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I: Thank your sir for your time. And just to start can you kindly tell us, what has been your experience, when you are providing healthcare services in this community?

R: What has been my experience...?

I: In providing healthcare services in the duration that you have been working in that field?

R: I have been working in this field for some time, and my experience, because I am working in the public healthcare sector, there are several challenges, in the public health care sector, mostly especially pertaining to mental health challenges, problem to include drugs, to include facilitation, so there are a number of challenges.

I: Anything else you would like to tell us, about your experience while you are providing health care?

R: Well, I have realized, okay I have days like I go for community psychiatry and most of the clients, mental health clients are usually like in an enclosed situation, their families don't want to bring them out, so they are usually not out, the caretakers are not ready to bring the patients to the facility. So it's also another challenge, the susceptibility of health care by this patient, client is hindered by social challenges, they are hindered by social issues and also economic issues.

I: Thank you for that...what would you say about the burden of epilepsy in the community that you offer services to?

R: I operate a psychiatry clinic at Kahawa west, and Health Facility MN. At Kahawa west, I have been there for some time, and I have seen quite a number of cases with epilepsy, and apart from those who are brought to the facility, as I have told you before, there are those quite a number I have seen, in their houses when I

I am doing community work.

So we have a big challenge in epilepsy, one, because the community does not know when there is any form of help, and the other thing is, another big challenge even as I am working in the facility, remember as I told you I am a trained nurse, a trained psychiatry nurse and a trained psychologist, I am a counseling psychologist. Apart from me you realize to get somebody like me in the public health care sector, we are very few, extremely few, so the issue of personnel is another challenge. So I have realized in the course of my working, I have realized that accessibility to health care for people suffering with epilepsy, knowledge of caretakers of these patients or clients is big another problem.

I: And just to follow up on what you have said on knowledge of caregivers, what do you mean, when you say there is a problem with the knowledge of caregivers of epileptic people?

R: The people don't know that, the caregivers, they really do not know whether there is help which and goes beyond the drugs they get at the health facilities. What else do we need to know? Things like, what do we need to do to prevent this person from getting these fits? How can we help these attacks? Are there triggering issues which we can deal with? those are the kind of problems that the caregiver doesn't know and I wish we get some information to them.

I: Thank you for that Sir...and are you aware of the different types of epilepsy? If so, which are they?

R: There are several types, maybe you could say there 2 types of epilepsy...there is complex and simple: Even in

presentation, what I know is that we have simple, we have complex...they are types of epilepsy.

I: Maybe just to tell us more about the difference between the 2 or similarities, between the 2?

R: We talking about Petit and grand mal kind of fits where one is a simpler form, the other one is a complex form. A complex form, grand mal, lasting 2-3 minutes and there is that nausea after the fits, the patients would have headaches, blurred vision and they really cannot recall what has happened.

I: Okay anything else, on the 2 types of epilepsy, anything else?

R: The presentations...how they come, you know the simple one, usually the fits are absent, sometimes they could be absent, you would get maybe twitch, and usually affecting the young people, sometimes can go way after puberty, but grand mal, this one even before its start, there is that, one would maybe hear voices, there are headaches, there is that aura, you see? before it happens.

I: If I got you correctly, I heard you mention that 2-3 minutes, I don't know if it's the presentation or?

R: These is the fits...

I: For the simple or complex?

R: For the complex.

I: And the fits for the simple, how long do they take or present themselves?

R: Sometimes you could get twitches, they would last a minute or there about.

I: As we go on, what are some of the types of epilepsy cases do you receive maybe at your facility?

R: Mostly you get the complex ones, these are the ones you get at the facility.

I: Okay...what do you think is the reason for that, that's it is the complex ones?

R: One, because there is that... the caregivers can see the twitches, he can see the patient has fallen down, this patients will mostly fall on the ground, has those jerky movements and as a result of this the caregivers will bring the patients to the hospitals.

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

R: For the convulsive...okay, with good management and good...maybe drugs, good information for the caregivers, mostly the clients that I get are those that come to collect drugs. They wouldn't come after a fit, but well there are those who would come just after a fit or maybe a fit that happened earlier in the day or maybe yesterday.

I: Previously I heard you mention the types of epilepsy cases you receive at your facility and you said it's the complex one, I don't know if you would say that's the most common among the patients you see or is it any other?

R: I would feel could be, I really haven't dug into that, could be, it could not be the common, it's only that since the caregiver becomes worried the person next to this client who has the fits is worried that's why they bring them to the hospital, maybe those people who don't have the convulsive epilepsy, it will really not be noticed. Maybe it happened, somebody was not watching and it went away, and then those people could not have access to the health care, because it's not creating immediate concern to their caregivers.

I: And still rotating on the same, I don't know if we would say it's the most common in the community because like you are saying, it's the one that the caregivers are able to

see and tell the symptoms, could we say it's the most common?

R: We wouldn't know from where I am sitting because, maybe it's the one with no convulsion, because it does not create attention maybe it could still be there, it's only that we don't have an effective way of really getting to diagnose it, that's my feeling.

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

R: You know from my standpoint, the community we have associate epilepsy with psychotic disorders, they really combine epilepsy with mental health challenges and mental health sickness. They would say it's one of them, and therefore because of that feeling, that this is a mental health condition, they would associate it with other non conventional issues or they even look for non-conventional solutions to epilepsy.

I: And when you say the community associates it with psychotic disorders, maybe you give us some of this psychotic disorders that the community tend to associate epilepsy to.

R: You know they would say, from what I have seen, they would say, "this is someone who has epilepsy, the head is not functioning properly" ...they would say this patient is not normal in his head, and that can delay seeking healthcare.

I: And why would it delay seeking healthcare?

R: Before they come to health facility, you know as I told you, I am a counseling psychologist, and I take time to talk to the caregivers when there are free medical camps. You will find that they will have taken these patients to so many other non-conventional ways of looking for help,

before they bring the patient to the health facility when they see that they don't have any other alternative. They come as a last resort.

I: Maybe for somebody who is listening, an example of the non-conventional ways that they tend to seek care before they now come to you or the health facility?

R: You know some associate this sickness with maybe something the parents have not done, say maybe, completion of payment of dowry, maybe the grandmother or grandfather had said something, a dead ancestor had said something, so they will look for traditional solution to that. So they will say "Let's go to our tradition, let's go prepare a goat or a sheep to appease our ancestors". Then if it doesn't work, they will go for medicine men...traditional medicine men and then if doesn't work, they will go to look for... see they are called witchcraft, they will go for those people who will tell them that if you do this...this will be...if you do this, this person will get better, such.. then, they will also go for traditional healers, then if that doesn't work, they will also go to Christian pastors and those people who pray, then after that they will come to the hospital, as a last resort.

I: And now since you have spoken about the places where they go to seek help for epilepsy, like you talked about traditional healers, witchcraft, Christianity, spiritual healers and what have you learned from the community about what they say are the causes of epilepsy?

R: You see these things sometimes can be very individual you will find a caretaker will come and tell you that they have really gone round and then they come to the hospital, another one will not have gone round, maybe they have a relative who have been to school, and then they bring the

patient as a first you know, option.

But causes are also as surrounded in those mistakes thinking, like the way they also look for help. So they will say, this condition was caused by a grandfather or a dead ancestor, who had said something, they would say maybe you did a mistake some place, the plot you are sitting on belongs to the other person, maybe that's why they bewitched you, such things, they will also say that this is a result of witchcraft, they will associate those mistakes and spiritual issues as the cause for the disease. And it's real; imagine they tell me that, for real, you know when I am seeing them, they will come and tell me...like there is a lady whose child is epileptic, she would come and tell me the grandfather...because the boy was born out of wedlock, the grandfather had said that the name should not be given to this child that's why the child is having those fits, so I have really come across it.

I: Since you have mentioned like the causes they give you that cause the illness, and also you mentioned like where they go to seek help, or seek treatment, why do you think they go there? Like the places you said for traditional spiritual healers, Christian and lastly that's when they come to you when they have reached the end, why do you think they seek care there?

R: I really don't know whether to say that, the way of life of our people is that there before, they used to have an explanation for any calamity befalling them, or any abnormality in the society was associated with a custom miss and place. We have always gotten an explanation for any happening, say a child dies, we would say this child died because you gave the wrong name, so when you give birth to another child you will not give the same name,

you look for another name, so we used to have an explanation for whatever is happening in the society. So when this child or this client is having epilepsy they would associate it with maybe a spiritual happening, and I believe that's why they would go for those unconventional means, to look for help.

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: The level of awareness... maybe say of the disease could really influence how people seek for help, but this is not the level of education. I have seen very many people going for traditional way of trying to solve their problem, but we have a good level of awareness, people will come to the health facility for the care.

I: So how does the level of awareness, affect how they seek care and treatment for epilepsy?

R: The moment when these people bring a client to me, they know that when they come to me, we give drugs and then we talk about good care for this patient, including their basic lifestyle, and the way of improving their lifestyles. There are people who understand and appreciate that when they look for healthcare, their clients life improves, that means that they have that high level of awareness. So the people with high level of awareness tends to seek for healthcare. So it has a direct impact for people looking for healthcare, people who are aware will go to look for healthcare for their clients. I don't know if I have given you the right answer...

I: Yes you have given me the answer but also looking at the other side of the coin what about those people that do

not have high level of awareness, how is their seeking of treatment?

R: Those are the people who don't have a high level of awareness. These are the people who still go to look for solution from unconventional manners. These are the people whose clients or the sick ones of these people, their life standards is low, most patients will get fits, the frequency will be more, and their life, how do I put? It...the status of life they are living is low, because these patients if they look for that unconventional means, then their health will not be well taken care of, these are the people who will not enjoy life as much as those people who seek healthcare.

I: And that's now when seeking care, what about taking up treatment, still on the same, the people who have high level of awareness, and those that do not have, how do they take the treatment?

R: The people who have awareness, if you give them drugs and you tell them this drug is to be taken twice a day, because the level of awareness is high, they will take 12 hours, but the people who do not have that high level of awareness, you tell them that the drug is twice they will take as in as in twice, not really taking into account hours, not really taking into account the priority of the timing such that those people who have low level of awareness, their clients do not take their drugs in time, they don't avoid the triggers. So their patients do not live a quality life. So people with high level of awareness they tend to take their drugs at the right time.

I: Okay, thank you for that. What care and services for epilepsy do you provide? I know you have told me that you

are a psychiatrist, and a counselor, but just for somebody who is listening, just tell us what services and care you provide.

R: As much as we give drugs, we get clients, we give drugs, and then we try in the best way we can to talk to the caregivers, about the care of these people, because care as important if not more, as the drugs. If these patients are taking the drug you have to make sure that they are taking the drug at the right time, if these patients are taking drugs, you also have to make sure that they are well taken care of.

I: **I have also heard you mention that you get clients, I don't know what you mean when you say that? you said you give drugs, you get clients?**

R: No, I said we give drugs, but we also talk with the caregivers of the clients. I am using the word clients instead of patients.

I: **I also heard you mention that the drug is as important as the caregivers...?**

R: Yes, the drug is as important as the information the caregiver carries with him or her, because you can give the drug and that drug is not taken in time, you can give that drug, and that drug is taken when the person is very hungry, you can give the drug and you are giving a person drugs who is maybe barely being mistreated, being overworked, or being abused because epileptic patients are also being abused, so you need to take care of the patient or this client.

I: **When you say the drug is being abused, maybe you just elaborate...**

R: No, I was saying the client is being abused, and also the drugs are being abused, so if you give the drugs you have

to make sure that the drug is for the intended client, and even this client is handled the right way when taking the drug.

I: Is it the patient for epileptic who abuses the drug, or the caregiver or who? or other patients?

R: Other people of the community, other people who can come closer to this patient, who is taking this drugs, you see this patient is not living in isolation, this patient is living with brothers, sisters, cousins, and unfortunately, people who don't get good care, are people who are coming from lower economic levels, so the relatives could also be of that lower economic capability and you see some of the patients with epilepsy, are also patients with psychotic challenges and maybe they are using some drugs, which can be drugs of addiction, they are using some drugs which can be drugs of stabilizing, and this drugs can be maybe abused by the people closer to them, that's what I meant. I also meant, that this patient can be living in a situation of being abused by the relatives, even the caregivers...the supposed caregivers.

I: Still on that, the point of the drug being abused, I have heard you say that the psychotic disorders that some of these epileptic patients have, are the drugs that are being abused; I don't if the drugs maybe that you provide for epilepsy also have that addiction effect? Are they the ones that are being abused?

R: You cannot rule out that...

I: The psychotic drugs and epilepsy are they the same?

R: You know these patients...say this is a patient you are giving some drugs, and this patient has psychotic symptoms, and you are giving drugs to stabilize some side effects of the psychotic drugs, a case in point you are giving (medical term mentioned) to stabilize extra

middle effect of psychotic drug this patient is being given, because he has psychotic symptoms, this drug is a drug of addiction, somebody can take this drug and misuse. So our patients miss the right dosage of the drug they are supposed to get.

I: Because of the abuse of other people?

R: Yes... and as I told you most of these clients live in... the level of poverty is quite high, so they come from...quite a number of them comes from families and situations which means that their relatives are also suffering. And these people have a likelihood of abusing drugs.

I: Okay, my colleague has a clarification on something..

I2: So you have mentioned about your patient being abused, and also the drug being abused, so when we go back to our discussion about what services you offer, what do you do, about that? situation of them being abused and the drug?

R: That's why I am saying, it's important to not only give the drug, but if you are giving the drug, this person who is coming for the drug, how much information does he have about the drug? This drug should be taken after every 12 hours, this drug should be taken by this patient..

I2: So you tell the caregivers, that's what you tell them?

I: And maybe the abuse of the patient or the caregiver, who is abused?

R: I said this epileptic patient, the likelihood of them being abused is high, you know mostly, in the society they are living in, they are not able to take care of themselves. Their immediate relatives are taking care of them, and in the process, you know sometimes immediate somebody is not able to take care of their basic needs,

they are bound to be more abused both psychologically and even physically.

I: What other services are provided beyond treatment? Maybe, I heard you mentioned counseling? Any other?

R: We are planning to do community psychiatry, but you see it's a challenge because we also need the community health workers to do that, and also help us to do that.

I: Any other? Like maybe campaigns, outreach services?

R: It's a challenge, we would want to, but that's what I was talking about initially... about facilitation, sometimes you don't have a way to do it, you would want to but you are not facilitated.

I: Who do you think should facilitate this?

R: The government should facilitate, but you also realize in the public health care system, even the money is not there, we are trying right now I would say in our facility, NMS is trying. When I joined, there were no psychiatric services being offered, as in directly, but right now, almost every other facility in a sub county you would find psychiatrist trained personnel. Though they are few but they are doing the services...we are going in the right way...

I: Any other person who should be, apart from the government you said NMS, people who should be in those campaigns, the services, to promote the health in the community?

R: Yes, if we can involve community based organizations, maybe churches, maybe community groupings, to disseminate information.

I: Thank you for that how would you describe your capacity to diagnose and treat epilepsy? I know you mentioned you are a psychiatrist...

R: My capacity... I can't even remember the last time I got

a refresher course or information or some training, maybe regarding new ways of giving services. So the issue of training and continued education is a challenge so if that can be facilitated, if we can find a way of imparting knowledge...that continuous knowledge, because like now, let me tell you, to be sincere, the information that we rely on is trying to read and by getting information by these people who sell drugs, so we really need that continuous training.

I: I know you had mentioned that you are a psychiatrist and also a counseling psychologist?

R: I am a psychiatrist nurse and a counseling psychologist...

I: I don't if I know it's in the same field, but I don't know if you have any training you have received on diagnosis and treatment of particularly epilepsy?

R: No I haven't...

I: Okay...and are there any other colleagues in the health facility maybe where you work that can diagnose and treat epilepsy?

R: Yes we have clinical officers, but there is no that current training on epilepsy.

I: A clinical officer who can diagnose and treat epilepsy...?

R: Yes.

I: What about at the community level, are there any trained providers?

R: No, there has not been any training which has been done.

I: And the clinical officer you are saying, exactly what do they do? Or...

R: They see any patients who come every other day in the facility...

I: Epileptic patients?

R: No, for epileptic patient when they are seen they are now referred to come for specific psychiatric days.

I: **By those clinical officers**

R: Yes.

I: **Okay, anything else that they do to the epileptic patients?**

R: They will give the basic treatment, and maybe they will refer for the counselors to come and see, and see their relatives.

I: **The counselor is from the same facility or a different one?**

R: From a different one...you see now like me, if I get clients at Facility MN, they will request me to come on a Tuesday to come and see their relatives.

I: **And community health workers, are they equipped and trained to refer individuals?**

R: We don't have...not that I know of... any I would know; I don't think they are trained. Of course with fits, in the community, people know some basics, they know this person is having some fits they will refer to the facility, but they are not trained on the first actions that if they see a person having convulsions...

I: **But they can refer?**

R: They can refer, but the only challenge would be, this referral is not coordinated...it's only belong to the patient and their people.

I: **When you say it is not coordinated, what do you mean by that? Please elaborate?**

R: There is no coordinated referral in the community regarding epilepsy, so if someone is having an epileptic fit, people will come try to do the small basics of opening the shirt. Then say I can I take this patient to the facility and the

burden of that will be the relatives, so we don't have a coordinated way of saying that if you have epilepsy there is a way you would be referred to a person who is well trained to deal with that. No we don't have.

I: And what is your opinion about the availability of necessary drugs and testing capacity for epilepsy in a health facility in this community?

R: We usually have the basic drugs and the supply is not even there. It's not like continuous, sometimes we have some (Medical terms of drugs names) to last just for a month or two, then maybe you don't have an(noise in the background), so drugs are also a big challenge.

I: What about testing capacity for epilepsy?

R: Testing we don't have, leave alone testing you cannot even imagine...let's say, assuming you were to give a patient maybe sodium valproate, there is no way of even testing it in the facility as you are treating the patient. So testing does not exist for epilepsy... testing for epilepsy...to the best of my knowledge? I don't think we have, or even for the drugs or even to see maybe you are to observe the drug reaction to this patient, or the suitability of this drug to the client, it's zero.

I: And going back to the drug supply, the availability you said the supply is not sustainable, how is the frequency, after how long do you they get the supplies?

R: I cannot even talk of the frequency, because, sometimes you will have in January-February, some other time in November, sometimes January, February then, April maybe... we don't have a regular way of expecting the drugs in a concrete way of time.

I: Okay my colleague here wants to seek a clarification on something

I2: When you talked about the services that you offer at your place, did you mention that you give drugs? Or?

R: Yes we give the drugs when they are there, but the supply is not consistent...once in a while.

That's what I was talking about, in a nutshell about the facility, you know when the patients come and they expect you to be giving and to help them and then you give them a prescription to go buy, it's a challenge. Although we can say we have been having the visits for (...medical terms for drugs used) for some times now, so we cannot say we are badly off now, but you realize this drugs are very basic for the management of epilepsy.

I2: You get it from the government?

R: Yes...you get it from the government.

I: As we are almost finishing now, I know when we started the conversation you told me about the challenges that you face, maybe you and your colleagues while you are providing care for epilepsy and treatment, you talked about lack of personnel, you talked about there is no much information, knowledge on caregivers, you also talked about like they do not know where to find help, or they don't know if there is help for epilepsy? Any other challenge that you face or have come across you and your colleagues?

R: Now, to add on that... the availability of drugs is another issue that causes that consistent supply, the ability of the laboratory to be able to test, there are good drugs, the hazardous level of the drugs is quite minimal such that you really need to check on this patient, for the

drug dosage should be calculated properly, those are the challenges we face at the facility level.

I: When you speak about the capability of the laboratory to be able to test, I don't know if you are speaking about the equipments, personnel or both?

R: We have trained laboratory personnel, the equipment is the challenge.

I2: About the laboratory, what's the challenge?

R: The equipment... we have a laboratory, the equipment and the regents are the challenge...

I2: For the epileptic patients?

R: For epileptic...

I: While we are still there, in the laboratory, what can be done to address that challenge, either the equipment or the personnel?

R: If we get the equipment then maybe a trained personnel or bring trained personnel, it would be a big boost.

I: And when we go to the challenge of information to the caregiver, how do we address that?

R: If we can get people on the grounds who are trained...trainers of this caregivers, they can train the caregivers, give educative information that would be a plus.

I: You also talked about a challenge of the drug being abused, and maybe also the client or patient being abused, what can be done to address that?

R: This will basically lie on the information we give the caregiver, it's very crucial that the caregiver is able to handle this patient, holistically, but if the caregiver has the information on signs and symptoms of an abused patients, the way the drugs are taken... if the

caregiver is able to take care of the patient holistically.

I: What about the challenge of that some people they hide these patients in the house, I remember you talked about that? what can we do about that?

R: We can do community outreaches, try to pass information so that these patients can get help, you know this is very important, outreaches are very important it can be done through community workers or organizing community...empowering the people who are giving this services to them in facilities. To be able to reach out in outreaches, this can be done through barazas, by conducting those outreaches.

I: I was heading there who is to facilitate those outreaches, you said the community health volunteers, the barazas...

R: ...and even the health care services, you see, people call me doctor in the community, another person is also giving services in a health facility, and then they go out, and people can see who is giving the services, and they can hear from them talking this is what is done, this is what we are going to do, this is what we are capable of doing and these people will bring their patients out to the health facilities.

I: Okay, you also talked about the challenge of you being a Health Care Provider, like you haven't had any training...let me call them refresher course, how do we address this?

R: If you can organize refresher courses for us, health caregivers, the front line care givers, then it would be a big boost in the management of epilepsy, because we would have newer ways of managing this

patients and we would have the right information, and maybe how to pass this information quickest. Though sometimes you would have the information but you don't know how to arrange this information to reach the sufferer.

I: Lastly you spoke about the challenge that you feel that most of these epileptic patients are coming from a social economic status that's low, how can that be addressed?

R: That's a big challenge, because it's a community challenge,

Because you realize that maybe the causes of the primary epilepsy, the causes are not...they are idiopathic, but the secondary ones there are issues to do with healthcare. How a child was born, whether the child had a viral infection, a child had a bacterial infection or you know these people if they had the information that when a mother is pregnant, they will go to the clinic, that they will deliver in a facility, then we would be able to minimize the challenge.

The bad injuries, or when this child is sick, and they are taken to the hospital early, we're going to avoid this convulsive disorders, which can progress to brain injury, this is what I am saying if we can do it thoroughly, and this all goes to getting the information out there, because these people because of their social economic activity they need to know that first, access to health care will prevent very many complications later in life for a child.

I: Thank you so much for that I don't know if my colleague Here has any other issue...She doesn't have, thank you. for time we really appreciate, unless you now have any

Questions, comments or suggestions, we have to the end.

R: It has been a good point of discussion.

I: Okay thank you so much.

[End of audio]