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I: We will start. We can start by identifying the names people in the community use to refer to epilepsy.

R3: Others call it *kathitima.*

I: When they call it *kathitima* what does that name refer to?

R3: It means that a person convulses and falls; most of them have seizures.

I: That *kathitima* does it refer to something?

R3: *Kathitima* refers to electricity, when someone is electrocuted, there is a way they get shocked, and in the village they call it that way.

I: Any other name?

R1: In Kamba we call it *mung'athuko*, where someone shakes, falls and foams in the mouth.

I: That name does it have a meaning? What does it mean?

R1: Which one?

I: *Mung'athuko.*

R1: It means falling.

I: R2 has something to add.

R2: In Luhya we call it *indurume* meaning someone falls and foams and bites their tongue. If someone is near you, take a cooking stick or a piece of cloth and put it in the mouth to avoid tongue biting.

I: What does *indurume* mean?

R2: It means falling.

R4: In our culture we call it *kifafa.* When you hear someone has *kifafa*, you know this person faints.

I: Any other?

R7: *Mung'aro.*

I: Does the name refer to something?

R7: It means drying something because someone falls. unexpectedly.

I: Mung'aro is drying something?

R7: Yes, a person falls unexpectedly.

I: Is it easy to identify an epileptic person?

R4: There are signs, you might be talking to someone, and they twist their neck and shortly the person falls. You might get scared if you are not familiar with the illness, but if you are aware and you are near the person, you hold the person.

R3: By just looking with your eyes it's not easy to know an epileptic person because they function normally as any other person unless they get the attack in your presence.

I: One sign of epilepsy is falling?

R3: There are different types of epilepsy, it is not a must for a person to fall. There those who get shocked they stand and it's over, others twist their mouth, and they don't fall for some minutes, there are those who fall completely and others who run and stand somewhere and it's over. Others sleep, they open their eyes, and they can't see anything and go back to sleep. Some of them know when the attack is about to happen, there is a signal that comes in the brain such that if someone was standing, they sit down, if one was near fire they move away.

I: These are symptoms of epilepsy?

R3: Yes.

I: Any other symptoms?

R5: The one I live with is my younger brother, he tells me when he is about to fall, he gets shocked.We usually advise him to sit somewhere when he gets the attack so he cannot get injured without holding him. When he falls, once he regains his consciousness we are called.

R6: The one I live with, it is very easy to tell he's epileptic when you look at him, there's a way sometimes his hands turn, his speech has a problem because sometimes the words are not clear. There are other epileptic patients who are completely normal. When you look at them you cannot tell that they faint but they do. The one I live with, even holding his head straight is a problem, his neck is very weak. He has a challenge in eating, he has to eat soft meals. You cannot leave him alone, there must be someone.

I: What are some of the symptoms an epileptic person shows for you to know they are about to get an attack?

R1: They complain of headache; the person can complain of headache today the next day they fall. They foam in the mouth, they get injuries when they fall, and when you tell the person they fell, they deny it.

I: Loss of memory is also a sign of epilepsy?

R1: Yes. [inaudible]

R2: The one I live with, you might be talking to him, he changes his facial expression immediately and says "let me go outside it's hot in here" he goes outside and if you don't follow him immediately you will find he has fallen. There is a day he fell and hit his head and got a big cut. I took him to the hospital to receive stitches and was bandaged. The next day I told him how he fell and injured his head, he denied, I took a mirror and I showed him. There is medication I give him, when he uses it, he can’t fall but when he misses medication, he gets the attack and he messes up.

R3: I have a sister, leave alone my child, most of the time she says she feels like it's a muscle pull in the arm, which goes all the way to the head. Mostly when sitting down, you will see her touching her fingers, and when she senses the attack, immediately the numbness starts, she knows automatically she will fall.

I: Thank you. What are the different types of epilepsy?

R4: We have no idea; you only know the type of the epileptic person you live with.

R3: What I know, every time we visit facility Y, they usually tell us about different types of epilepsy and the causes. For example, my child used to convulse a lot, within one hour she would convulse almost 200 to 300 times. We were told that it is more harmful than the person who convulses for almost 12 minutes. The more a person convulses the more it damages the brain. They explained to us that the person who convulses a lot, usually loses their memory, but a person who convulses once a month, it doesn’t affect their brain much.

R1: Some people get attacked because of taking alcohol. When a person takes alcohol they get the attack. After one month they get the attack, too much alcohol in the body causes the attack.

R2: Many of the epileptic patients take alcohol, smoke cigarettes and bhang. Once they mix all these they can’t think straight, they lose their memory, they are absent minded, even if you ask them what you talked about the previous day, they can’t remember anything. Some of them eat a lot. You might have a meal together, but after a very short time they start asking for more food.

R4: There is something I have discovered from the one I live with, if she gets so angry, or gets over excited, that will affect her. The next day she will get the attack. That is something I have discovered with my daughter.

R7: You have said when someone smokes cigarettes they get epilepsy?

R2: The one I live with smokes bhang, cigarettes and this causes him to get the attack, then he adds chavies, they all contribute to him getting the attack.

R7: I was asking because I know of someone who smokes cigarettes, he gazes for like two minutes, then he falls, can we call that epilepsy?

R1: It is *kathitima.*

R2: Yes, I would say it is epilepsy--

R7: When he falls, he can last up to 30 minutes, then he wakes up, that happens when he smokes a cigarette.

I: R7 is asking, his friend falls after smoking a cigarette, then he bends as though he is getting an epileptic attack, he is asking whether we can call it epilepsy? R1 said that is not epilepsy.

R3: It is one type of epilepsy because the more he will continue bending it will reach a point he will fall. It starts slowly then it reaches a point where it becomes epileptic.

R7: His friends say he has *kathitima* when the attack happens.

R5: I have my brother whom I live with, they are twins, but one is not around, they were told not to take beer and sugar, they take long before they get the attack. They should not get rained on, when they do, they can't stay for two days without getting the attack. They can't bathe with cold water, it's something we avoid. Cigarettes are an enemy to this illness.

I: Cigarettes are enemies? --

R5: Alcohol too.

R6: My uncle is very much okay when you look at him, he performs his duties very well, but he also falls. Sometimes he falls for no reason or any problem. He speaks well. You can't tell he is epileptic.

I: Thank you R6. What other things that harm people with epilepsy if they use them?

R6: This illness is God-given because he uses everything, he takes alcohol, smokes bhang, cigarettes and he works very well on his duties, and still falls. Even when he doesn't smoke or drink alcohol, he will still fall.

I: I would like to know, from your understanding, what causes epilepsy?

R3: According to my understanding it is caused through head injury or genetics from the family.

I: What are the other causes of epilepsy?

R6: You can be born and start having problems while young, you start collapsing and it continues until you are a grown up.

I: It starts in childhood?

R6: Yes, it starts in childhood.

R7: It can be true because the one I have, started as an infant, the child used to gaze. We didn't know what the problem was, right now he is 30 years old and still has epilepsy.

R1: Others get epilepsy when they're already grown.

R3: It can also start as any other sickness, but if it is severe and it affects the brain, then you eventually become epileptic. Or you fell as an infant and injured your head, that can also be another cause.

I: What do people of viwandani say about the causes of epilepsy?

R4: Some say it is inheritance; they disrespect you and your child.

R3: Others say it is caused by demons.

R2: Some people tell their children not to associate with another person's child because they think epilepsy is contagious.

R6: The one who gets epilepsy in their adulthood some people think they have been bewitched.

I: Any other causes? There are none. From your rural homes, what do they think causes epilepsy?

R3: Most of them say it is in the family. There are those who treat epilepsy and a person gets healed as long as they have not gotten burned. Most of the time an epileptic person dies as a result of water and fire. They used to believe if it's genetic and a person has not been burned you can be treated and you get healed. They used to do that because they believed it and I have witnessed people who got healed.

I: Any other beliefs that people have from family or traditions that cause epilepsy?

R4: Where I come from, we have never come across epilepsy, but where I'm married, that is where I came across epilepsy. My people think there's witchcraft where I got married, people blame each other.

I: They say it's genetic?

R4: Yes.

I: How is an epileptic person affected in life?

R3: First an epileptic person is sidelined when it comes to getting jobs. They can't work in companies because the employers are afraid they might get injured and die while working. Secondly, for both male or females getting married becomes a challenge because one is asked," You want to marry that person who is epileptic will you manage?" People sideline you because of the illness, your human rights cannot be actualized.

R4: Others get affected in their academic work, because sometimes the attack happens when one is in class. Those who get attacked frequently they might not be able to understand what other pupils have gained. Other fellow students might not want to get associated with an epileptic child. His academic level goes down even if he was a bright child but for those who accept their condition, they cope very well with their studies.

I: Therefore, it affects one's education?

R4: Yes.

I: Any other effects of epilepsy in someone's future?

R5: It's a challenge getting married but it is possible if you are interested. You tell your wife in advance that you are epileptic, for example, my twin brothers have epilepsy. One did not tell the wife and she found out, she ran away and went to call the wife of the other twin, she asked,” What is this?” The other wife asked,” You have never known? My husband also gets those attacks” That is when she was told. On August 29th, [inaudible] someone told me about a certain medication. My brother left the house, he got attacked. I was called, [inaudible] picked him and took him to the house. One person told me,” In case you see your brother faint again, remove his shoe and put it on his nose, and he'll never faint again.” By good or bad luck, since then he has not fainted in my presence. I am waiting for that day.

R3: It is called a step of faith.

I: Which other methods can be used to cure epilepsy?

R4: There's a time my child fainted in front of the doctors, and they told me to turn him and position him on his left side to prevent the foaming in the mouth and from choking him. Before then I used to put a spoon in her mouth. An epileptic person is usually very strong when the attack comes they can even cause you to fall and they are younger than you. I was told she can even hurt herself until the tooth gets cracked. It's better for her to bite herself than the tooth getting cracked. We were advised not to be putting a spoon in their mouth when the seizures happen because it can harm them or even break their teeth.

R3: What I was told is that it's not easy for the epilepsy to be healed but if the patient takes their medication continuously, it reduces the strength of the epilepsy. When the attack comes, the person senses the attack is about to happen, but it disappears. Whether someone is a grownup or a child they must live under medication. My child used to fall down within one hour almost five hundred times. I went to Facility N and she was given medication. She slept for three days and she lived for 6 months without falling. She started recognizing me as her mother and became jovial despite the fact she never used to know me. She started sitting down the third day and initially she wasn't sitting yet she was 7 years old. It had affected her spinal cord, when you hold her she starts bending. Up to today you cannot see her fainting. She would remember someone she saw 2 years ago as much as she is not talking you sense she knows the person. What I can tell my fellow parents whether it's a child or a grown up, when an epileptic person finds a doctor who knows what they are doing, a person can be partially healed.

I: Which other preventive measures do you take on epilepsy?

R4: Mostly taking medication, even if you don't have money, you go to the clinic as the card is being given, you tell the doctor," Today I don't have money for the medicine". You will be given at least two days. Once you get money you pay. Mostly, medication is what I see she does not have. [inaudible]--

I: Which facility is that, where you are given medicine on credit?

R4: I used to visit Facility H in Huruma. It used to deal with epileptic patients but when I saw she had fainted so many times, I took her to my grandmother. There is a facility near our home where she gets medication.

R3: What needs to be put into consideration and we usually do, whether it's a child or a grown up, you should tell other people about their condition. Most of them, when they feel pain when you hit them they can get attack. Tell other people how to handle them.

I: According to you, you have lived with epileptic children or relatives, what are some of the things an epileptic person cannot do?

R3: The first thing has to do with fire and a lot of water. Growing up I knew that an epileptic person should not go near a fire, because the attack is not something that announces when it is about to happen. It can happen and the person falls into fire. When it comes to water, one should not be released to go and fetch water.

R4: An epileptic person should not be left alone for a long time. When leaving, inform the neighbors to check on the person. You find that people are aware even if she goes far and gets the attack people are able to call you.

R1: Epileptic people should not smoke or take alcohol.

R2: An epileptic person should not use Chaves, or smoke bhang.

I: What is Chavis?

R3: Tobacco.

R4: They should not skip their medication and should be taken at the prescribed time. If they skip medication for two to three days they will faint.

R6: A woman should avoid at all costs to be in the kitchen cooking and fetching water, because it can be very risky.

I: Thank you so much. Is there anything else an epileptic person should avoid doing? None. According to you, how has living with a person with epilepsy affected your life?

R3: Sometimes you find it is very difficult to get someone to look after the child in order to go and work. I might want to go to work but looking at the child I wonder if she might faint if the one I have left her with is not keen, so I end up suffering with that child because I feel I don't want to leave her. You fail to trust the person you have left her with. You find that my life is affected in such a manner that whenever I am called for work I can't go.

R4: I hawk clothes, and I'm never at peace especially when I go far, I am usually thinking about her, "how is she?" When it rains I have to know where she is. I start making phone calls asking about her whereabouts and then I request a neighbor to stay with her until I return. You are never at peace; you keep making phone calls.

R6: The one I have, the mother cannot go anywhere unless she leaves him with someone. He can leave without knowing where he is going, you start looking for him and you might not find him. You leave him with someone without going far. You cannot go somewhere for a whole day.

R7: When I'm at work, my friends call me and say," your guy has fainted somewhere". I am forced to tell them what to do," remove his sweater and put it aside after twenty minutes he will regain his consciousness" When at work you cannot just leave [inaudible]. I have given people my contact when they see him because I am known. Therefore, it affects someone while at work.

R3: I'm a single mother, everyone likes getting married. When you get married in a family, they see your child and they feel as though she is a burden to them. I have tried getting married twice and left because of my child. I decided not to get married because people feel the child is a burden to them. It hinders one from getting married because of the perception people have of you.

R2: The one I live with is a relative and is grown up. This Covid season has been a challenge because his work was affected and he lost his job. He became my dependent, I had to pay his house rent and feed him. I'm a widow, my children and him are depending on me and it is a burden. There is a lady who came and asked me," Where is that young man who used to live with you?' I told her "he is around," I asked her," What do you want?" She asked me, "Which medication does he use that prevents him from fainting?" I told her, "Perhaps if I ask him if he takes it or not I cannot know". When I asked him and he told me then I went back and told her. She told me, "Tomorrow I will bring for you a sample you go and show him if they are the ones and if they are the ones it's okay." The next day she brought the sample and I showed him, I asked him," is this the one?" He said," yes it is the one I am using." I went and told the lady," he has said it is the one." She brought for me a whole box, which I gave him. It would last him a month and some days. He used them and finished. I told that lady," Now that he has finished, how will it be?" she told me, I was also given by an epileptic person but the person gets them from a NGO. I asked her," can you talk to the person to assist me?" She said," If you are interested give me ksh 300" so that she can give me the medication in plenty that can last up to six months. I told her that ksh 300 it's a challenge.

I: Any more effects of living with an epileptic person?

R4: My daughter has two children, one in form one and another one in class six. The children ask me," grandmother what happened to our mother?" You are not able to explain to the children where the illness came from. When they come from school they are not able to do anything without first looking for their mother. The children start blaming grandmother for giving birth to their mother with epilepsy.

I: The questions make you feel heartbroken? --

R4: They feel I know the cause of this illness.

R6: It's a challenge at the moment because the mother is the one living with him. At the moment I am jobless and a lot of things require finances.

I: How does the viwandani community perceive people with epilepsy?

R2: It is very difficult to make friends with people, they think if they come to your house, they will get epilepsy, friendship comes to an end. They think it is contagious and they avoid you.

R3: While in the rural home I used to go to the clinic and I would pass by a relative and ask her," give me ksh 20 I buy something for the child." She would give it to me very fast. After almost four years she said," do you know why I used to give you the cash quickly? I used to do it because I heard your child convulses and I didn't want her to convulse while I was holding her. I was not giving you willingly, I was doing it so that you leave quickly." You find that even if someone is assisting you, you imagine they are doing it out of a humane heart but they are doing it out of fear. If it's a friend and you tell her that I will be going somewhere on a certain day, she also says she is going somewhere. Friendships end up dying, people don't want to associate with you lest you start becoming a burden to them because of your child.

R1: Most of them think epilepsy is contagious.

R4: Other people think you have not taken the initiative to take the person where they can get helped and be healed. They advise you,” take her to a witch doctor and find out if she has been bewitched.” They feel you don’t deserve to live with her, it’s like you are weak and you are not doing anything to help her. They are not aware that the epileptic person is under medication. They look down on you and feel as though you are not taking your responsibility seriously.

I: They blame you—-

R4: They blame me and feel like I have relaxed with her.

R3: Some give you advice which is not helpful. My daughter is 16 years old. Apart from being epileptic she does not walk or talk. A certain lady came and told me,” Let us go, I will show you a children's home that takes in grown up when we go there, leave her. How long will you live with her and she is a grown up?” You find the advice being given cannot help you. When you leave the child there it means you will never go back to check on her. The children’s home pick those who don't have families.

R2: My friends told me,” how do you feed a grown up why can't you chase him away.” I told them I cannot chase anyone. God cannot be happy and He has a reason why He brought him to me. If I don't help him tomorrow, who will help my children? Who will help me? They tell me,” continue living with your humane heart.” I know what I'm doing.

I: How do people perceive an epileptic person interacting with them?

R6: Some people think an epileptic person is a burden because he depends on you for most things. Some feel they cannot come to visit; they feel as if he is not a human being yet he is a normal person just like any other human being. They feel he should not be living.

R3: Other people, in case someone is looking for you, they introduce you using the epileptic child as a reference. They ask each other, “you don’t know that lady who has a child that faints?” They cannot use normal terms, “I know that lady” they use stigmatizing terms.

R4: I used to live in a smaller house, I found another bigger house I wanted to move in, when I went there, another lady passed in front and said to the landlady," don't give this lady the house she leaves her epileptic child in the house what if the child touches electricity? Your house will be burned." I had already paid and I had arrived with my items. I was told I won't be given the house. Your name gets distorted because of your child's condition.

R7: They fear epileptic people, especially when they see them fall, the one I live with when he falls on the other side, they can't go near them, they must call one of our family members to go and pick him up--

R1: They cannot touch him.

I: Why can't they touch him?

R3: What people have lacked is awareness, being explained that it is not a must for them to have an epileptic child, they need to be taught how to handle an epileptic person and be told this illness is not infectious. They lack understanding.

I: What are your wishes for the person you are taking care of with epilepsy?

R4: If possible we can be helped with medication, sometimes we lack the money to buy medicine, if it can be brought at Facility R and let them be free. We lack money to buy these drugs.

I: Free medication in future.

R3: The kind of future I think about, although at times it looks farfetched. I would be happy when I am called a grandmother because my daughter is the first born. I would be glad when having a family and being called a grandmother and she has her own family. It reached a point I wonder, "yes I would be glad, but who can I trust to take care of my child?" You think about it but it reaches a point it becomes a challenge. Who will understand this child if you are not there, I am her feet, I usually carry her. You think about these things and you lack an answer.

I: You fail to understand what tomorrow holds for them?

R4: I would wish for the government to provide epileptic patients with cash transfer to support themselves, even if it is not much, it can help a lot. They can be giving them cash monthly.

R7: The government does not care about epileptic patients because the medication is very expensive. In the government facilities I don’t see these drugs. Like mine I pick medication for him at Facility G and it’s far, one-month medication is Ksh.1000. It’s a facility that deals with epileptic patients, but I have not seen a facility in Viwandani that deals with epileptic patients.

I: In what way do you think your child or the epileptic patient that you live with will be affected in future?

R3: I will be affected unless God does something. My daughter is almost a teenager. As she continues to grow, I’m growing old. There will come a time I won't have energy to lift her. How will she walk?

R4: There is danger when I will not be around. I wish the government could provide epilepsy medication like they provide medication for TB. If epilepsy medicine can be available in all government facilities, my child will continue to get the medication even when I’m not around.

I: R5 you are too quiet.

R5: I’m okay.

I: Have heard some of you say you go to the hospital for medication. Where do you go for medication?

R3: I take mine to a clinic in Facility Y and most of the time the medication is not available. I usually buy from Mumbi house, prescribed to be taken twice per day and the cost is almost Kshs.4700 for a month. Mumbi house is cheaper. At Facility Y, they refuse because I am given a clinic to attend once per year. They say you can only buy medicine for one whole month because if they give you for two months, other patients will lack it. When you go the following month you still find they don't have it. You spend money for transport in vain. In most government hospitals the medicines are not available, and one must buy in a chemist.

I: You go to facility Y and the medicines are not available there, so you get them from town, you called the place Mumbi House?

R3: Yes.

I: Where else do you get—- [Inaudible]

R1: When you go to the hospital, they tell you the medicines are not available, you go buy in a chemist.

I: Which hospital do you go to?

R1: Facility R.

I: How much is the medication?

R1: Ksh.150 and Kshs.200.

I: That will last for how long?

R1: One week.

R6: I took my patient to facility S. I was prescribed medicines that cost Ksh.1700 per month.

I: Where do you get the medicine from?

R6: The Chemist.

I: Where is the chemist?

R6: In town.

R3: The other challenge is when you loose the prescription paper for those medicines, at Mumbi House they cannot sell to you any medicine without it. So, you are forced to go back to Facility Y and for them to check in the file you must pay to get the prescription copy. If they can come up with a way to computerize their systems to avoid using the prescription paper, it can help a lot. Because they only give you one prescription paper to use for one year, it can tear up or even get lost.

I: Are you satisfied with the services you receive at the hospitals and the chemists?

R6: From my own research, if we can get government hospitals where we can be taking them to get tested and get medication monthly without paying, would help a lot, because sometimes, we lack finances especially for testing and medication. The patient's condition deteriorates in that month by the time one gets the finances because at the moment due to lack of a job. You find the patient is under a lot of problems.

R3: The challenge I face at facility Y is terms of payment because we pay via MPESA, there is no way you can skip the fifty people who are ahead of you in the queue and be served first. You carry your child while standing until the time you will be called. There is no wheelchair you can place her on. You stand for almost two hours while carrying the child on your back. It would be better if there was a wheelchair, it would make it easier in terms of movement. You find that you cannot go to the washroom while she is on your back, this really affects me.

R4: I'm happy with the facility I take her. At the moment, she does not convulse a lot, the only challenge I have is transport. I looked for a facility in the rural home–-

I: What's the name of the facility?

R4: It's Facility D in North Kinangop. I usually leave here in the morning and go all the way, I am given medication, even if it's an injection I am given and I bring it here at the chemist and the doctor there injects her. I feel that is okay, transport is the only thing that challenges me. If her medication can be available here, I can rest and be very happy.

I: What other challenges do you face?

R3: The other challenge especially in the government facilities is the washrooms. Most facilities don't have washrooms for special people with disabilities. If they can also have someone allocated to take care of epileptic patients when they visit the washrooms just in case an attack happens when they are in the washroom.

I: Do people understand what epilepsy is here at viwandani?

R3: They don’t understand.

I: Why don't they understand?

R3: They lack information.

I: What challenges did you go through before you understood what epilepsy was and which hospitals to visit for epileptic care?

R3: I had never seen an epileptic person. I thought my child had refused to sit down.

R4: Before it was discovered, my child was being treated for pneumonia. I thought she had pneumonia, I would go and she would be tested, I don't know what they used to see. I didn't know what it was and how epilepsy looked like. I discovered she was epileptic when she fainted when she was in class six. Once she takes medication I would think she is okay, she used to bend for a while when you talk to her, so when she became a grownup it increased because she was not taking the right medication.

I: Is it easy to identify an epileptic person?

R4: There was a time I was somewhere in a meeting, we were many and someone fainted. People thought it was because of the high temperature in the room, when I saw those signs how he was behaving, I knew it was epilepsy because I live with an epileptic patient. I told them to create space for him to get enough air. I knew because I live with an epileptic person but the other people were saying the person was drunk. When he gained consciousness and we went outside, he removed the card he uses for the clinic. At the moment I am able to know.

I: If you didn’t live with an epileptic person, you wouldn’t have known that person was epileptic?

R4: I wouldn't have known.

R3: It's difficult for people to know about epilepsy, even if you call a meeting right now to educate them on epilepsy, people will start speaking sarcastically asking whether they faint. You might call them, only those with epileptic patients will show up, those without epileptic patients it is difficult for them to come. Someone will show up briefly and leave they feel as though their time is being wasted.

I: To educate people will it be difficult?

R3: Yes, it is difficult.

R2: You might call them and they show up, or you meet someone on the road and explain about the meeting. The person will tell you," have I lacked something to do? I don't have an epileptic person, there is no need for me to go, how I am I benefiting?" The person doesn't know even if she doesn't have any epileptic patient, that education can help. You can find a mother who has gotten the attack or you can go to your relative and find he has the attack so you educate him.

R3: A lot of people are ignorant. They want to go where there are financial benefits. It can be very beneficial if people would learn because, even if you don't have epilepsy, you might come across someone who has epilepsy and help them, your relatives might be epileptic.

I: In case you call people to educate them without paying them they won't attend?

R1: They can't.

I: Can someone know which hospital they can take an epileptic patient in Viwandani?

R3: They can't know; they don't see the benefit of knowing if they don't have epilepsy.

I: Epilepsy has been ignored in the community?

R3: Yes.

R6: Many people have ignored this illness. You see someone faint, but people start saying this person is drunk, instead of helping them to stand up. You know when a person falls into fire it's usually a challenge. Others say when this person bites you will be infected.

I: What causes the financial challenges in treating epilepsy?

R3: I face these challenges because I used to receive cash transfers. The government has been donating Ksh.2000 monthly, but now I don't remember when I received the cash last. It's cash you cannot depend on, the little you get you buy medication and forget about food. Someone asks you "why don't you save?" but what you can save. The little you get you rush and get ten tablets, they get finished, you can't manage to save. The cash you get you buy medication and diapers, because she is a grown up girl I have to purchase the ones for adults. At the moment she is going to school, I go to friends asking them what they will buy for me, some tell me soap and others toothpaste. In her school, because of Covid there is no visitation, you buy medication that costs almost above ten thousand yet that is only medication, for pampers you also get the one that lasts the duration she will be in school, you find that you cannot have money to save. Unless the government supports us because maintaining this child is difficult.

R4: Lack of knowledge of where one can get assistance, like those cash transfers.

R3: The government should consider helping all epileptic patients, yes they say they want severe cases, mine was selected because she is severe, there is someone who is walking but he cannot do anything. The government should consider this because even blind persons don't get any support. When one takes the medication on credit at the end of the month they are able to pay. Epileptic persons have been sidelined completely. Even when they talk of other disabilities like cerebral palsy and blindness they don't mention them.

I: What can be done to help an epileptic person?

R3: In my opinion, what can help, if the epileptic persons are given a letter from the national council to explain that the epileptic person is able to work. They can be given certain jobs like sweeping or watering the flower. They should not be sidelined at work. They can work and earn like any other people, only that their duties should be specified because they cannot perform all duties like working on a machine.

R4: I would like the government to recognize them and provide medication free of charge.

R5: I second R4 point, for the government to recognize epileptic people.

R6: Epileptic patients to be given financial support because they are maturing and they need to develop in their lives.

R7: Treatment to be brought nearby, even if it's here in Facility R let them have a specific place for the epilepsy patients just like I saw in Karen.

R4: Mine is an addition, the epileptic patients are willing to work but this illness hinders them. Let them be given cash transfers so that they can support themselves and be like the rest of the people.

I: What can be done to educate people on epilepsy?

R3: What I feel can help is that, most people have televisions, there can be a channel like Citizen and NTV. They set a specific day aside to weekly from a certain time to educate them in Swahili a language everyone is able to understand. This way the information can spread to all people.

R4: In the government facilities before the services begin, there is some health education that takes place while waiting. Let there be a nurse who can teach epilepsy.

R7: Seminars can help.

R1: Have a meeting in the hospital. Even some doctors don't understand epilepsy.

R2: Even if they will show on television, all of us are not equal, there is one who has television and another who does not have. Those teachings can also be put on the radio.

R6: Announcing in the community and sensitizing them on causes and the signs of epilepsy, the hospitals to take them. This can help people.

I: I don’t know if my colleagues have anything to add? We have come to the end of the discussion. I don't know if there is one who has a question or anything to add?

R4: My request is that, if it's possible to have medication at facility R, because it is the facility that is near. If possible we can also have identification cards for people with epilepsy. It becomes easier for one to be assisted when he gets the attack instead of being rained on and people ignoring him saying that he is drunk. I am not sure if they will accept because the

Majority don’t like exposing their condition.

I: Those who are epileptic don’t like sharing their condition?

R1: They refuse being exposed because they think it will affect their lives negatively.

R3: It is not their doing, the people we live with have caused this, some tell them,” leave alone the way you fall down, I will beat you until you fall down and die.” You find that the words used by those around them, cause them to hide. Initially HIV was an illness that people were not aware of but currently people have confidence to say they are HIV positive.

R4: I used to blame myself earlier, but I realized I am not alone when I visited a facility and met so many people with epilepsy. Let the government have seminars for epileptic patients and a lot of them will know they are not alone and stop hiding their condition.

R3: R4 has said what I was about to say. Call them and let the person speak about his condition and he will discover it is not an illness that should be hidden.

I: Anything you would like to add or ask? We have come to the end. Thank you so much.

[End of audio]