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I: Welcome.

R: Thank you.

I: What has been your experience providing health care services in this community for the time that you have been working here?

R: Experience as in mental health or generally health care service?

I: Yes, generally.

R: Most of my time I have been practicing in Viwandani but recently I moved to Health facility K on one day that is Wednesdays where I offer mental health services to the clients. I am not sure if I will talk about this community or the one in Viwandani because I have been here for just a few months. What I have experienced is that most of the community are the youth and there is a lot of drug abuse in this community. Most of the conditions I come across are alcohol induced psychosis and it's mostly affecting the young. I work in the CCC department when I am in this facility because that is where most of the referrals come from. The clients that I handle are those that have socio- economic issues which contribute to defaulting of medications that is ARVS and this comes up with some complications. I have also experienced comorbidities. You find a client with HIV, depression and a type of cancer, prostate for men and cervical cancer for women. Those are the clients with complex issues that I deal with, and it is as a result of all those factors, they default their medications and they get complications. The economic situation in this place is a low socio-economic community. We refer them to other facilities for further investigations and tests. We also link them to social workers so that the cost can be waived in the referral facility. Another thing is follow up from the clients. At times when you give a client a date to come, especially in the mental department, it's like you have to keep reminding them on the phone that they have an appointment. Others don't respond but some of them do, they don't come the exact date they come some few days later. Follow up becomes an issue, but we have a strong team of community health workers who we are able to link with so that they can bring back the clients in the facility. That is what I have experienced every Wednesday when I come. In the outpatient, I give a health talk especially on the availability

of the new service. I talk about other facilities outside because in this place people keep on moving because they are business people. (*Inaudible speech*) I want them to get the service wherever they are. I inform them of other facilities where they can still get the mental health services and the days they can get them that is in our notice board. I pass information and I have realized that people don't want to ask a lot about mental illnesses because of the stigma associated with it. I have realized that however much I try to engage them they would not want to ask as a group they want to follow you as an individual. There are stigma issues when it comes to mental illness. I have clients who are sisters and have bipolar mood disorder. The mother wants to relate this to witchcraft and it becomes a problem when I have to talk about how medication is for the long term. She still wants to go to upcountry and get some other medication. We have a lot of health education to do to avoid the mixing of these drugs, the herbs and what we give here. (*Inaudible speech*) They belief in witchcraft and so we have to educate them so that as much as they want to go to get the alternative medications we explain to them about the interactions of drugs.

I: What would you say about the burden of epilepsy in the community that you are serving here?

R: In Health facility K, we usually get around five clients in a month. There are clients who come as transit. You find a client coming with a very old prescription, they just want the medication they don't want any contact with the health care worker. When I interact with them, some say that people call them mad, and they don't want to be seen interacting with a health care worker. They just want the medication and there might be many others stuck there, who don't want to come to the facility because of that. They get the complications, the seizures continue and they get the severe form of epilepsy as a result of this. We are able to trace them through the community health workers too so that they are brought back to the facility. I join the community health assistant during their meetings to give information on availability of these services. People are there but they are not aware of the services but the moment I get an opportunity to share the information, there is always someone coming to seek for the services. The patients are there, but there is that fear that "when I go to that facility people say I fall, people say I am possessed so I wish to go and get just the medication

and get out." Since we started this, I have seen a positive response. Community health workers accompany them to the facility, they have my number through the community health assistant and even the staff here are aware that I come every Wednesday. We are getting a positive response though we have not yet gotten many, especially the children. I feel that they might be there but they either go very far for medication because they are not aware or parents don't wish that their children use chronic drugs for longer times. I had a boy of 14 years, the mother was worried about why that boy should continue taking the medication, and it's a lost to follow up. She told me she wants to go and seek opinion from the grandparents' upcountry. That one the convulsions will keep on coming but they are not willing to get the medication even though I prescribed, because they want to hear an opinion of someone else outside the facility.

I: When you talk of transit you mentioned some of the patients are on transit what do you mean?

R: Someone who is visiting from upcountry and they don't have the medication, they come directly to the pharmacy to ask for the medication, they don't want to go and register in the records department and go through the consultation room. They just want the medication and nothing else. They just want to be there for a few minutes, talk with a few people and get the medication and leave. When we try to interrogate such a client, they say they have been buying from the chemist and have decided to pop in and check if they can get this medication as long as they cannot get into the consultation room. We have been able to bring a few and encourage them to come so that they can be monitored and assessed at each visit. If there is need for adjustment on doses we are able to do it because some of them are on very high doses which are not necessary because the convulsions are not there.

I: Talking of high doses maybe now we can discuss on different types of epilepsy, the ones you know and the ones you receive at this facility

R: We have two major groups, convulsive and non-convulsive. The convulsive we have tonic, chronic and the tonic chronic and I don't recall the others.

I: Which ones do you receive at this facility?

R: Mostly is the tonic chronic, the severe form where the whole body is involved.

I: The one that you are talking about, is it the convulsive one?

R: Convulsive. The issue with the non-convulsive is, it is very hard for the parent who is not very keen to realize that the child is having it. They are very brief and frequent forms of convulsions.

I: Okay. How often do you receive patients with convulsive epilepsy?

R: Actively convulsive clients, we might get like two in a month because those who are already on medication, the convulsions are already under control. You might find one or two, mostly the children because of the high fevers. The numbers are not as high and it is children who mostly come with convulsions yet to be confirmed epileptic.

I: What about the non-convulsive?

R: Non-convulsive in this community not yet.

I: Why do you think the convulsive one is the most common in this community?

R: I would talk about factors; drug abuse is one of the risks. Some people get it as a withdrawal symptom from the alcohol or a complication of alcoholism when someone becomes addicted. That is the main reason why it's very common.

I: Do you think the community members have knowledge or information regarding epilepsy disease and the causes?

R: With mental illness information is through health education, in the facilities, through support groups and follow up. If mental health was an appraisal but it was isolated somewhere where people talk about breastfeeding, pregnancy and how to get a healthy baby but no one talks about these things. Information is lacking, people have a lot of myths and misconceptions about epilepsy. Now that we have started and not every day we find people to talk about the same thing. There is a lot of stigma when we try to engage the clients and discuss, as you discuss breastfeeding, they don't want that to be an intensive discussion. People want to come one on one but within the group you are able to reach many.

I: What have you learned from the community themselves about the causes of epilepsy?

R: Most of the things I hear are the myths and inheritance and some say that "this is a communicable disease when someone gets convulsions you should not come near them." Others talk about noise, "I was exposed to a lot of noise my grandmother said that is why I got this." Others talk of witchcraft and evil spirit possessions; those are the common ones.

I: That is what the community says causes epilepsy?

R: Yes, the genetic prepositions come out and the misconceptions about being demon possessed or bewitched.

I: Where does the community commonly seek care for epilepsy? Where do they commonly go to seek treatment and care for epilepsy?

R: This being the only facility, we get some here. Some would go to Health facility L which is just across and others who maybe started a long time go to Health facility M. When I do a health talk at times I find that people go as far as Health facility M and I am able to tell them this service is available here and they can get the same services and in case of a referral it will be facilitated, you don't struggle incase referral is necessary. With good adherence to medication they don't get those convulsions. The clients I have interacted with since May when we started this, none of them has had a convulsion, although initially some had stopped medication and went to seek help elsewhere like prayers.

I: **Those who go for prayers and as far as Health facility M, why do they seek treatment there instead of coming here?**

R: With convulsions people run and get so scared they start looking for taxis and go very far. Once they take their clients there and are prescribed for medication after the investigations, they are closed up. They are not aware of any other places. They go there and they pay, the prescriptions they get the drugs are very expensive and they start missing the medication. Unless the information starts and is given to them that the services are available nearer that is the only way they can know about our presence. They have started knowing now through the community health workers and it is working though we still have a long way to go.

I: Do you think the level of awareness regarding epilepsy affects the way community members seek treatment and care?

R: Yes, the level of awareness does and stigma. People are not aware or they say this is a mental illness and Health facility N is the only place that people should get the assistance. The stigma associated with the way the convulsions come. Awareness is low people are not aware of what it is, where they can seek the treatment and then the stigma.

I: That affects how they take up the treatment?

R: It does because the first visit determines how a client adheres to the treatment thereafter. If someone is taken through the process and then we have their contact, we assure them of support and we walk with them in case of anything they are free to come and when they come they find we are available, that helps.

I: What care and services for epilepsy do you provide?

R: A new client we do some investigations; a convulsion can come with many other conditions. We do baseline investigations, the basic tests that are available in the facility. After that we give the emergency care if someone is in active convulsion. Most of the people that come with an active convulsion become a referral depending on how it is. Mostly, we would like to refer them for further investigations because it is a new client. Most importantly we take a very comprehensive history from birth to where they are so that we are able to relate events. Prescriptions for those who are coming for a revisit we know this is a confirmed epileptic we are able to continue with medication. Another important thing is about drug interactions and reproductive issues. Most of my clients I have seen are females, with the drug interaction with family planning there are risks of pregnancy with certain types of contraceptives. That is something we take them through, we also want to know about their reproductive plans. We invite their partners where possible to discuss issues about reproduction so that when we are giving medication and a pregnancy comes we have congenital malformation as a result of medication. We do psycho-education a lot. The drug interaction we talk about with family planning, we advise them on the best according to their reproductive needs.

I: In regard to the treatment that is provided here, is it available? Which treatment is available?

R: The one we have for now is carbamazepine, phenobarbital is out of stock. For now, we have nothing because the carbamazepine that was available is now over. It was expiring in December but we don't have the stock. They are buying.

I: Most of the drugs the patients get you give them prescriptions and they get outside?

R: Yes, they get from outside.

I: Okay. What other services are provided beyond treatment? You had mentioned health education.

R: We do psycho education, there is health education, psychotherapy that is the top therapy, family therapy because epilepsy comes with a lot of family dysfunctions. I work with counselors. Some of them are trained in psychology. When I feel overwhelmed I talk to them so that they can assist me so that we don't lose the clients. Family planning for a female client, I take them to the room after explaining so that they can get the method. We talk about comorbidities for HIV and epilepsy, for the defaulters some of them develop this. Another thing very important is rehabilitation, with epilepsy there is the care one has to take to avoid injuries during convulsions. We talk to the caregivers about how to handle one when there is a convulsion to avoid further injuries. We also talk to them because the caregiver also gets stressed up especially when the convulsions happen at night. If it's a mother who is living alone and the convulsion happening at 3am we talk about all that about their feelings, we do some debriefs.

I: When you talk of comorbidities what do you mean?

R: Two chronic illnesses existing at the same time in the same person, HIV is a communicable chronic illness, epilepsy is non-communicable. You find such a person has hypertension, high blood pressure, the person might have several drugs at the same time. This is one thing that is very common. It means they have to be on many medications and they might get into depression because they don't understand what is happening. That is why we do a lot of talk

therapy. We teach them about breathing exercise because anxiety also comes with it especially, “you have to buy a lot of medication, very expensive no cash you are afraid that maybe it’s the end of my life and I am not able to purchase this medication to keep me away from this convulsion or high blood pressure.”

I: In the community do you have outreach services?

R: Yes, we do outreach services only that we had paused a bit because of the Covid. The community health workers are attached to households. Most of the time the outreaches are for family planning and general outpatient. The community health workers act as a link, they are able to move from house to house, identify the health needs and link the referral using the referral booklets to us. Some of them accompany them to the facilities. For now, outreaches have not been there but before the Covid issue came we used to do this side, but in place J even during the Covid we used to carry them out because people stopped coming to the facility that time.

I: How would you describe your capacity to diagnose and treat epilepsy?

R: The issue comes with diagnoses because we are not very much equipped especially with the investigations and the tests that we may require. Another thing is the drug stock out. Being a primary health care facility, it is important if all the clinical staff have the basic information on what to do so that we don’t miss any client. For the non-convulsive, we have to be very keen to be able to diagnose a non-convulsive epileptic patient. We are not well equipped to do this. The human resource, the specialist nurses and clinicians if we have more, the psychologist someone to assist us with the counseling because the process takes longer and some people get tired on the queue and they would like to leave. When they leave, they may go to buy drugs or miss the medications. We need to train JATs and CMEs so that each of the staff can have a feel so that whenever they have a client they are not stuck on what to do or book them on a date which is very far and in between here things happen.

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

R: I learn online to improve my skills.

I: The one you do online is in regard to diagnoses and treatment of epilepsy?

R: Not specifically epilepsy, it is all mental illnesses.

I: Are there other colleagues here who can diagnose and treat epilepsy?

R: Yes, the clinicians working in the outpatient can, at least the prescriptions are done.

I: Are there community volunteers or community health workers who have been trained and equipped to diagnose and refer individuals with epilepsy?

R: Have not heard any trainings for community health workers. They are trained on other areas such as reproductive health, wash and sanitation, nutrition. Those are the major ones but epilepsy and mental illness not much.

I: In the community are they able to refer an epileptic patient? Are they able to identify someone with epilepsy and refer them to the facility?

R: The community health workers with the training they have when they get someone with abnormal behavior or something that according to them is not within normal range they just refer and they indicate referred for health services. On our side we are the people that decide which department one is taken especially for the outpatient cases. For the family planning it is just obvious they just go to the room.

I: What would you say about the availability of necessary drugs and testing capacity for epilepsy in health facilities around this community?

R: Unless in the private sector, in our public facilities we don't have medications and even the testing and investigations, the capacity is low. We are stocked out, lab reagents. If we need X-rays we have to refer to Health facility P is our nearest.

I: When you talk of the private sector you are referring to other facilities that are not governmental?

R: They are not government like Health facility Q which is just here. The cost implications and people around here use NHIF and not everyone, out of pocket payment might be a

challenge. If we make referrals they will opt to go to Health facility P still to pay out of pocket because to be served there with NHIF it has to be a hospital of choice if you are not a civil servant. According to the economic situation in the community there is an issue because of cost implications.

I: What would you say are some of the challenges that you and your colleague face in providing care and treatment for epilepsy patients in this community?

R: The first one is drug stock out, baseline investigations and tests at times they are not available. Being a level three some of those tests cannot be done at this level, so referrals are necessary. With referral, it takes time for us to get the results and the patients to go for the tests we referred to, the outcome becomes poorer than if the resources were available in this facility.

I: Earlier on you had mentioned of human resource, when you were talking about the services and treatment you are offering here. You were saying human resource is a challenge, probably you could expound on that. It is a challenge in providing care and treatment for epilepsy or it is a challenge in what way?

R: I was talking about the capacity building, the training and the refreshers. When we do these things in college we need refresher courses, some MDTEs where you discuss about a certain client, maybe who is not improving. If people are not equipped with information and knowledge such things cannot take off. On specialties we don't have many of the staff who are specialized especially in that area. Generally, the patient will be seen but the quality of the service would be better if we have people trained.

I: When you talk of MDTEs in full what does it mean?

R: Multidisciplinary teams. The HIV department is very organized; it is well build when it comes to that. When a client is failing first line treatment of HIV, people meet from different departments. From the HDS department the one who tests, the one who does adherence counselling, the clinician, the nurse, they meet and discuss "what might be happening to this client, what can we do to improve the outcome?"

I: What can be done to address these challenges you are talking about the drug stock out and the one you have said baseline investigations, what can be done to address the challenges so that you can be able to give better services in regard to epilepsy?

R: The issue of drugs is an issue with a county government NMS. We usually do our orders every three months and we have done it. It's a system issue, it's from above. On our side it's just reporting from our level upwards, from Sub County, to the NMS or County, we keep on reporting on the challenges that we are having so that they can be addressed. Some of those challenges are beyond us including the reagents in the lab, all those things are paid for by the County. There was an issue with KEMSA now moving to MEDS, the corruption issue has been a challenge. With time things would be better but for now we are still struggling. As MEDS come in to start supplying us, I think that's where the problem was when there was scandal on the KEMSA issue. We just report on our side. We usually hold meetings every month. The facility in-charges they report the challenges they have. As a focal person in the Sub –County as I move I report on the challenges I am going through. These reports are communicated to the higher levels and through that things might improve though they might take longer. Some of my clients talk of support groups in the community. They come together as people with disability or suffering epilepsy, those people that feel like they are disadvantaged and through that they can be able to negotiate as groups and get people to assist them to get drugs. They can go out for some debriefing and discuss their issues far from the community. It works because they are able to share. One person may decide to buy the drugs for those who are not able to buy, that might be a little effort but it goes a long way maybe for one or two individuals who are in the group.

I: Any other solution can be done to address those other challenges, the one for trainings, having specialists?

R: For trainings, organizing continuous medical education for all staff in the facility. We can do CMEs and sensitization. CMES are better for everyone, not only for the clinical staff even for those people working in other departments. They may have such an experience, maybe the watchman is the first person who meets the client there. If they have the knowledge about

how to handle such a person who is having a convulsion, it would be easier and reduce the injuries that come with it and save life. If someone is choked as a result of that process they might die, so if people are able to handle and to know, to have the basic knowledge on how to handle such clients when they come into the facility and you are the first person to meet them, it is very important. I would talk of all staff being sensitized and continuous medical education for the clinical staff on how to care and treatment.

I: Do you have any other recommendations in regard to treatment of epilepsy or just epilepsy in general?

R: Yes, I have a concern about epilepsy in pregnancy. I once had a client who was an orphaned client, that was in Health facility R. She was from an orphanage and now married and she has been epileptic since she knew herself. The fits had increased and she was past the first trimester of pregnancy, at that time we needed to have changed the medication to a safer drug. She didn't have the information. She came when it was past three months and she complained that the convulsions have increased since pregnancy. That is an area of concern, we need to equip all the departments including family planning, preconception care area, so that people are aware and they can save a situation. When someone is epileptic and she gets a child with a defect because of a drug it becomes another burden. Epilepsy in pregnancy and in other special populations in children, mostly in children they get absent seizures, the non-convulsive epilepsies. In schools, the teachers realize that this a funny behavior. Some people just stare and they are having a fit. As a parent the way you are busy you are not able to realize that this child is having a convulsion. We have the school health focal person and we visit schools. Those teachers, if they are able to realize what is happening and get to know the signs and symptoms. There is one I got from school. He got the fit while in class and the mother was called to take him to hospital. The situation was not very good because the boy bit his tongue. If teachers have basic information, the first aid to give such a child the outcome would be better. We would not have to treat the wounds and the bitten tongue. With the stigma, in school you can imagine the child falls in the presence of others and they have to go back to the same school. That is why the mother would say it was not epilepsy and would not want to adhere to medication because of the stigma associated with this. The

public schools here the pupils are from the same locality, that family would be stigmatized. We usually go for debriefs sessions in schools with the school focal person. It's very important for them to understand what they expected to do in case of such emergencies.

I: Basically, what I am getting is that apart from the mental health care service being given for epilepsy the sensitization should be done in schools–-

R: Even in schools.

I: In other department in the facility like in the family planning department?

R: In the morning health talks so that our clients would know. There is also social contact where someone who is epileptic, is linked with someone else who is newly diagnosed. The person can come to the facility and talk to the clients and explain to them, "that this is a disease and I have gone through the same and one should not feel that they are a lesser person." The social contacts are for stigma reduction.

I: Thank you so much. I don't know if my colleagues have an additional point or something they need to add.

I2: Okay. Earlier you mentioned that some patients seek treatment from this facility and others like Health facility M. Is there any other place that they seek treatment for epilepsy apart from the hospitals?

R: They just say they have gone upcountry and others say they have gone to their pastor to the church. They say that "even if you have been given medication, I have to go upcountry so that we can solve these issues according to our traditions."

I: We have come to the end of our discussion. Thank you so much for your time.

[End of audio]