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I: Thank you, Mr. (name mentioned), for your time and agreeing to be part of this discussion. As we start, kindly tell us, what has been your experience providing health care services, in this community for the duration that you have been working here?

R: Pardon what is the question?

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

R: Generally the experience has been good, but maybe the main challenge is the socioeconomic status of most of the people around here, you know, being a semi informal settlement. So the biggest challenge is usually maybe the issue of drugs: for those which we don't have, for those that have to buy it becomes a big issue, most of them cannot afford. But generally, the community is very receptive and very positive in seeking the services.

I: I don't if I got you correctly, you talked about if the community is not able to buy what?

R: If there are drugs we don't have and they have to buy, it becomes a challenge and also those services we don't offer and we have to send them out, it becomes a challenge.

I: And what are some of the services that you don't offer?

R: If you need an x-ray, in cases of like a fracture or some chest diagnosis, like TB, we don't have sputum, major test like we would like to test Kidney function, full body blood check, liver function for those ones, we have to send them outside. Where most of the time, not most of time but they have to pay.

I: And examples of referral places that you refer them to?

R: Our main referral site is Health Facility L, but for x-ray we

also have Health Facility C, where we send some of them.

I: The facility C, is in kariobangi?

R: Yes, just like 200 meters from here.

I: Okay thank you for that. What would you say about the burden of epilepsy, in the community that you offer services to?

R: Do I have to quantify?

I: Not really…it's an informal discussion, you don't have to give exact numbers.

R: For the duration that I have been here, we have several clients, like in a month I see about up to 10, yes on a higher side.

I: Anything else you can say about that burden of epilepsy?

R: Mostly, I haven't seen the elderly, but I see the younger people, below 30years to 10 years, yes those are the ages of the most clients I have seen.

I: Among the 10 you see in a month, how many are elderly, and how many are the young ones?

R: I would say 7 out of 10 are the younger ones.

I: And why is it that more are the younger ones, or why is it common in young people, compared to the elderly?

R: Maybe it because of the population, the elderly are not many.

I: Okay thank you for that. Are you aware of the different types of epilepsy?

R: Yes, I am aware.

I: Which are some of those?

R: Types of seizures… the generalized, absence seizures, I

would say those are the ones I have dealt with mostly here.

I: Okay…and how often do you receive patients with non convulsive or convulsive epilepsy?

R: How often?

I: I know you had told me that you receive like 10 patients in a month, but now coming down to how many of those are convulsive or non-convulsive? Like how often?

R: You know I have been here for like for the past 7 months…for the 7 months, I have not received the convulsing ones, but mostly are the ones who are on follow up.

I: And the non-convulsive ones?

R: For the non-convulsive ones so far I have dealt with like 2 since I came here, whereby according to the prescriptions, and then to come up with the diagnosis they are non-convulsive.

I: And the ones who come for follow up? How often do they come?

R: They come…like there was one I was following up, but the seizures were a bit persistent, I saw him after 2 weeks, I reviewed him after 2 weeks, then now he comes on monthly basis to collect the drugs, so most of them come once in a month, to collect the drug. Only, the major issue is about the drugs, if they are not available, then you might find them coming much earlier than you had determined. Because maybe they don't have money to buy for the whole month, so maybe they get for 2 weeks, and then come back to refill, that's the time they come more frequent, but mostly, it's after a month.

I: I don't know, you said non convulsive is the most common?

R: No, the convulsive.

I: Okay…Why is it so? That the most common is the convulsive?

R: No, I don't know…

But I think also there may be some issues with the health education to some patients, they may be having the non-convulsive and they don't know exactly what they are going through. Because maybe the absence seizures you may find, a parent comes and they don't really find it's a major issue or they say as a by way or they tell you that "My baby, my son or my daughter sometimes gazes in the air, gets confused sometimes" so they don't have that knowledge of what exactly maybe. I feel that could be the reason they don't seek the medical attention.

I: When you speak of health education is it on the part of the caregiver, parent or patient?

R: The caregiver mostly or let me put it as the community.

I: And why is that at the community or the caregiver they don't have health education, tell me more about that?

R: You know most of the times, the convulsive types they will rush to the hospitals because of the incident, but the non-convulsive they don't have that patient down with convulsive fits. Then some may not take it as a serious issue, not knowing what is really happening. They may not want to come to hospital to seek medical attention, I presume that. They don't know what they are going through.

I: Thank you for that…and in your opinion, how much information does the community have, regarding the disease

of epilepsy and the causes?

R: To a scale of 10, maybe I will rate at 5, because especially with causes, it's mostly it's more of superstition, witchcraft and such like things… but with the disease itself, most may recognize what is happening because with the fits and…yes they may recognize, especially with the convulsive types, but with the non-convulsive…

I: And going back on that, you have told me about the causes, you have said about witchcraft, maybe you tell us more on that? May be what they tell you they think is the cause?

R: Some they blame their ancestral homes, maybe they say it's a neighbor or grandmother or somebody caused that, because of malice, and there are few who would like to understand the medical side, and there are few cases that understands it's some sort of injury, some accident…they tell you this one had an injury, after the accident and afterwards they had convulsions.

I: Any other that you maybe have learnt from them or the community that is a cause of epilepsy?

R: There is also drunkenness, alcoholism, they say it causes, but I don't know some cases, you find its just withdrawal effects.

I: Where does the community commonly seek care for epilepsy? why do they seek care where they do?

R: Spiritual…mostly its spiritual intervention, there are a few, some you treat them when they go home they go for spiritual guidance and they are told this is the cause. They even stop the medication, stop follow up, then

later they come when things are not so good, when there are worsening symptoms. That's when they now come back, but mostly spiritual is like their first option.

I: So they go to spiritual men or?

R: Yes… churches, shrines.

I: Any other place, apart from spiritual, churches, shrines?

R: Not so sure…and just the hospital now.

I: And why do you think they seek care where they do? Like at the shrines?

R: I think it's just lack of knowledge and understanding of what is happening to them.

I: How does the level of awareness regarding epilepsy, affect the way the community members seek care for epilepsy and take up treatment for epilepsy?

R: They risk stigmatization; sometimes you find that some parents even hide their children, because of fear of stigmatization, so you find that's one issue. There is that fear, this person faints, so they don't want to associate with them, so you find some parents will hide or it's even an adult they hide and they are not free from that. There was an incident I had, I think it was around May, there is boy around 13 or 14 years he was joining form 1, he went to a school, after being there for 2 weeks, they realized he is epileptic, they expelled him. He came back here so they had come for the medical report and fortunately I am the one who filled the first one so when they came back I am like,"Why are you changing school this early?" They told me that after the school realized that he was epileptic, the other students rejected him, they didn't want to sleep with him in the same dormitory,

so they had to expel him, from the school. Now he was looking for a day school to study from home. So stigmatization…

I: So stigma, parents hide their kids and being chased from school, is there any other way it affects?

R: I think just socially, fear of how the community will perceive.

I: How does the community perceive?

R: Of course like even the children in school, they are part of the community, so you find if they are rejecting this person because he has this kind of problem, some even think its communicable, so due to that fear that's its communicable they don't want to associate with this person. We have superstitions that like if you touch the urine you may get it, if they are frothing then you touch them, due to that fear…

I: Still on the same, how does the level of awareness regarding epilepsy, affect how the community now takes up treatment?

R: With proper counseling, there is very good adherence, with proper education, health education on the causes, on the mode of treatment, possible outcomes, importance of follow up, and any other precautions. For those who come for services, there is a good adherence which is now okay. They keep coming for the appointments, but just for a few who now seek second opinion from the spiritual, then you find they are not coming anymore for the treatment.

I: So they first come here for the conventional treatment, Then they still seek a second opinion at the spiritual…

R: Yes, you see in the night the patient was convulsing,

in the morning they are here you treat them, but they keep asking and asking, and you find there is someone else who has a different opinion, that this is not medical, take them to this place and you find the patient has just disappeared like that. But for those who understand and with proper education there is good adherence.

I: As we continue, what care and service for epilepsy do you provide?

R: We have a clinic every Tuesday.

I: For epileptic patients?

R: For generalized mental health.

I: And during the clinic, what services do you offer, now to particularly epileptic patients?

R: Mostly health education and medication…now the prescription.

I: Any other care or service?

R: We address it as it comes, now personalized.

I: Even if it is not Tuesday for the clinic?

R: Yes… maybe now if it's beyond us, referral is the next option.

I: And referral you said… where do you refer now particularly for epilepsy? Is it Health facility L?

R: No, we now have Health Facility M; by the way I forgot to tell you that Health Facility M is one of our referral centers, now for mental issues.

I: Which particular situations do you refer; because like on Tuesdays you have health education and medications, in

what instances do you refer to Health Facility M for this epileptic patients?

R: We have some cases; you find being…though mostly now after we refer to our psychiatrist clinical officer she is the one mostly who deals with that.

I: Is she based here?

R: She is the lady (name mentioned) she has been our in-charge, until last month, I think that's now when she was promoted to county level.

But we have some staff from Health Facility M who comes here and she also does the same.

I: Do they come on Tuesdays during the clinic or?

R: Yes they come on Tuesday during the clinic days, but for those who come on the other days, we handle it as it is.

I: Are there any other services beyond that treatment, health education, medication…counseling do you do it here or you refer?

R: Counseling I am not so sure, since I have not attended the clinic fully, but we have the general knowledge when we encounter them we try answer their questions, their concerns as they raise them.

I: What about outreaches or campaigns?

R: Specifically for epilepsy?

I: Yes.

R: For the short time I have been here, I have not heard any.

I2: Do you have provision of drugs for epileptic patients?

R: Yes, unless they are out of stock, but when they are there we normally provide.

I: How would you describe your capacity to diagnose and treat epilepsy? Although I know you talked about the

lady (name mentioned) like your psychiatrist person?

R: Now as for me?

I: Yes.

R: I would say I require some more training.

I: In fact the next question was if there are any training you have received on diagnosis and treatment of epilepsy?

R: I went for some NCDs, but it was generalized non-communicable diseases, but specifically for epilepsy not yet.

I: I know you talked about (name mentioned) who is your colleague here, who can diagnose and treat epilepsy, are there any others?

R: We are 2 clinicians, and her, but she is our main person.

I: The clinicians are able to diagnose and treat epilepsy?

R: Yes,

I: And for her…her cadre is? For (name mentioned) now?

R: She was the in charge, but right now she is the Sub-County focal person.

I: Okay thank you for that.

I2: When asked about the capacity, you said you need more trainings, and then you said, you are 2 clinicians, who are able to tackle the issues, so where do you need the training?

R: Where?

I2: Yes, specifically where do you need the training on?

R: Let me say the title epilepsy, diagnosis, management, any new guidelines, any updates.

I: And now, apart from the 2 clinicians, and (name mentioned) who was your in charge, that's at the

facility levels, at the community level maybe do you have a person who is trained on that? Maybe the CHWs?

R: The CHVs are there, but I don't know if there is anyone specifically trained on diagnosis of epilepsy, but they have that general knowledge, but it's…

I: So it's the 2 clinician and the former in charge?

R: She is a clinical officer, but now specialized in Psychiatry.

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

R: The drugs availability and supply is just poor, is not good all, most of the time we don't have the drugs...

I: What about other health facilities in this community?

R: It is just the same…

I: When you say poor, what do you mean? Maybe the supply or?

R: Yes the supply…

I: How often do you receive the supply for the drugs?

R: KEMSA…KEMSA…KEMSA, we don't get the supplies as often as we should. There is no certain frequency let's say after every 6 months or after one year, just receive a call and they say they are bringing the drug, stay for 6months there are no drugs. So there is no particular pattern, with the supply of drugs.

I: What about maybe the testing capacity, I know you are talking about drugs, I don't know if it's the same with equipment or?

R: We don't have them.

I: And you said it applies also to the other health facilities in this community, maybe around or?

R: I don't want to talk about the other health facilities…for the drugs I know…because…now for the government facilities it's all round, because it's just KEMSA.

I: And I know when we started you talked about some challenges like hiding of children, that they are hidden in the houses, and you now talked about the supply of drugs, you have talked about the trainings, that you have not received adequate, if I can say that, maybe any other challenges that you and your colleagues face in providing epilepsy care and treatment in this community, on top of those you had mentioned?

R: Are there any others, those are just the main issues…

May be the follow up, just in case a client doesn't come back,so maybe we need a focal person with the community health volunteer, who can help us to trace them and do that, if like for those who don't come back on the said date, so that you understand what exactly is happening.

I: What can be done to address, now like I remember the first challenge you mentioned is, that due to the socio economic status of the people in this community, maybe they have no jobs so they are not able to afford drugs, maybe what can be done to address such a challenge?

R: If we get the drugs, they are provided for at the Facility, that would be a boost, because you cannot give them money to go and buy, so the best thing is to find the drugs here. So if we get them or maybe if we get a friend of the facility to donate for us, then it will benefit us.

I: And still on the drugs, like now KEMSA, you said there is no consistency, what can be done to address that challenge of KEMSA and supply?

R: Maybe through the sub county pharmacists, maybe it can be addressed, they can help to find a way forward.

I: What about follow ups? You talked about challenge of follow ups? I don't know if it's like defaulting?

R: Yes for those who default, there is no specific mechanism that can easily trace them so…I know we have the records, but if there may be a…I don't know, it's hard, to have a person in the community who can trace each of them, but that would be a plus.

I: Still on the same, in the community, since you have the Community Health Volunteers, or workers, you said they are not well equipped, what can be done to address that?

R: Just trainings…and training them on that, it will help because they can easily identify because you see most of people when you say epilepsy, its fits, yes anything other than the fits nobody will think about epilepsy, so even which applies to the caregivers, the patients themselves, the community health volunteers, so if they get proper trainings on all that, then it will enable them to help us to get all the clients in the community.

I: And who is going to give this education, or information to the caregivers, CHVs, who can give this education?

R: Through the trainings, I don't know if there are some sponsors, who can help in training especially to the health providers, to disseminate the education downwards, to the clients, to the Community health volunteers. Once we are well equipped as health providers, then we can easily pass to the…we can organize for trainings, because like in this facility we normally have CMEs…for those CMEs we all attend, from up to bottom, all

staff.

I: Who is the facilitator of these CMEs? Who coordinates, or who is the sponsor?

R: We have different people who help sponsor it, we have different people… who help… like we have… Sponsors? Most of….

I: **Sponsors, should I say stakeholders that you mentioned because even the training of CHVS you said they need to be trained even the care givers, who are some of this stakeholders who take up the role of training this people, or even giving information?**

R: Like mostly in… is it in-house we do trainings amongst our self, like from each department, there is somebody like from mental health department, and they give a health talk on that. We have some few cases where we have external…yes.

I: Like from external, who are these that come?

R: Mostly pharmaceutical companies, we have other hospitals, especially private, like now we have the one for dental … yes so now… those are some of the people who help.

I: And when you talked about the internal one, since this a government facility, is it the county, sub county or is it at the facility level?

R: Mostly I can say 80% are facility level, but the same up to sub county, we have some cases where they come and give us, but mostly we have at facility level.

I: And as we are almost coming to the end, there are still 2 challenges I want us to address, like one, how can this be addressed. The challenge of stigma, you talked about the stigma of patients that maybe they are even hidden by

the parents, how can we address that?

R: Education…even now with this we are not just targeting the clients and the caregivers, we are targeting the whole community, so even if through the media, that can really help, so that you know when people understand. Like nowadays, I will give an example of TB, you will hear somebody coming and they are telling you I am coughing, I have night sweats, I have lost weight, even before you probe to specify whether its TB or not, like they have that knowledge of which you even hear on radio, if you cough for this duration of time, you have night sweats and you lose weight, such a thing should be happening with epilepsy. I think it would really be beneficial to us, because that's the only way you can reach the whole community. Because in health facility, it's a bit difficult, patients come at different times. So there is no time you will gather them and talk to them about epilepsy. And in such a sitting, someone is in pain, there is no way you will sit them down, somebody has a cut and you are telling them about epilepsy, they may not even listen to you, but if it's on radio, or in chief barazas, then it can easily reach them, so that when the community has the information, even if somebody is trying to write their trend, they will know how this is happening, and if you go to the health facility you will be helped. So that health education to the community would help.

I: I even wanted to probe on that education to the community;you talked about the radio, TV, chief barazas, any other?

R: Churches, or any other meetings where there are people gathering…yes.

I: Okay thank you for that…I want to give my colleague an

opportunity, maybe there is clarification she needs or?

I2: No, everything is clear.

I: Okay, now we have come to the end of our discussion… and thank you…I don't know if you have any question, comment suggestion, you would like to ask us, or any comment you have?

R: No maybe just to thank you for the opportunity, and I believe it will contribute to the care of our clients…so thank you.

I: We also thank you for your time.

[End of audio]