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I: This is a KII with a health care provider at health facility E on 1st December 2021. We can start by telling us your experience in providing health services to this community.

R: I serve at the CCC department where we have integrated services, which includes epilepsy, sexual gender-based violence, among others. This is my third year of service in this facility and I find it interesting offering services to the facility's catchment population which I think totals to 25,999 which is as per the 2019 report although I'm not sure of the source. Serving persons living with epilepsy is an interesting venture, it is not as easy as well since there are so many issues surrounding that area such as the stigma that arises from the clients and staff as well as the people they interact with.

I: Thank you, what is the burden of epilepsy to the community sounding the facility?

R: Looking at the community that surrounds the facility and to the extension of those who come around, they are financially disadvantaged such that people living with epilepsy may not be able to access the services in the facility because they are probably engaged to find a meal for themselves. They would rather go find income-generating activities than come to the facility. Then number two for those clients who do not have drugs or supplies and we prescribe them unfortunately 95% might not be able to afford them despite the low charge of medication. We also have low health-seeking behaviour for people living with chronic illnesses especially those with epilepsy because of the stigma, fear and discrimination as well. Those are some of the challenges. Also, probably what the NMS is trying to cure is the shortage of staff which at the end of the day will have a detriment to service delivery. It is something that is being secured but time and memorial we have had a shortage of staff which by the end of the day affects how the services were delivered.

I: What are some of the other factors for low health-seeking behaviour apart from the ones you have indicated such as stigma and discrimination?

R: Going by the mind of our patients some of it is due to ignorance, some will choose not to seek services thinking that it will go away probably due to religious reasons or due to

seeking services from a traditional healer, those are some of the possible reasons this could be occurring.

I: Kindly tell us the different types of epilepsy and how you would differentiate them?

R: From what we witness around, we have clients presenting with different symptoms and different durations. We have some who report that they have had the convulsive disorder since birth and there are those who have acquired the convulsive disorder which we cannot say is epilepsy until a number of tests are done. What we diagnose is a high index of suspicion with a secondary tool, the history, the clinical examinations, and others. The majority around over 60% have had a convulsion at one time in their life and it went away then after 10- or so years they had a relapse. Very few report with an index case at the late stage of their ages. We also have a few who present as a result of trauma especially head injuries and also due to drugs.

I: Which type of epilepsy do you mostly experience in this facility?

R: I might not give you the exact data due to the difficulties we have had with data collection and because we do not a specific tool or indicator to have the data for our consumption, but the kind of epilepsy that we have been able to witness numerously is that the convulsions because we do not have adequate structures to have that done, but what happens for those, we also referrals as a modality of management. The majority of whom we have high suspicion, we refer for further evaluation, for diagnosis but unfortunately, we lose them in the course of it because of the possible reasons I mentioned previously. Majorly the convulsive disorders that we witness in our facility are those with index incidences of convulsions.

I: Is there a reason why you would say is the reason for the type of epilepsy that is common in this community?

R: I may not be able to have the figure because we may not have been able to study the geographical distribution now that we do not have the data but probably it could be because of is a lot of similarities in the exposure since this is an industrial area and there

is a lot of chemicals that are being spilled in the air and water and whatever they consumed probably this could be a triggering factor that needs to be studied as well.

I: Do you think the community has enough information on epilepsy?

R: Unfortunately, I might also not be able to give you the exact figures but the probable hypothetically based on how we interact with them is that majority do not understand what epilepsy is about unless we educate them and of course being that they are a social group they talk but then the primary source but there is less knowledge and education… information regarding epilepsy. The majority do not understand what epilepsy is and how it occurs but they take the convulsive disorders to be caused by something different, away from epilepsy.

I: What does the community understand as causes of epilepsy?

R: A huge percentage, probably 90%, do not understand the exact causes of epilepsy; it is just insinuations, the thoughts and beliefs.

I: What are some of the perceptions on the causes of epilepsy?

R: The religious background influence how they make their thoughts or how they make their deductions based on some subjects so that that one would think that probably someone has bad spirits and that is why they are convulsing, sometimes they also pin it towards their traditional believes that someone has gone to the witch doctor or they have done something bad and it is catching up with them.

I: Where do you think most people in the community seek treatment for epilepsy?

R: On and off they come to the facility because unfortunately many will not be able to disclose directly that they have had these convulsions or convulsive events. It is something that you will have to find out for yourself, but then they will come to the facility such as here but the only point, it's something that you have to derive from their history or clinical judgement.

I: So most of them seek services from the hospital?

R: Yes in the healthcare facility but less often do they disclose that aspect of convulsion. It's something you have to find out from them based on clinical judgement.

I: **Why do you think they mostly want to hide?**

R: This is because of the discrimination, fear, stigma, ignorance, lack of proper knowledge on the need to speak about this.

I: Do you think they fear expressing it to a healthcare provider?

R: Not all of them will be afraid to express it but they would want to put it in a way that does not picture out convulsions or epilepsy, but 70% are not afraid, they will speak out. 30% will be afraid or even delay to say it though at the end of the day they will speak with reluctance.

I: Now that most of the community members do not understand epilepsy how does that affect their health-seeking behaviour.

R: What they usually say is that you seek the knowledge and the rest will come now. I think that lack of this particular knowledge affects the health-seeking behaviour and they are less inspired to speak about it because when one has information on the consequences of the same they will be able to speak about it such as one conversing at a place that is not safe. if they know the consequences of that then they will be able to speak about convulsive disorders.

I: Where else do they seek services for epilepsy?

R: Patients have a right to seek services at any point of service delivery. Unfortunately, I may not have the data specifically of other facilities they may be seeking the services from but my assumption is that they could be seeking in other adjacent facilities because we have Health Facility R, M, and D which are near this facility.

I: Why do you think they seek services elsewhere?

R: It is their choice, they have a right to choose even those that are far, sometimes they feel less stigmatized when the facility is not around where they live and do not have

fear, also the drug supply because sometimes we do not have commodities to meet their needs and therefore go to a different facility with desirable commodities.

I: How do patients take up treatment for epilepsy

R: We usually prepare the patients psychologically and also try to reach their treatment supporters, we have established a system by which they are self-reminded and they own the whole concept of treatment therefore the retention is good, we are able to retain them in to care because of the good information we give them, the preparation and the good follow up that we do have helped to retain them and enhanced adherence to the medications.

I: What other services do you offer on epilepsy

R: We also have psychosocial support.

I: What treatment is available for epilepsy in this facility?

R: Psychosocial support is always readily available but the problem we have had is with the commodities recently we had pregabalin and carbamazepine. We have also ordered other drugs.

I: Any other services offered apart from, medication and psychosocial support for epilepsy

R: We also link them to other desirable services if one has a communicable disease or issues we ensure that we are able to link them to every respective service they may need.

I: Do you have any outreach

R: We have both in reach and outreach for the services.

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

R: I have not had any specialized training on epilepsy therefore mine is general capacity, non-specialized but we also have a specialist who comes to help with the review of the same.

I: Do you have other colleagues who also help you diagnose epilepsy

R: We have around 5-7 colleagues who help me and they offer the rest of the other services.

I: Do you have CHVs who help you?

R: We have CHVs but they are not specific to this project. We have not had them adequately trained on this.

I: Are they capable of diagnosing and referring patients with epilepsy?

R: They cannot make a diagnosis but have a high index of suspicion even on our end it is the high index of suspicion until we have the appropriate diagnosis given.

I: What is the ability of this facility to offer services on epilepsy and how they are stocked in terms of medications?

R: Not very stocked, no adequate diagnosis facilities, staff not adequately trained on the same.

I: So we have a problem with the tests, adequate medication and also staff?

R: Yeah and specialized skills in this particular subject.

I: How can these be addressed?

R: Capacity building the staff through training, sensitizations, on job training and mentorship.

I: What are the challenges you face providing the services?

R: Drugs stock out, and as we talked about the need to capacity build and training as well as empower myself, sensitized and mentored.

I: When was the last time there was training on epilepsy?

R: Not any recent that I can remember.

I: Why do you think there is always not enough supply of medications

R: On epilepsy, less concentration has been given, unlike other conditions such as TB, cancer and HIV. There has not been much focus on epilepsy. Probably it has led to some sort of disinterest in providers, to continue doing continuous medical education.

I2: What is the profession of the other service providers who help you diagnose epilepsy?

R: We have clinicians, as well as specialized personnel who is specialized nurse in mental health who come periodically since they visit other facilities.

I2: Apart from the health facilities do patients seek care elsewhere for epilepsy?

R: Patients have a right to do what they want with their lives and health. What we can do as providers is to provide enough information to get to a particular point of interest. If a person has chosen to do the traditional and they find it doable or working for them, we do not have a problem. But as health care providers we never stop giving enough information and interventions that we believe is evidence-based and beneficial to the patient. So I may not tell you that they go to traditional healers but it is a subject that has become a concern. If they think that it has been caused by some external powers then possibly they could be seeking the external powers to solve this particular problem.

I: Thank you, we have come to an end of our conversations. Do you have a question?

R: I don't think I have any questions. I trust that the findings of this interview are going to be useful in bridging the gaps that we have been able to identify from this particular conversation. That is my prayer that it benefits the providers and by extension the users living with epilepsy.

I: Thank you very much.

[End of audio]