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I: Thank you. Welcome. We will start. Do you stay here in Viwandani?

R: Yes

I: How do people refer to epilepsy? Mostly what do they call it?

R: Epilepsy, sometimes people view as though someone has been bewitched. Some view it as though someone was born with it. There is a case where a person was born when they were just fine then it begins later on in life.

I: Okay. Are there names people use here in the village to refer to epilepsy?

R: I don't know many names but I know it is epilepsy, collapsing and fainting. They say this person collapses or faints or has epilepsy. Those are the names I know.

I: Okay. So they call it fainting and the like?

R: Yes.

I: Are there reasons why they call it those names, do those names have a reason for example like the way they call it fainting?

R: Reason could be, for instance when they see someone has fallen down, they start saying it's epilepsy or that illness of fainting.

I: Now that you have lived with an epileptic patient what are the things or some of the symptoms you will see on a person so that you will know that person is epileptic. What are the symptoms of an epileptic patient?

R: The first symptom I see is gazing for like 10 minutes. You might talk to the person and they will not respond as if the person does not know anything. There is the other one that comes with force: the person faints and starts stretching themselves. That is how I can know the attack is coming to that person.

I: Are there other symptoms you will see and know someone is epileptic?

R: There are those that are not easy to identify, a person feels dizzy, sits down, relaxes and once they gain their consciousness they will stand. Then there is that attack that comes in the

style I had mentioned to you. Those who have not lived with an epileptic patient cannot know.

I: Okay. What are some of the things an epileptic person must do and you will be sure this is epilepsy? What are some of those things?

R: The things I understand mostly are, someone who does their own things, and who is not friendly with a lot of people. That is what I know.

I: Why is the person mostly not friendly? Have you ever asked yourself why?

R: No, I have never asked myself. I have never known.

I: According to you what causes this epilepsy illness?

R: I have not done a lot of research but what I understand is a person is born with it and another one, people say it's being bewitched but I don't know much about this.

I: Which ones are people saying?

R: I know this illness is there, it depends, and it could start from the brain. I do not understand much; I only hear people talk about it. Others say a person can be born with it, perhaps it is the parents. When you hear people talk about so many things, you cannot understand what to believe but I understood it is an illness that has its own meaning.

I: What do people mostly say are the causes of epilepsy?

R: Mostly they say a person has been bewitched. Most of them believe that.

I: Okay. So mostly is being bewitched and such things? When you say being bewitched what do you mean?

R: It means someone else has gone to see a witchdoctor in order for the epileptic person to get this illness. I was asking myself when a person is born with epilepsy, was the person bewitched while in the mother's womb. Those are some of the questions I usually ask myself. I have never found out the truth. While here on earth, so many things are being

discussed. You cannot know which one is the truth, you just keep quiet and see how things are.

I: What are some of the family traditions apart from someone being told they are bewitched that some people believe causes epilepsy?

R: Tradition, it is the one I am talking about being bewitched. I saw my mother's sister sick and I was asking my grandmother how my mother's sister got this illness. She didn't know either where it came from because my aunt was born when she was just fine. Then when she was around 12 years it began. By the time she was 25yrs she passed on.

I: Okay

R: We stayed for a while then I saw it with my brother. My brother would gaze and fall down. The attacks began when he was 4 years old. My mother would leave us with him and I would run with him up to where she is because we were still young. As we went to church, I would tell her whatever my brother is doing I do not understand. Then I remembered my grandmother's story and wondered if it could be genetics attacking these children. Then my brother passed on. Then there is this other brother of mine I am living with. He would come and gaze and I discovered the same symptom I saw. He gazes, other times he sits down and when I ask him what is wrong, he does not respond. Then I knew it was the same illness that wants to affect him.

I: Which one do you take care of?

R: That one.

I: Your brother?

R: Yes, my brother. They were two and one passed away. The one who passed away, I was not around and he fell on fire, before he could regain his consciousness, he was severely burnt in his intestines. I stayed with him for one year in Russia, Kisumu. He passed on. I have seen this other one and I have lived with them and I understand them.

I: Okay. What about aunt? Who is taking care of aunt?

R: Aunt passed away.

I: Okay.

R: My brother also passed away. Now I am left with only one brother.

I: Okay, thank you. How has living with your epileptic brother affected your life?

R: Life?

I: Yes. How has it affected you personally?

R: My life has been affected because sometimes I am anxious when leaving the house. I feel it might happen to him like it happened to the others. My mother's sister cut herself with an axe and since people were not around, she bled too much until she died. My other brother fell on fire while we were not around. He got burnt a lot and by the time he was gaining his consciousness, he was really hurt. It really challenges me leaving him. I am forced to cook everything if I want to leave and switch off any source of fire. He is a grown up but I feel it can attack him like the other one who died while in class 7. It really affects me concerning fire, water, and being on the road alone. He might be crossing the road and the attack occurs at that moment. Those are some of the things that I am concerned about but it is not wrong to live with an epileptic person when you understand the person everything goes back to normal.

I: Okay thank you. What are some of the activities or duties an epileptic person cannot do?

R: An epileptic person can carry out all activities because the person can study well. The person can perform all duties well; the only problem is when the attack finds the person in the wrong place.

I: Normal activities the person can perform?

R: Normal activities they can do as normal people. It is something that shocks you but the person is normal just like us it is not something bad. He is not mentally ill or mad, he is just okay. The only problem is that illness. One can stay two or three days before getting the

attack and there are times they happen frequently. That is the only challenge but if it is studying the person studies as a normal person and does everything just like us.

I: Okay. What about in the community when you live in the community like Viwandani how do people perceive an epileptic person like your brother how do people perceive him?

R: An epileptic person, mostly many people fear him. They fear when the attacks occur. I do not understand everyone has the way they are in their hearts. There are those who have a humane heart who will assist and there are those who will fear and cannot come near the person. That is the challenge with people. People are different. Those who know about the attack, they will come and hold him and fold him, some will start giving him fresh air or pour water on his head for the attack to subside. There are those who will leave him, until he gains consciousness and the person might bite their tongue a lot or hit his head on the wall badly. It is required if there is someone who is near, at least to fold him. That person has got a lot of energy at that moment, the attack comes with force, even if you are two or three people you hold him at least so that he does not injure himself. When he is alone that is where the problem lies. Even if the person has fallen in the seat and it is a metallic seat he will get injured and when he starts bleeding it will affect him. People are different.

I: Mostly why do you feel people fear relating with an epileptic person?

R: People fear being infected when the person falls down yet this is not an infectious illness like Tuberculosis or an injection or probably Human Immunodeficiency Virus. This is an illness only on that person. Even if you touch him or do anything on that person it cannot affect you. The person is just there. If at all it was infectious I would have been infected because of those I have been with.

I: Okay. You had mentioned how people behave, some reject him, Right?

R: Yes

I: Let us say such things as when he is working. Have you ever found that he has been denied work or he goes to a place and people have rejected him because they know he is epileptic?

R: When it comes to work that has not happened yet because the one I live with is still in school, he is yet to start looking for employment. But I see him play football with his friends in school, they just do things as usual.

I: Okay. They don't sideline him?

R: Yes, they don't sideline him but he also does not like being close with someone for them to find out about his condition.

I: Do you live with other people at home?

R: Yes, I am with my cousin, him, myself and my children.

I: How has their lives been affected by living with an epileptic person like your brother? Have their lives been affected?

R: They have not been affected in any way, they are just okay.

I: What about in terms of mannerisms, like you had said you spend your time?

R: They are just okay. For example, my child is used to calling him uncle. Sometimes they play together, he teaches him to study a bit. They say "I usually desire to act; will we act? How will we do it?" I usually see such games as they continue.

I: What would you hope for him in future?

R: I would hope that the Lord makes a way for him to study, so that after he studies he can explain to the people who are epileptic that this illness is not caused by someone's desire, people to love one another in case you see someone hurting and you are close to that person, you help them. He likes development. He usually tells me that he will study despite the fact that our mother passed on and left, "I must carry you in my car, do not worry. Do you know you are our sister; you are our mum." I usually tell him not to worry, work hard, not to play games, sideline himself or bother on people talking ill. Just to focus on what has taken him to class. He tells me not to worry regarding his studies.

I: That is okay, at least he gives you hope.

R: Yes.

I: You feel you are okay right?

R: Yes.

I: Okay. At the moment he is getting treatment for epilepsy?

R: No treatment.

I: Not even medication?

R: Medication not yet.

I: He has never gotten any medication or taken any treatment?

R: No.

I: He has never?

R: No.

I: Why has he not received any medication or treatment?

R: This one he has not been so serious like the other one whom we kept rushing to the hospital.

That other one, the attack was very bad, the one who passed away.

I: Okay

R: Yes

I: Where was he getting medication from?

R: We were in the rural home in Siaya.

I: Russia?

R: Yes. He would get medication for minimizing the attack.

I: Why have you not taken this other one to the hospital?

R: It is just that this one sometimes is just gazing for like 15 minutes. Then he is back on his senses. What bothers my mind is if I take him to hospital then I give him medication, he might end up fainting more often or how will it be? These are some of the things that bother me.

I: Ooh. You are afraid you might give him medication then it goes up?

R: Yes, it starts becoming too much like the other one, who was falling on the road and everywhere else. I feel let me leave this one first and see how it goes.

I: Okay. Let us say the time when you used to take your late brother to the hospital were you satisfied with the treatment or the services provided in the hospital?

R: Mostly it was my grandmother taking him.

I: Okay. Was the treatment available or was it difficult to get treatment?

R: In rural homes the distance is quite far, by the time one reaches the hospital, probably using fare and walking is also a long distance. Those were some of the things that used to disturb grandmother at home. We could see she was not so happy.

I: The challenge was that it was far?

R: Yes, it was far. It was not making me happy.

I: In this community do you think people know where they can receive treatment for epilepsy?

R: They don't know much besides; I have not seen the doctors back in the rural home take this illness seriously the way I have seen currently.

I: Where have you seen it being taken seriously?

R: I usually hear sometimes on the television, and on radio as they discuss it.

I: Why do people not know where they can get treatment?

R: We have not been directed where to go. The nearest hospital is this Health Facility L here at Mareba or one goes to Health Facility M. I have gone there several times and I have never heard them say that they can treat this illness.

I: Where have you been going? Health Facility L?

R: Yes, I have not even heard of it here at Health Facility M. Probably at Health Facility K they can treat this illness but here in the neighborhood I have not heard.

I: You have not heard anywhere you can get treatment?

R: I have not heard around here.

I: Okay. What about the time you were taking your late brother to the hospital, what are some of the challenges you encountered as you took him to hospital?

R: Probably the attack comes while on the way to the hospital yet you are walking and it is far, you arrive there while you are already bored and tired. When grandmother goes with him sometimes, she is old and not so strong and perhaps he falls on her and this is a young boy who is strong so I felt like we were mistreating her. I would go out to look for casual labor in order to be able to provide food. Those were the challenges I was facing back at the rural home.

I: Okay. The challenge was finding someone to take him to the hospital?

R: Yes

I: Okay. What are some other challenges you faced, especially knowing where to go to the hospital? Are there challenges that people face when going to the hospital or knowing where to go for medication?

R: When the medication has run out and you are required to go for it and probably you are not around or he is in school. If the medication runs out earlier and you know the appointment time of when you are required to go for the medication, you plan earlier.

I: Okay. Have you seen other people like your brother who are epileptic in this community? Right?

R: Where I stay I have not come across anyone, only that as I was walking on the road one time, I saw someone who had fainted. He was injured and he had collapsed near a trench and I saw the sewer is just near him and he might fall inside. This illness does not like people being close to water or fire. I felt this person might get injured, so I told someone we pull and move him beside the road because he might rotate and fall inside and it is not good. I did not know where he was from, I had just seen him on the road and I did not know him either. You know if you have lived with an epileptic person, when you see a person on the road you have to assist them because when he is near the sewage he might swallow that water and die and that is not good. I told them we help that person and they began asking how I can touch someone I do not know. I told them this is not a drunk person, he is injured already there was foam in the mouth and he was biting his tongue. This is epilepsy they started saying, "with this good heart of yours touching people on the road." I told them we assist and put him aside and once he gains consciousness he will go home. He was the first person who had collapsed in that area but where we stay I have not seen anyone.

I: Why are people finding it a challenge to know where to find treatment? Like you have said people are afraid of touching such a person, why do people not know these things that you know?

R: If someone has lived with an epileptic person you must know but if one has not lived with such persons they cannot know. Besides, when they see someone who has fallen down, they will not bother because they will imagine these are persons who like drinking alcohol in the slum.

I: People associate this illness with being drunk?

R: Yes, if someone finds the person lying on the road they will imagine this person is drunk but a person who has lived with an epileptic person will know the signs. There are those who have foam in their mouth, others drag themselves, and bite their tongue. It usually depends on how the attack has come. There are those who know when the attack is coming, they hold a

tree and sit down until they gain their consciousness. Small children cannot know, but a grown up like me, someone who has grown with epilepsy will know how to handle the attack. Like if someone was teaching in class the person will sit down and lay their head on the desk the students will not understand. Such people are using medication.

I: What are some financial challenges that a person goes through while seeking treatment for epilepsy?

R: Epilepsy, on the issues of medication uncle was the one dealing with it. I felt it was a bit difficult for me, probably I would carry my brother and go with him to Health Facility K and be told it is quite expensive and yet I do not have money. Such challenges hinder people from seeking treatment because of the high cost. They lose hope and decide to live with the epileptic person until their demise.

I: So one lacks someone who will deal with it?

R: Yes.

I: Okay. Do you think treatment for epilepsy is costly? Like the time you were taking your brother to the hospital was it costly?

R: That one my uncle was the one dealing with it. I could not bother to ask because I did not have money. I could have asked if at all I was to chip in the expenses but he would have wondered what kind of questions I am asking as if I want to chip in the medication. You know when you lack parents' people tend to think you are not important, so you keep quiet and get assistance.

I: You realize many people are not aware but you have said you are aware because you have lived with an epileptic person. Right?

R: Yes

I: What can be done to bring awareness here in Viwandani? For people to be aware concerning epilepsy?

R: Being educated the way they do for HIV. Being given such an example, everything will be okay.

I: So they should be explained to?

R: Yes, let them be explained to, know the causes and how to live with epileptic patients, it can be good. It is just like HIV. Before, people did not want to share cups with a person who had it but after being educated they can live with a HIV patient. My mother was telling me, before people used to run away from a HIV Person, sidelining them until they were committing suicide but after being educated people took medication and have lived for long until I was born and have found them. It is because they were educated on how to love one another. They take care of each other.

I: So you have said they should be educated the way it has been done on HIV, to be done on epilepsy? What else can be done?

R: Just that. That education and also loving an epileptic person the way you love yourself, do not leave them on the road, once they gain consciousness ask them where they live they will explain or ask for their relative's phone number, call and request them to come and assist that person or child. It would make it easier for the epileptic person because what if it is on the road and they get knocked? When you help him you have also helped others. That is my opinion.

I: When we say supporting epileptic persons what else can the community do to support epileptic persons?

R: Let people who have epileptic patients come out and speak. If you know your neighbor has an epileptic child or person and you have heard any medication or treatment direct them. Sharing by word of mouth can be effective for people to come together to know which area or village has like 20 or 100 persons, it will be easier. Keeping the information to oneself and people are suffering in that area is not helping.

I: What else can be done to ensure an epileptic person lives a good life?

R: Talk to the person so that he does not get injured. I usually talk to my brother and tell him when he feels the symptoms especially on the road, to move and sit down without minding people's perception because he knows what he is doing and if he is near fire to move away from it and sit in a corner and relax.

I: Teaching them how to protect themselves?

R: Yes, teaching them so that when walking their mind will direct the person not to cross the road. When they feel the symptoms near water or near fire they do not go near it. It could help them despite going through treatment. This could help so that they do not find themselves in trouble like the ones I have lost.

I: Okay. Do you know any treatment used to treat epilepsy or have you been told to use this treatment? Like which one have you been told to use?

R: The one I have been told is looking for traditional herbalists, the witchdoctors. I was told to look for Ksh.13000 and take him to be tied to some things but I told the person I do not have the cash and I do not have any cow to give them I will leave him to live that way. That is what I was told but anything else I do not know.

I: You have been told mostly about the traditional healers?

R: Yes, traditional healers, witchdoctors. I told them my blood does not cope with such things, leave him like that.

I: Which other treatment have you been told for epilepsy?

R: Have not been told of any other treatment unless the other one my uncle was seeking for my late brother but I do not know any other.

I: We have come to the end of our discussion unless my colleague has something to add. Do you have something to add?

I2: Probably I would like to ask, when you are saying people to be explained to like they are being explained on HIV would you expound a bit on what exactly are they being explained about on epilepsy.

R: Let them know that this epilepsy is just like any other illness because first, we do not know where it came from. Secondly, you see someone collapsing, getting hurt and with wounds in the body. Probably he collapses and no one takes care of him and he gets hurt. Even when HIV came, we did not know where it came from but it started killing people. Even with this epilepsy if you do not take care of the person they will die. There are those that I know in the rural home whose families are well off, they take care of them, follow up on their education, some of them are even ministers and they are epileptic, because their families took care of them. They are taken to school and they become just like other members in the society. If it is a woman, she has her own children and if it is a man he has a wife and children. The young ones can be taken care of like those other families that follow up on their children. At least they would continue living in the world. If we neglect and sideline them, like my brother when I was not around he died, but if I was there he would not have died. I would have assisted him very fast and the burns would not have been severe and I would have rushed him fast and he would be healed and finish his schooling. When I was not around he died. When grandmother was not around my mother's sister died but if she was near she would have recovered. Those who are taking care of an epileptic person even if you have left, think about that person because of the timings let there be a person around them. Even in school, I told the teacher about my brother, on the time the attacks come and to speak to the other students to help him. At least it helps.

I: Like you have said there are times, is there a specific time for example your brother gets the attack?

R: Yes, mostly during cold seasons. Cold season is the worst and in the evening.

I: Cold season and evening?

R: Yes

I: You had also shared an opinion that people should be advised, you said you talk to brother that when he feels the symptoms, probably you can explain to us, are there moments that an epileptic person feels the symptom that the attack is coming?

R: This one even the mature ones they know; they even tell us. They feel weak in the body and even feel dizzy, go and sit before the attack comes with force. The one who was telling me was a teacher, that it has signs. One can feel very cold, dizziness that comes with force and one sees darkness. I was explaining to my brother. I asked him what he feels and he said he feels dizzy. I told him if he sees those signs, he needs to go and sit somewhere else and relax. That is what the teacher was telling me. The teacher was under medication.

I2: You have said your brother so far he is not under any medication or you have not taken him to hospital because he is in that stage of gazing so he just gazes but he does not get the attack forcefully and collapses?

R: He was collapsing before; he is not like the other ones in the past. He can feel the dizziness, see darkness and fall down or other times fall but without force like the other brother. That is why I saw this one has not matured like the others. Have you understood me now?

I: Yes. So that is the only reason you have not sought help from the hospital or is there any other reason or challenge?

R: The challenge was I would go to the hospital and be asked for a lot of money and I do not have money. I want to know how they will study, how they will feed and how I will pay rent. Now all these I feel they will stress me a lot, so I pray to God to protect him. If I had the capability, I would seek help before it spreads.

I2: Okay. Thanks

I: Thank you so much we are delighted.

[End of audio]

