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I: **This is an IDI with a caregiver at Viwandani field office, Lungalunga square. Welcome, we are going to talk about what I briefed you on. When people want to talk about epilepsy, how do they refer to it here?**

R: Sickness of falling down.

I: **How else do they refer to epilepsy?**

R: They only refer to it as the sickness of falling down.

I: **What reasons make them refer to it as sickness of falling down?**

R: The reason as to why people refer to it as sickness of falling down is because they observe the persons with epilepsy fall down.

I: **Thank you very much.**

From your understanding, what do you think is the cause of epilepsy?

R: The major cause is thinking too much. The epileptic individual I live with experiences falling down while walking and have been buried in thoughts.

Another cause is exhaustion from working too much and failure to adhere to intake of epilepsy drugs.

I: **Therefore, these are the causes of epilepsy?**

R: This is what causes epilepsy.

I: **How do epilepsy start...? How do you tell a person is epileptic? How does epilepsy manifest?**

R: When it first began for our individual, we never thought that it could be epilepsy. Since the individual was experiencing dizziness; we assumed it was normal for one to fall down while dizzy. It came to our attention when it became persistent and therefore, we went to a hospital for checkup, that is when we realized that it was epilepsy.

I: **Okay. Thank you very much.**

What symptoms should one look for in a person to conclude that they have epilepsy?

R: Eye observation will show weariness and sleepiness.

They will also stagger while walking. This also happens to little children. That's how you know that one has or is about to get epilepsy.

I: **Okay. So, these are the symptoms for epilepsy?**

R: Yeah. Those are the symptoms to look for.

I: **According to your understanding of epilepsy, does it manifest the same way in different people you encounter?**

R: It displays differently to individuals. When I encounter other individuals; the establishment is different from the ones I'm familiar with. Other individuals fall by the road, urinate on themselves and gush saliva from the mouth. My individual doesn't suffer from the above rather when they are unconscious the eyes keep on moving or close them as if preventing something from getting in.

Another different case that we were briefed on is; you might be conversing with a person, they are staring at you and they don't hear what you are telling them, also no response is relayed back. When the episode leaves them that is when they go back to normal and give responses.

I: **You have briefed me on how one becomes epileptic, the signs and symptoms. What is the understanding of epilepsy to people in the community…? You may include things on religion and so on.**

R: They don't think that it is normal. Their understanding is that a person suffering from epilepsy has been bewitched or demons have been cast upon them.

My experience from having an epileptic individual proves that that is not the case.

Others believe that the person is haunted by the dead.

I: **They believe that it is something associated with sorcery…**

R: Witchcraft, sorcery and so on.

I: **How do people in the community treat epileptic persons?**

R: They are fearful and stigmatize these people because they think that it can be transmitted through contact. Hence no one associates with them because they don't want to go close to them.

I: **How has having an epileptic child affected your life?**

R: It has affected my life since I was the one to pay for hospital bills whenever we went for checkups. This dragged me behind in terms of money. I had to accept the situation since knowing where the problem was or the reason for the faints, I would have peace instead of watching the child suffer and doing nothing.

I: **Okay. I understand the child is a pupil, how has being epileptic affected her life?**

R: Since the disease has affected her brain, her performance has also been affected. It also makes her forgetful. When I request her to do something, after sometime you find that the requisition is not done. After reminding her again, she also forgets.

I: How else has it affected her life?

R: Majorly it is on her education performance. Due to epilepsy, she is not able to attain her educational target because the condition makes her forgetful.

I: About her daily chores at home, are there changes on her performance compared to previously?

R: Yeah, she is slower. Due to the fact that she may get into the episode when she is too exhausted, we have to go with her pace. Also, we ensure that we don't give her a lot to do.

I: Due to the condition, what tasks are you not supposed to assign her?

R: Fetching water.Making two or three trips carrying a 20 liters Jerri can make her too exhausted, this can easily trigger the falling down therefore, we don't give her a lot to do.

This also poses a great danger because without being able to undertake such tasks, life in adulthood will be very difficult. When the time comes for her to get married and she is unable to work, it would be very difficult for the marriage.

I: Has her association with friends changed?

R: No. It hasn't changed. The interaction is still intact as before.

I: In the community, how do people treat her?

R: We don't allow her to intermingle with people a lot, she may go into the episodes when no one who knows her condition is around. People who are unaware may therefore conclude that it is just a young girl under the influence of alcohol and therefore may not help her. Those who are familiar with her condition gives us alerts whenever she goes into the attacks and we aren't around.

Today on her way to school she went into the episode before getting there, a *boda boda* operator together with a young girl helped bring her home because they knew who she was. I wasn't around and they called me up; she was able to report to school after regaining her consciousness.

I: **Okay. So, the assistance comes from those who know her?**

R: People who know about her condition help her. The community is a large area, those who are unaware of her condition don't understand her at all.

I: **On her association with friends, does she interact freely with them?**

R: She is okay when it comes to that.

I: **Do they discriminate against her?**

R: No. Her age mates come to visit her at home, they walk together and exchange pleasantries. When I observe them, she doesn't have any problems when they are around because they get to talk and keep her company.

I: **My understanding from your earlier remarks is that; people who think she is going to transmit the disease are other community members but not her friends and age mates?**

R: Yeah. Her friends and age mates interact freely with her and also walk together.

I: **Okay. Thank you so much. You said that your life has been affected, how do you feel knowing that your grandchild is epileptic?**

R: It is not pleasing and the picture is not so loving. What hits you is that; this child is attached to you and you can't cast them out. They will remain so whether they are young or elderly, bad or good therefore, you can't discriminate against them.

I: Okay. Who else do you live with at home?

R: My wife, her brother and uncle.

I: How has the lives of these people been affected?

R: Their lives have mostly been affected emotionally. When she has to go anywhere, we are left troubled mentally and wondering whether she is going to get there safely.

I: Okay. So, the major effect is mentally?

R: Yeah. That is the only major effect.

I: Among these people that she lives with, are there those that discriminate against or talk badly to her because she is epileptic?

R: No, there are none. We take her as normal as anybody else. We wouldn't want her to go into stress from wondering why she is treated differently from others.

I: What would you wish for to happen as she gets into her adulthood? What would you hope for as she turns from being a young child to an adult?

R: I would wish for her to get well. Her vision is being a lawyer when she grows up therefore, if she would get well, she would be able to attain this.

I: Your hope for her is that she gets better.

R: Yeah.

I: How would you predict her life if she remained been epileptic in the future?

R: It would have a great negative impact on her life. When it comes to employment, it would not be easy for her to secure a job because she would be discriminated against due to her condition. The immediate belief of an employer would be that due to epilepsy, her work performance would be low and hence she won't even stand a chance to defend herself.

Another issue would be time. She may collapse even while seated forcing a pause to the work undertaken therefore, an employer wouldn't want to take such a risk at their work place.

I: Has she been undergoing through any treatment?

R: Yeah. She has been under treatment and taking drugs. The drugs she uses are for mental health to prevent her from stress; which otherwise would cause her to fall down.

I: When did treatment commence?

R: It began last year. When she enrolled for Form one, that is when the falling down began.

I: So, it started last year…

R: Yeah.

I: Prior to that, had such an encounter been seen?

R: According to me; she didn't have any problem previously. It began when she relocated to live with her mother. When I did a follow up with her mother, she claimed that the faints were as a result of hunger.

After observing her for a while; I noticed that hunger was not the cause; rather, there was something really wrong with her. That is when I took the initiative of taking her for a checkup.

I: **Currently, where does she receive her treatment?**

R: Thika.

I: **Where exactly in Thika?**

R: Health Facility T.

I: **Is this where she goes for her clinics?**

R: Yeah, she goes for her clinics once per every month.

I: **Are you satisfied with the health services she receives at the institution?**

R: Yeah, I'm satisfied by the services she gets.

I: **How was the relaying of information about her condition at the hospital? How did the hospital help you understand her condition better?**

R: When I first got there, I was referred to Health Facility M where an E.E.G was undertaken. This is a computerized process where the brain performance is monitored. The doctor there helped me understand what was happening with the machine. Sometimes the waving would go up and I was made to understand that this was as a result of her thinking too much, followed by falling down.

I: **How was the examination?**

R: The examination showed that she was suffering from epilepsy. The doctors took us through types of epilepsy and how they manifest themselves.

We also learnt that it occurred differently to different individuals; others would fall, stare at one place or a person for a very long time. They would go back to normal after the episode leaves them.

I: **Were you familiar with epilepsy prior to your grandchild becoming epileptic?**

R: Yeah. I was familiar with the one that an epileptic person urinates on themselves and the one that individuals bite their tongue. In the latter, one was told to put a hard object in the mouth of an epileptic person to prevent damage to the tongue, that is what I had knowledge on. I had no clue of others that I later came to learn about.

I: Previously, were you aware of any places to seek treatment for epilepsy?

R: No, I knew none.

I: Is the Viwandani community informed of epilepsy?

R: I don't think so.Unless one has an epileptic individual, they get information on the disease from the institutions they go to seek treatment. Other community members who don't have any incidents are not informed.

I: Okay.

Are they aware of places where epileptic individuals may be taken for treatment?

R: No, they don't know.

I: Okay. Thank you.

What challenges have you encountered since taking your child to Health Facility T and Health Facility M?

R: Before clearly knowing where the problem was with my child; I had prior visited other hospitals such as Health Facility A where a different diagnosis was made, treatment undertaken and no improvement was visible.

Thereafter I went to Health Facility G in Kikuyu, treatment commenced and the assumption that it could be epilepsy was made. Since I was not familiar with her type of epilepsy, I stopped her from taking the drugs prescribed. Out of fear that these prescribed drugs would give her epilepsy or other conditions because I was unsure of this epilepsy thing, I had to make her stop.

After Kabete that is when I went to Health Facility T, they checked her up and told me that it could be epilepsy but to be sure, they referred me to Health Facility M for further analysis. At this time, I was pretty sure that she was epileptic. These are the stages I went through.

I: **What was the major challenge as you went through these stages?**

R: The major challenge was funds, everywhere I went, I had to spend.

I: **According to you, is epilepsy treatment costly? What are your opinions about the cost for epilepsy treatment?**

R: The treatment for epilepsy is too expensive. Her being a grandchild; she is not included in my N.H.I.F card therefore, I had to pay the bills in cash everywhere I went for treatment.

I: **Don't the health institutions accept N.H.I.F cards for students? Is she not included in a parents N.H.I.F card?**

R: The parent is not registered for N.H.I.F.

There is a health fund for students from the Ministry which also covers Epileptic individuals. I came to learn of this later.

When she began getting sick; I had to ask for a transfer from the school, because I was worried that it had demons. The fact that I had taken her there while she was mentally okay and now, she had fallen ill; triggered my actions. On 19th, she joined Ithanga where she studied only for one month (until Friday 19th the following month) and fell ill during prep time. Here I had paid Kenya shillings thirteen thousand, three hundred (Ksh. 13,300.00) for school fees. I was called up and my feedback to the matron was that she was going to be okay after a short while. The matron observed that there wasn't any improvement and she thereafter called the Deputy principal; who insisted that she undergo treatment, he requested for my approval and she was taken to a hospital.

The following day, which was on a Saturday, I was called in to take her home because the Deputy wouldn't permit her to continue studying there.

I: Why wouldn't they permit her to continue studying there?

R: Because she was sick, they issued me a transfer letter and she never went back.

Afterwards that is when she came into the current school.

I: Why did you think that there were demons in the first school you had enrolled her before?

R: We hear that certain schools are demon possessed, some teachers also believe in worship of these demons. You as a parent; you will start having question marks when things such as sicknesses befall on your child, this is especially if they have not had such cases in the prior moments.

Even after taking her to Health Facility G where assumptions that it could be epilepsy were made, I was astonished because the disease never manifested during the time we were together; rather, it began when she enrolled for Form one. This was what prompted for transfer from the school.

I: Why do you think the Viwandani community is unaware of what epilepsy is and the places to seek for treatment?

What should be done to make the Viwandani community aware of epilepsy?

What are the challenges that make the Viwandani community uninformed on epilepsy?

R: Not having epileptic individuals is the main cause. The ignorant don't even care of what is going on, they don't mind how those with epileptic individuals are faring let alone knowing where the person goes for treatment. Individuals who have epileptic persons get aware as they try to make their persons better.

I: So those individuals who are well informed are the ones that have epileptic persons?

R: Yeah. You find that they are familiar with the situation and even if they find epileptic individuals by the road, what troubles them is where to take these persons maybe because they don't know their relatives.

I: Okay. Thank you.

Why did you encounter challenges seeking treatment?

R: Let's say it is normal to encounter challenges while trying to seek the best treatment, this is because there is no way to know for sure whether the individual is going to get well. I first took her to Health Facility A where when the diagnosis that she could be suffering from epilepsy was made; I wasn't satisfied.

It was so hard for me to believe since she had been well all along. Her type of epilepsy was also new to me. Again; looking back in the family, no one had ever been diagnosed with such a condition, so it got pretty hard to come to terms that she was really epileptic.

I: The major challenge for you was accepting the situation?

R: Yeah.

Being epileptic is not like being insane. Insanity may sometimes be caused from too much abuse of drugs in epilepsy, the individuals don’t abuse any drugs which may prompt to the condition. Therefore, you have to be mentally troubled and wonder where the condition came from.

I: What do you think can be done to make the Viwandani community educate on epilepsy?

R: I think that they should be educated on the condition. Seminars should also be conducted and chances for people who are familiar or have epilepsy should be created. Through the interactions, other ignorant people are able to learn what epilepsy is and places where to seek treatment…

I: Okay.

R: There was a time that I was diagnosed with diabetes; a certain card which indicated this problem was issued, this would help in case I fell by the road. A person assisting me would be able to know what was wrong. Therefore, if people are educated, they would be able to do first aid in the right way.

Earlier, people thought that epilepsy could be transmitted through coming into contact with an epileptic person. When educated, people realize that this is not the case and are able to help epileptic individuals by maybe taking them to a hospital.

For fear of transmission through contact; people wouldn’t help epileptic individuals. Nowadays, this has changed because people are well informed.

I: Thank you.

Apart from your grandchild, are you aware of other individuals who are epileptic in Viwandani?

R: Just one.

I: What can be done to ensure that those living with epilepsy live a better life?

How can we help epileptic individuals live a good life?

What improvements should be made to help epileptic individuals?

R: Drugs for epileptic individuals should be issued for free because this is something they can't live without.

Organizations that advocate for these people should also be established.

Guiding and counselling should also be conducted, this would help reduce stress because epileptic individuals are able to express as well as interact with others.

We should make epileptic individual comprehend their conditions without any difficulties. Teaching them that what they are undergoing is normal would make them happy because they won't view themselves differently.

I: Okay.

So, you are talking about free medication, acceptance and sponsorship.

R: Yeah. I would majorly insist on free drugs.

I: What else do you think should be done to improve their lives?

R: People such as yourself should make follow ups on epileptic individuals.

Like I said, guidance and counselling would help them understand that they are also important in the community just as anybody else. It would also make them aware that epilepsy is an illness such as any other.

I: **My fellow workmates, do you have anything to say?**

I2: **Okay. You talked about how people treat your epileptic grandchild at home, how the Viwandani community treat other epileptic individuals in the area?**

What are their behaviors when they encounter these epileptic individuals?

R: People in Viwandani don't like being associated with these people therefore, they discriminate against them due to their conditions. To me; this is not good, we should associate with these people and exchange pleasantries; this would help reduce stress which is the major cause for them to experience falling down.

I2: **Thank you.**

I: **Thank you very much.**

As we wind up, I would like to thank you for making time for us.

Do you have anything else you would like to add?

R: I would only insist on the point of you people following up on epileptic persons.

I would also like to thank you for volunteering to look for epileptic individuals.

We had challenges with you people in the Viwandani community because you would find that a person would come, knock at your door, ask you to fill some questions and they go. After maybe a month or year another would come and repeat the same process. This became a challenge because no assistance was offered.

There came a time where, when these individuals came, we would refuse to answer their questions. Later your directors came, we sat down and talked. They informed us that there was a community hospital known as Cana which your organization sponsored. After verifying we came to understand that the hospital was known as Cana families not Cana community.

Also, the treatment for epileptic individuals wasn’t for free there, we requested them to intervene but no response has ever been made since that time. Recently, I see a difference in how things happen compared to how they happened previously. If a research on a certain disease is carried out and the people get supported that is what is important.

The community should also be informed in advance before any research is undertaken, this would help take the matter in a positive manner and make them assist where they can. It would also make people feel at ease airing their problems and also pointing on those who may be undergoing hardships.

I: **Thank you so much. I appreciate your opinions and what you have commented on.**

R: I’m grateful too.

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