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I: Thank you, Doctor, as we start, what has been your experience providing health care services in this community for the duration you have provided?

R: The experience has been good, we have been getting these clients from the community, others have been referred from other facilities since we have a psychiatric clinic, we also attend to epilepsy patients so we have been attending to those clients.

I: Where do you have the psychiatric clinic?

R: We have the psychiatric clinic here in the facility every Tuesday. I am the one who usually attends to them. We also have a team from hospital M, but they have not been coming since Covid came but they came back 3 weeks ago.

I: Those are?

R: The team from hospital M.

I: So, they come, the last time they came was 3 months--

R: Was 3 weeks, so we usually have a clinic every Tuesday.

I: That's nice, any other experience you have had with the community while providing health care?

R: With the community experience?

I: Yeah, the experience you have had with the community in terms of providing care and all that health services.

R: The experience is that the uptake is not very good.

I: Why?

R: Because they have a lot of stigma in the village, in the community. So they don't want to go to the facility to seek the services.

I: Which patients are those?

R: The epilepsy patients.

I: The epilepsy patients, okay.

R: But when they hear somebody was attended to in our health facility, we usually get at least get one or two.

I: Okay, they come in. Any other experience?

R: Coming to the facility is a major problem because they don't seek the services.

I: Why is it a problem or why don't they want to seek?

R: One is about the stigma because you can get a patient who have been attended to in hospital E, hospital L or somewhere else. They were told they have epilepsy but they don't want to seek the services because of that stigma or fear in the community.

I: Thank you. What can you say about the burden of epilepsy in the community you offer services to? I have seen you have mentioned about stigma and once they are aware of their condition, they don't want to come seek services from here but they are aware of their condition. What other burden do you think there is on the epilepsy condition in the community?

R: The data.

I: The burden of epilepsy in the community that you offer services in—

R: The burden is low because they still don't have the knowledge. There is a lot of knowledge gap in the community but it's a condition you are supposed to be notified of and go seek services. So, the burden is still very low.

I: When you say the knowledge gap, what's the gap about?

R: When I talk about the knowledge, in the community they are still not aware that the condition can be controlled through drugs or other seeking services in the facility. So what we do according to the report we get is that when you get a client, they seek other advice like traditional healing, prayers, they also take herbs or other herbal treatments. Others are neglected or locked in the houses.

I: Any other gap you are aware of in the community?

R: The other gap is that they don't seek the services, that's one thing. So they are there in the community, the conditions are there but they don't seek the services. They also have the fear of the unknown. The stigma is also in the community because they don't want to be associated that you have the condition. They associate it as a curse, you did something wrong.

I: Are you aware of any different type of epilepsy?

R: Yes, I am aware.

I: Like?

R: We have different types. One we have the generalized tonic-clonic seizure, tonic seizure--

I: Tonic?

R: Tonic, we have the clonic, the flying span or myoclonic seizures.

I: Flying Span?

R: Flying pan, sorry, flying pan or myoclonic seizure.

I: You were saying the other one.

R: The other one is absent seizures.

I: Absent?

R: Absence. We have said we have tonic, clonic, then we have tonic--

I: Generalized—

R: Those are four?

I: You have given us five, generalized—

R: Then we have the partial seizures.

I: What is the difference between the different types?

R: The generalized is the one which is most commonly known or is what most patients have had and it is what is most known by the clients where we have the tonic and clonic combined together.

I: In the generalized?

R: Yes, in the generalized. In the Tonic, there is the stiffening of the body. Then the Clonic is like being floppy, somebody was walking then they fall down. Then the flying pan or myoclonic is where somebody was holding a pan or something as a plate or cup, all of sudden it is thrown away.

I: They throw it?

R: Yes. Then we have the absence seizure, where you get you somehow confused and you start doing abnormal things, you can get somebody clapping hands, touching something, you might be here after the attack you find yourself somewhere else, after the attack you come back to your senses.Then for partial seizures is when it affects one part of the brain and you can get a seizure in one part of your body like your heart, one hip or even one part of the face.

I: It's the word partial part?

R: The partial part.

I: Okay, thank you for that. What are the types of epilepsy cases you receive in the facility?

R: Most of the cases we receive are the generalized tonic-clonic seizures.

I: Among the other ones, have you ever received any around the community?

R: Yes, there was a time I had a girl who was around 6 years, she had the absence seizures which was reported by the teacher to the parent. Though they never knew it was a seizure. They were assuming it's laziness or the girl does not want to go to school, something of the sort, that's when I explained to them the type of the seizure.

I: How often do you receive patients with convulsive and non-convulsive epilepsy?

R: With convulsive they usually seek at every week you cannot miss--

I: With convulsive?

R: Yes, they usually come.

I: Okay, and the other non?

R: The others are not very common but at least you cannot miss a case once in a while.

I: Why do you think the convulsive one is common?

R: Because of the knowledge, because when it is convulsive it's when the community realizes it's a problem but when it's not convulsive, they don't know it's a case or it's a problem so they won't go to seek for services.

I: So, the convulsive one is the most common?

R: Yes.

I: You have said the most patients that come are for the convulsive one, why do you think the case is most in this community for the convulsive one? You have said one is because they can be able to identify it, is there any reason why it might be common in the community?

R: Because you get a comorbidity or other illnesses, after you get the convulsions, you can get a cut or you can get burns and when you begin convulsing, the community or relatives will make you go and seek the services.

I: For the service of the cut or burn?

R: No,

For the seizures, now plus whatever you are going to get for others.

I: That's why it's so common.

R: It can also be triggered by other conditions, the patient may have other comorbidities, for example it's a child and has fever, now the other cause will make the patient go look for the other services.

I: That's nice. In your opinion, how much information does the community have regarding the disease of epilepsy and its causes?

R: The information is very low.

I: Why do you think so?

R: I think so because they don't seek services and the cases we get are very few but I know the conditions are there but the seeking services are very few.

I: On a scale, how is the seeking services? If you rate, how would you say the seeking service is at the community?

R: 2 out of 10.

I: 2 out of 10?

R: Yes.

I: What have you learnt in the community about the causes of the illness? The few ones who come in, what are their thoughts on the causes of epilepsy condition?

R: Some of them say it's a curse, others associate it with other illnesses, for example in children, if a child had meningitis or the others are bad trauma. Others say it was thrown to them.

I: What was thrown?

R: I don't know, it's a belief, being thrown at that thing is evil eyes. I don't know how I can call it but that's what they say, it's one of them.

I: So, they were looked at with evil eyes and they got the condition?

R: Yes.

I: Okay. Any other cause you have heard?

R: The others are inherited, an uncle or a relative had the same problem. Others is secondary to trauma; they say after the patient got an accident is when the problem began or other illnesses.

I: Where does the community commonly seek care for epilepsy? You have said you have epilepsy clinic here every Tuesdays, but where do they seek care most of the times?

R: Most of the times some of them go for prayers, they call them healers.

I: Who are the healers?

R: They are the religious people. I call them in quotes. They go to the healers they get prayed for.

I: Why would they choose that?

R: It's their belief. There are some, I call them in quotes 'those houses you go to when you have a problem and when prayed for, the problem will disappear'. Others go for prayers by their religious people, the pastors or those religious people, others seek for those traditional medicines. They are given some mixed things and told if they take it they will be healed. In other traditional healings the body is scratched and traditional herbs put in thinking it's going to heal. The few come for services in the facility.

I: Why do you think some will come and some will go to the spiritual healer, for the herbs and even scratch their body in the community?

R: One is because of the knowledge gap; they are not aware they are supposed to seek for medical services which is the right thing. Other one is about religious believes and traditions especially those people from the rural—-

I: Rural?

R: Yes, they believe that someone else went to a traditional healer, was given some herbs and they were okay but the main is the knowledge gap.

I: The knowledge gaps?

R: Yes.

I: How does the level of awareness regarding epilepsy affect the community members in terms of how they seek for the care of epilepsy, how they take up the treatment of epilepsy and their knowledge level on epilepsy?

R: The knowledge level is very low.

I: How does it affect how they seek care for it and the treatment?

R: Because of the knowledge gap that I have said, they don't seek the services. That's why they go for other services like the traditional healing. They think that when you go there you will be okay. Also, the community have a right to choose, so when they choose those areas because of that knowledge gap that's why we have the problem or the knowledge gap.

I: What about treatment, how is it, you said there are a few who come to the hospital, how is their seeking care and treatment?

R: For those who seek for the treatment and we do the follow up, at least when they come for the services the seizures are usually controlled depending on how they are adhering to the treatment.

I: How is the adherence level?

R: The adherence is very poor sometimes because you may find since we don't have the drugs, we prescribe the drugs and they don't go to buy and if they buy it's for a few days and later on they are left with no drugs.

They come and tell you "I took drugs for a few weeks then I didn't have money". So the control of the seizures is usually poor because of the adherence.

I: What is the condition of the other people who seek for the other means like the spiritual, the herbal, the traditional? Because you said the others who don't adhere as they don't take their drugs as needed, their adherence level goes down. So, what about the other people who seek for other means?

R: The other means, when they go for the traditional healing, they also pay for them. It's not for free plus they are not seeking the right method or right treatment. So, the adherence or

control of the seizures are usually very poor. That’s why you will get somebody telling you I have been going to such and such a place, seeking services but the control was very poor. That’s when they come seeking services when it's already very late or with complications. So the control is poor.

I: They first try other means and then when it's too much then they come in?

R: Yes.

I: Okay. What care services do you provide as a facility?

R: We usually have the Comprehensive history taking, it might be a new client or even a follow up, we do the Comprehensive history taking after--

I: Comprehensive history taking?

R: Yes.

I: Okay. What happens here?

R: For example, somebody has been referred from the village or from any other facility, I do the history taking after that I come to differential diagnosis of this is epilepsy, depending, now it will depend whether you need to do further investigation and now when you take the diagnosis of it being epilepsy, we start them on treatment after counselling. You will have to do thorough counseling.

I: So, you have counselling services?

R: I am the one who is supposed to do it. So you do it, you don’t refer. It's holistic, you do the examination, the counselling, prescribe the drugs and you give a follow up.If they need other investigation, you refer.

I: So, you said you do comprehensive history taking if it’s a new client, counselling and then you do--

R: We also have psycho social support and you also have to involve the family because this one you have to involve the family.

I: What do you talk to the family about when you involve them?

R: In epilepsy, most of the patients don't realize what happens when they get the attacks. It's always a matter of getting the relative to give what happens, the trigger factors, you go digging deeper and you are at least able to know what are the trigger factors of the attacks, why or where it started.

I: We have talked of the different services you offer; we have said counselling and all that, but is there a time you need to refer?

R: Yes.

I: In what instances do you need to refer?

R: If the seizures are not controlled you need to refer or it might be a first case and you are not very sure. You will have to refer EEG or for anything like a CT Scan or the patient has other comorbidities which you cannot handle in the facility.

I: Where do you refer to as a facility?

R: We refer to hospital M or hospital L.

I: Any other place that you refer?

R: If it's severe, although it's very rare, you are suspecting cancer or whatever, you can refer to hospital E but our referral center is hospital L. You cannot refer directly to hospital E. We refer to hospital L or M but if they need a referral to hospital E, they are going to refer from hospital L.

I: Okay. Do you have outreach services about epilepsy in the community?

R: No, we have never had one.

I: Why is that not possible because you have said before in our previous talk that you feel the problem is lack of information among the community members, why haven't you done any outreach services before, any challenge why you can't do that?

R: One challenge is about the financial because most of the outreaches we usually conduct are usually supported and most of them target the OPD minimal, plus the other services is about the MCH FP.

I: OPD

R: OPD is virtually very minimal.

I: It means?

R: Outpatient department but when we are going for services for outreaches it's mostly targeting the MCH and Family Planning.

I: They don’t prioritize on issues of epilepsy?

R: Yes, it’s rare.

I: How do you describe your capacity, you have told me you are able to prescribe and you do counselling, any other way you are able to describe your capacity to diagnose and treat epilepsy? How can you rate your capacity in doing that?

R: How can I rate my --

I: Capacity to diagnose and treat epilepsy?

R: That one I don’t understand but when we go to the community, at least when we give the health talk,

If we can go to the community and give health talk, we can be able to get so many cases from the community depending on how we give the health talk.

I: For example, someone has come in, you are supposed to diagnose them and be able to treat them on epilepsy, what is your capacity on that? Your ability to be able to treat and diagnose epilepsy cases?

R: At least I have the knowledge. Through the knowledge that I have, I am able to diagnose the epilepsy and also to do all the other necessary treatments.

I: So, you feel you can be able to handle that?

R: Yes.

I: Are there any trainings you have received on the diagnosis and treatment of epilepsy?

R: Not really, the last training I did was in 2003, but during my higher diploma, at least we had a topic on epilepsy.

I: And are there any other colleagues in the facility who can do the same treatment and diagnosis?

R: Unless from the basic diploma, but if they get the capacity building, they are able to diagnose.

I: Right now, are you working alone or do you have someone else who supports you in the department of epilepsy?

R: No, I don't work alone, we work as a team but most of the time if they get a case they usually refer to me, but the clinician we have, most of the times unless somebody comes with a prescription they have been followed up in another facility or they come and give you a history of convulsion or whatever, they prescribe the treatment but at least from there they have to refer the patient for thorough history taking.

I: Who does that thorough one?

R: Sorry?

I: Who does the thorough history taking?

R: I am the one who does.

I: You are alone in this facility?

R: Yes.

I: From the community level, is there anyone who helps in the diagnosis?

R: Not really.

I: The {Community Health Volunteers} CHVS.

R: They don't have the knowledge.

I: They are not trained?

R: Yes.

I: What can be done to help on that?

R: We can train the CHVs so that they can be able to diagnose from the community and refer the clients to us.

I: Okay. What is your opinion about the availability of necessary drugs? You told me sometimes you prescribe drugs, what is the availability of drugs in this facility?

R: We don't have any. It's zero.

I: Is there a time they are in, once in a while?

R: Very rare.

I: Very rare?

R: Yes, I think was it last year? We had very few carbamazepine and phenobarbital but they are never supplied. The supply is very low and not erratic.

I: When you prescribe where do they get the drugs from?

R: They go and buy from the chemist.

I: You told me you see clients; the epilepsy patients and you are able to diagnose and offer counselling services. In what instances do you refer like a number you do refer among the clients that come in to seek services?

R: For me what I usually do is, when I see clients, with the little knowledge or the knowledge I have that's when I attend to them. You may get a client comes, you have prescribed drugs and they are not getting controlled so that triggers me to refer the patient, or they have so

many other conditions, they come and tell you I have this, or through the examination you find they have other conditions. That makes you to refer the patient.

I: What are other conditions?

R: For example, there is a lady who came in, she had so many comorbidities, I can't really remember what she had and she had two MRIs from hospital E. For such cases, I always refer them to the right place for example back to hospital E or to hospital L to be seen by the physician or neurologist.

I: How about the testing capacity for epilepsy in the facility here?

R: Testing?

I: Yes, the equipment needed in testing--

R: We don't have anything for testing. It's only through history taking, so we have nothing we can say we use for testing.

I: We are about to end our discussion, but before that we will try to look at some of the challenges. You have talked of issues with stigma, drugs where it's rarely in here, issues with equipment to test not being available, also you have said of trainings the last one you had being around 2003 which is a long time, so of the challenges and if there are others you will be able to add, are there any other challenges apart from the ones we have mentioned before we start looking at what can be done to address the challenges.

R: Other challenges?

I: Yes, to add on those before we address them. Anything you think you would add that you face in your line of work?

R: We can also add about support. We can be trained to get supervision training then after whatever we have been taught or trained, we can be followed to make sure we are doing the right thing.

I: Who is supposed to provide the support?

R: I have said after training.

I: Okay. Also, one is the training?

R: Yes, after the training we will need support supervision.

I: So, you lack that as well?

R: Yes. Because we don't get support from anywhere. Somebody can come and support you if there is need for you to continue. But I believe now we are going to get the support.

I: Who can be able to provide the supervision?

R: Whoever will be trained, can be the trainers.

I: Who are supposed to be the trainers who can give you the trainings as health care providers?

R: You are the one who is supposed to give us the training, I hope so. [laughs]

I: Us?

R: Yes, or at least you look for us the partners or if the Sub-County head people are trained, they come and train other staff from the ground.

I: So those who are trained from the sub county--

R: Or wherever, at least they come and do the support supervision.

I: About the other challenges you had mentioned, we can begin with the drugs one, what do you think can be done about it?

R: About the drugs, it's a major challenge because one, the data is very low and they supply the drugs according to the data, if the data is low, they cannot supply the drugs.But after the training, we will get the cases escalating and at least through the data we can be able to lobby for the drugs. We can say we have this number of clients and we need these drugs through the data.

I: You need the data?

R: Yes.

I: But you said the cases are in the community—-

R: The cases are in the community but they are not diagnosed.

I: What can we do about the diagnosis so as to get the data?

R: The diagnosis we need to go to the community, we create awareness in the community about epilepsy. The other one is we need to train the CHVs and we need to do the outreaches.

I: Who will be in charge of that, training the CHVs, the awareness creation, doing the outreaches?

R: If I can get support, I can do it.

I: Which support do you need?

R: I need support of facilitation of the training.

I: Facilitation.

R: Yes, facilitation of the training and I also need to be trained.

I: Yeah, you also need to be trained?

R: Yes.

I: Okay. Any other of the challenges, how it can be addressed? We talked of stigma.

R: The stigma and the myths in the community can be dispelled through the knowledge capacity building of the CHVs and the community. They are made aware or we create awareness that it's not a curse, the seizures can be controlled, you don't need to go to the traditional healers. Through that capacity building, we can bridge that gap.

I: The last one was about testing equipment and personnel at the health facility level. What can be done about it?

R: First of all, I don't know what is required to test.

I: You need information about that as well?

R: Yes.

I: Okay. I think I am done and my colleague says she is fine with that. Thank you for the conversation and I hope we are going to get the equipment, the trainings for a better community and better work ahead.

R: Okay.

I: Thank you very much.

R: You are welcomed.