy drugs to last him for 3 months and he takes them in the morning and evening.

I: Do you go to the hospital for a prescription or...?

R: I use the prescription I got from Hospital when they diagnosed the illness.

I: Apart from Health Facility B, Health Facility M and the chemist at OTC,

Is there any other place you seek treatment?

R: No...

I: Do you think information or awareness on epilepsy can easily be found in this community?

R: Information is there, like I was told if I go to Health Facility R, I can get the drugs for my patient there.

I: Who told you about Health Facility R?

R: I was told by a nurse at Health Facility B...and so I am waiting

for the drugs I have to get finished, and then I go to Health Facility R.

I: Apart from Health Facility B, is it easy to get information about

epilepsy within the community?

R: Yes, on your way to Health Facility P in korogocho, there is

another lady who also has a child who suffers the same illness. We help each other when in need, she knows where to get help. I consult her once in a while.

I: And apart from such persons, who also have children living with epilepsy, is there any other place you get information?

R: I can get information from St John's...

I: What is St John's... is it a hospital or?

R: It's a school. I go there for meetings and get to see other parents who have children also suffering the same illness. I came to know I am not the only one. I used to fear that people will not come to visit me since I have a sick child.

I: What are the meetings that you attend at St. Johns for?

R: They are for parents with children living with disabilities, epileptic conditions and mental illnesses.

I: **Who invites you for those meetings?**

R: There is a lady whose work is dealing with such children, and she comes from abroad to motivate and talk to parents with such children, and she tells us not to lose hope. She was here during the Covid period.

I: **And apart from motivation, does she inform you about epilepsy and maybe where to get help?**

R: Yes she does, she tells us to go to Health Facility R or Health Facility D for any assistance.

I: **Now you have talked about the women with children suffering from the same illness as your child, and the lady that' invites women at St John's, who gives information. Is there any other place you can get the information?**

R: No...I haven't heard.

I: **What are the challenges in getting the information on epilepsy in this community?**

R: In this community, there are challenges because there are children living with the condition but they are hidden in the houses. People are afraid that they will be laughed at.

I: **Is there any other challenge in getting information?**

R: No I don't know any other.

I: **And what are the challenges that are there when you are seeking treatment and services for epilepsy?**

R: When I go to seek treatment, I go with the hope of finding a drug that can cure the illness once and for all, but

that's not the case. If they got ARVs for HIV/AIDS, why can't they do the same for epilepsy? If even for this Covid 19 That just came the other day, they have a vaccine for it, we also want to get a solution for epileptic patients. We hope God shows us the way.

I: And apart from the challenge of getting a drug that can cure epilepsy... is there any other challenge?

R: Yes, if I approach somebody when I don't have money for the drugs, I get abused..

I: Who abuses you?

R: Let's say I don't have money to buy drugs and I approach someone for help, money to buy drugs, they start to abuse me and I feel hurt, and sad.

I: And is there any other challenge you face while seeking treatment?

R: At Health Facility B, there is a doctor, after he felt pity and told me that at Health Facility S, in Lan'gata, I can also get Drugs for 6 months. But I was unable to go there since I didn't have money for transport. Going to Facility S is 150 shillings to and fro is 300: and you cannot just go with exact money because even the child will want to eat, or drink something on the way, and I didn't have that money.

I: What can be done to inform, create awareness among the public on causes of epilepsy?

R: If we can get a teacher, someone to take us through epilepsy, just like the way you people have called me here and you inform us, about how to take care and look after the patients, how we live them, and also motivate us, not to give up on the patients. When you hear there is a gathering or meeting on epilepsy, you go

and listen to what they say...

I: Who will be inviting or talking to people in the meetings?

R: Even people like you, the way you have invited us here in your offices or it can be doctors from hospitals like Health Facility K, they too can come and ask for parents with epileptic patients, they sit us down and talk about the illness.

I: You have mentioned organizations like ours, Doctors from Health Facility K, are there other people, who can inform people

On causes of epilepsy?

R: No I don't know any other.

I: As we continue, and we now almost coming to the end...how can people living with epilepsy be supported towards care and living a quality life?

R: If I was to be asked I could say, the patient needs to eat, drink, bathe, sleep in a good place and be like ordinary children. They should not be discriminated, treat them just like the way you treat others.

I: Apart from giving them food, clothes and shelter, avoiding discrimination, is there any other way the patients can be supported?

R: Take them to school, if its uniform they don't have, buy for them just like the other children, if its school fees that's being paid, pay for them, isn't that okay?

Let him be just like the others, that's what I am saying.
don't discriminate against them.

I: Any other way they can be supported?

R: If the person taking care of them is not well off, and you are there and you can assist like a good Samaritan with things like clothes, blankets, and if the child is sent home from school due to lack of fees, you can give even if it's 500, tell the caregiver to send them back to school.

I: And apart from your neighbors or those living around you, are there other persons who can support towards care and living a quality life?

R: It's only here in Kariobangi, where I was invited in this same building, by some young girls who had seen me in korogocho with the patient, they gave me a blanket and his clothes for changing.

I: Who were the young girls? Or where were they from?

R: They were from one organization; I don't know the name.

I: As we come to an end of our discussion, I don't know if you have any comment, suggestion or question you would like to ask, regarding all we have discussed.

R: I would like to ask you now; how can you help me... either with drugs, school fees, clothes and such... and if I have offended you, please forgive me.

I: No, you have not asked a wrong question or offended any

one, we gave you an opportunity to ask any question.
For us, here me and my colleague, we are field
interviewers for APHRC, which is an organization that
does research, collecting data, and share with policy
makers. We thank you for your time and even sharing the
Information with us.

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