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

R: Challenging. The clients are there, but even just having the room to see them is a problem. Then also in terms of medication, commodities, they are not there. You see a client, prescribe for them, and being in informal settlement, they don't even buy those drugs. So it's quite challenging.

I: What would you say about the burden of epilepsy in this community that you are offering services to?

R: The burden is there, because we see around five per month, and we have just started. The Health facility is old but this Department of Psychiatry is very new. It's just three months old. So in those three months, and you are seeing five per month... we have not been able to even reach everybody because it's a new service. Not everybody knows that the service is available here. So the burden is there.

I: Okay. Are you aware of the different types of epilepsy? And if you are, which ones are these?

R: There is the grand mal, that's the biggest one, which is an emergency then there's petit mal, absence seizures…there are different types.

I: Okay, and what types of epilepsy cases do you receive in this Health facility?

R: They come, been diagnosed with epilepsy. It's just a generalized tonic clonic kind of epilepsy.

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

R: So far, the ones we have been getting are the convulsive types. We have also had one non-convulsive type.

I: For non-convulsive you have only had one?

R: Only one.

I: Why do you think these types of epilepsy like you have said, the ones that you have seen mostly are convulsive, why do you think the convulsive one is common in this community?

R: Most of them if you look at history or the causes of epilepsy, for us, the cause has not really been established. We have a few which resulted from…one from a traumatic brain injury. Then the rest are the ones whose causes haven't clearly been identified. They were just convulsing, went for the tests and they were told they are epileptic. So you find there is no family history, it's not occurring post an illness or an infection.

I: What about that one for non-convulsive epilepsy? You have said that one is not common?

R: No, it's not common.

I: In your opinion, how much information does the community have regarding this disease of epilepsy, and the process?

R: Very little knowledge and information. Considering that we even had to do a bit of community sensitization. We had a partner who we support in that. Not really on epilepsy, but on mental health, and epilepsy falling under mental health. So we had a community dialogue on epilepsy one day, and one of the participants is actually a client I see here. We were able to give information about epilepsy, because initially, they were really going through a lot of stigma even from the neighbors. But now after that dialogue, they were able to say that at least the community was able to understand. Right now if that girl falls, even the neighbors know they can touch her and assist her. There's still a big gap, but we are doing something in our own small way.

I: Does the community know the causes of epilepsy?

R: Yes. So during the dialogue we tried to highlight, but actually they don't know. So it's an ongoing process. We are doing enlightenment in our own small ways.

I: What have you learned from the community about the causes of illness? When they come, what do they say?

R: For them first obviously, because of the stigma associated with it, they say either those traditional myths and beliefs. "Someone threw them to us or we were bewitched ". They still associate it with a lot of that. They say if you touch somebody who has epilepsy it will come back to you. So those are the things they attribute it to.

I: Okay. And where does the community commonly seek care for epilepsy?

R: They don't, we have so many who are just here in their houses.

I: Okay, and those that go to seek care or treatment, where do they usually go?

R: I have realized they go far and wide. There's one who was going as far back as Kitengela in Health facility W. You know they just go once like in Health facility X. Then they are put on medication, when they stop that's where it ends, even Health facility Y. They try to seek help from far and wide. Those are the commonest. It's very rare to find somebody who has just come first-time epilepsy. They normally come after they have gone and have been told, you can be seen the service is also here. So they go far and wide even Health facility Z, some as far back as Kitengela.

I: Apart from seeking treatment in a facility, where else do they seek help for epilepsy?

R: Obviously, there's the traditional healers, the witchdoctors. They also go there.

I: Why do they seek--

R: And prayers, church…

I: Traditional healers then also--

R: Also, there church.

I: Why do they seek care where they go? The way you have said they go far and wide, then there are those going to traditional healers and church why do they seek care--

R: For the far and wide, they didn't know that service was here. And right now, even if that service is here, the drugs are not here. You will see somebody one time, prescribe for them drugs, they will go to the pharmacy, the drugs are not there. Next time you schedule them for an appointment, they don't come. If you do a follow up and ask them why they didn't come, they say that “even if I come there, and you don't have medicine”. Then the ones who go to traditional and churches it's only because they don't have the information that it's actually an illness. So they still attribute it to those traditional things.

I: How does the level of awareness regarding epilepsy affect the way community members take care of epilepsy?

R: It affects in a very big way. Because “I don't know, I am attributing this thing to traditional things, to curses, or I have a problem with God, so I am not coming to seek care”. But once they have the information that it’s an illness like any other, it's manageable. We can’t really say it's treatable, it’s manageable under medication. With medication, you won’t be falling down, you will be able to do your things like any other person. They don't have that information, that’s a big hindrance and barrier.

I: Does that level of awareness affect the take up of treatment for epilepsy?

R: Yeah, it does. We have a very interesting mother here who has a teenager with epilepsy, but she doesn't even... we try to do even a follow up until where she works, she said, “That is not an illness it’s something which requires prayers, I will look for money and take her for prayers in upcountry where she can be prayed for properly". So for her, she doesn't even understand why that child has to come here for treatment. The child just comes because she's aware "If I don't take drugs, I will keep falling down".

I: So the child comes and goes without the mother?

R: She’s a teenager, and because of epilepsy, she actually has intellectual… she had a bit of mental retardation, because previously, she used to fall, it was not controlled, so it affected her a bit. She's not really like 100%, but at least she's aware that “If I don’t take medication, I

will fall down”. She will come even if I am not here, scream this place down and they know and the clinicians will prescribe and she will be fine. But the mom doesn't know, she doesn't understand.

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

R: There is consultation, I am here to see them apart from that, drugs are rarely available. For any imaging services we don't have, in case somebody requires imaging, we normally send them to Health Facility Y and Health Facility Z, where they can be able to afford. So what is standard, what is really available every other day in case an epileptic comes is consultation.

I: So those are the services that you personally provide?

R: Yes.

I: What treatment is available? because apart from, you have said medication is not there. So you just do consultation--

R: I just do consultation; I write for them medication they go buy. Most of them don't even buy, they just… [Inaudible].

I: The other services that you provide you had mentioned you do the community dialogue--

R: Yeah, we do community dialogue, hinge it on another partner because that partner is doing depression, really just mental health in the community. Their key focus was on depression in pregnant and breastfeeding mums, but we told them because depression is not stand alone, mental health is wide, and because they were already going to do this community dialogues just to create awareness in the community, so we hinged on that program and we heaped everything concerning mental health. So I will then go and do depression, but we will still touch on the other aspects.

We do community dialogues, and we have also trained the CHVs. They are able to identify the cases in the community and also are able to refer.

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

R: I am able to take history for epilepsy, refer for the necessary tests, and to prescribe.

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

R: I have done psychiatry, and epilepsy is under psychiatry.

I: It's under psychiatry?

R: Yeah.

I: Are there other colleagues in this Health facility who can also diagnose and treat epilepsy?

R: We have clinical officers in this facility, if they are trained, a specific training targeting epilepsy, they would be able to because they are clinicians already. They are diagnosing other conditions and treating, and epilepsy is not any different from the other conditions they are already seeing. So if they are empowered, they would be able to so that they don't keep telling those patients "Wait for psychiatry".

I: So you have them who are already empowered to diagnose and treat epilepsy?

R: It's part of the basic training. It's only that it's not focused and targeted specifically for epilepsy. So if they get a booster training, now specifically for epilepsy to really empower them, then it will go a long way.

I: Okay. You have mentioned that you have CHVs who are trained…

R: Yeah.

I: Are they equipped to diagnose and refer individuals with epilepsy?

R: Yes, they are.

I: What is your opinion about availability of necessary drugs and testing capacity for epilepsy in health facilities in this community?

R: They are not there.

I: This one you had mentioned you refer them to Health Facility Y...

R: Yeah if you want a diagnosis imaging, you have to refer, drugs we write for them to go buy, they are not available.

I: Okay, and what are some of the challenges that you and your colleagues face in providing epilepsy care and treatment in this community?

R: First, is the stigma which is outside there in the community regarding epilepsy. Then when you come to the facility we don't have a designated room for mental health, of which epilepsy is part of mental health. Then we don't have diagnostic services, treatment, and medication.

I: What can be done to address some of these challenges?

R: You buy us a container, to get a room. Obviously infrastructure needs to be factored in because having a room is part of infrastructure. Also even if we can't get diagnostic services, but we can get medication, just medication, it will go a long way.

I: What about stigma? What can be done?

R: For stigma, it's already ongoing. Obviously, you are going to come and back us up. But something is happening, at least it's better than before. We have trained CHVs, they are able to identify because they know everybody in this community. My problem is, even them they say, "We brought you these patients but there was no medication, that’s why they have refused to come for follow-up." They are the ones who do follow up and remind them "Remember you are supposed to go and see the doctor”. So they tell her "We went there, talked with the doctor then he only wrote us a prescription”.

I: And the one you had mentioned about colleagues who need a booster?

R: Yeah. It's just like a refresher, but specifically targeting epilepsy. We have trained them on mental health. But you see that was broad because it covered everything from depression, anxiety, substance, everything else dementia, and then epilepsy obviously you just pass through. But now if they have a targeted small training even if it's a one day or a two days thing, specifically just for epilepsy.

Because they meet those cases in the outpatient, and then they tell the patient "Today is not a day for psychiatry, come on the day for psychiatry". Some of them never turn up. If they are empowered to be able to identify, diagnose, treat, we won't loose those patients. We are losing them along the way because I am not here every day.

I: You are here on specific days?

R: Wednesdays and Fridays, because I cover the whole sub-county. This sub-county starts from here until Kayole. So all those health centers along the way are my health centers. I have to go there, specific days. If they are empowered, even if I am not here, we know that an epileptic patient can get treatment because we have trained them on mental health, some of them. So they are able to screen for depression, and tell this person, may be able to give if they are not so busy, talk to the mom, and then they tell her "You are coming on this day to see the psychiatrist or psychologist". That was specifically targeted for depression and it's ongoing, we are still training more and more. If we have another one targeted maybe towards epilepsy, because it depends on the partner and their interest. This one was only interested in depression. So we did but we touched on other things. If you have one targeted on that epilepsy, we will major on it, even if we touch on other things.

I: You have mentioned that the CHVs are the ones who follow up, do they usually go door to door or what really happens?

R: A CHV is assigned households the way they are divided. So maybe this one is assigned eight households in this area, because they cover specific areas. In case, the place where she's covering, she has an epileptic patient, so she has a patient I see for mental health. In fact, they are very good because they normally escort them on the days of the clinics. They come

with them so they know whatever you have told the patient. They know this patient is supposed to come back on this day. They are able to follow-up and find out did they come, did they not come and why didn't they come.

I: Again, you had also mentioned that in the facility you don't have the testing or imaging capacity. When you refer the patient to Health Facility Y, Health Facility Z, do they usually come back here to continue with the clinic or what really happens?

R: Yeah the ones who go and do they come back but the ones who didn't do, they didn't have money; they just get lost.

I: Okay, and once they get lost there's no way of doing a follow up or something of that sort?

R: If they had come with a CHV who knows where they are coming from, it's easy, but the ones who just walk in, it becomes very hard. They just get lost like that.

I: Okay, apart from the solutions you had given to those challenges, any other solution you feel that can be done to address the challenges you are facing?

R: No, maybe just really creating awareness about epilepsy both to the community and to the facility. So not just the clinician, but any other person, because it's these same people who are still members of the community, so if they have the right information, they are able to even give accurate information outside there. If they see any form of stigma or discrimination or even just to refer. Maybe I have a neighbor who has epilepsy, and I work in Mukuru, even if I am a cleaner, and I know epilepsy is actually a disease which can be managed in a hospital, they can be able to refer. Even just sensitizing the other healthcare workers.

I: The community dialogue that you talked about usually happens here in the facility or you just go to the community?

R: You go to the community.

I: On specific days, or it's just random?

R: We have a whole community unit in NMS which is dedicated towards community work. In the community, they are normally chiefs barazas, community dialogue days and now this community unit under NMS is the one which organizes the dialogue days. Once they have said that today, we are going to have a dialogue, so it's to inform the CHV of the area, to mobilize people to come for that dialogue. Then now, if it's a dialogue on mental health, I will be invited and I will be able to direct the discussion towards mental health so that we are able to get perspective of the community, and also to be able to inform them what we can offer for them at the facility. So if it's for HIV, we have somebody from TB. You work with the community team; they are called the Community Health Assistants but they are under NMS. So even the CHVs report to them.

I: Apart from the community dialogues and chief barazas, are there any other promotions or outreach services that are done in the community?

R: They have a lot. I am not actively involved in them. I am only involved in the aspect of mental health but there are a lot of activities happening in the community, by different organizations. We have some who are supporting alcoholics, we have those supporting young girls in schools…it depends with a partner and their interest, but there are a lot of activities happening in the community basically.

I: So this one that you mentioned for community dialogue, is it the only one that is dealing with the mental psychiatry part and in that aspect touching on epilepsy or is there any other outreach that also deals with the issues to do with mental health like epilepsy?

R: I know there is the Red Cross which also does a lot of activities in the community towards mental health. They actually have psychologists who are stationed at various places in this community. As much as their focus is on SGBV, they are able to handle any other issue under mental health. We also have media; we have engaged media, it's called Ruben FM. We normally have mental health days where we go and give talks through the radio station. It's normally on Thursdays, it had taken a break but it's resuming. There's a lot happening in the

community, I can't really say it specifically but I know there's a lot of things happening in the community. It just depends with what you want to do now and just engaging those CHAs.

I: That is now directly connected to this facility. Are all those things that are happening directly connected with this Mukuru facility?

R: They are connected to all these Mukurus. If you are coming to do an activity in Njenga we will involve the CHVs who are stationed in this area. If we are doing in Ruben, we engage the Ruben CHVs. They are the ones who know the best days for dialogue, and who they are going to invite for that dialogue. So it depends, but in all these facilities we have CHVs who are attached to them. Even if we are doing an activity in the community, they are able to mobilize the people and book for you the venue.

I: Okay, anything or any other recommendation you need to add?

R: No.

I: Okay. So I don't know if my colleague has something to add? We have come to the end of our discussion. Thank you so much for your time.

[End of audio]