**FGD-003**

INT: Thank you for your readiness to be part of this discussion, today is 4th of February 2015, we are in …. Centre discussing about the health services at the HIV care and treatment unit in this facility. We are not going to use names in this discussion but numbers given to you. As I have already explained were going to record this discussion to make sure I do not miss any information in today’s discussion since I will not be able to write everything as we discuss. Is there any one with problem for recording our discussion?

RES: No

INT: Okay thank then let’s start our discussion please speak freely and if there is information that you would like to keep it for yourself please do not say it because we are in a group here, I as a PI may not be able to control what other participant may talk out of here.

RES: okay

INT: My first question is where do most people from this area go for HIV test?

RES: Tunduma health center

INT: really only here,

RES : The main centre is here but there is also …. and ….

INT: mmh!

RES : Some test here and others go to … and ...

RES : It means for … is …, …. and here. If somebody wish he/she may go to … even though they do not have any services, after testing they are given results and come back here.

INT: Ok thanks, there some people who go for HIV testing and they are diagnosed infected but they become reluctant/hesitating to register into HIV care services? Does this happen here in …?

RES : ... (all)..... yes it happens, many times

INT: What do you think are the reasons?

RES : Let me start, I have my landlord who is coughing too much for a long time now, but if you tell him to go for health check up (HIV testing) he refuse and say if I go for testing they will tell me I am infected so it’s better, I remain not knowing, I might take poison or commit suicide. I tried to insist that I am in my second week now taking this drugs.

I now feel better, I was also having chest tenderness I couldn’t even eat, I had swollen nodes, but since I started using drugs (ART) I am doing fine, I don’t have any problem. Still he told me I don’t want to go, you just go yourself as you have decided as for me I will not take Mashudu (ARTs). Those are Mashudu ….., but he is still coughing up to now even at night…...... he is coughing all over the night.

RES : There is a lady who died here in …., she was using drugs without informing her husband, when her husband knew she opted to die.

INT: Do you mean she committed suicide?

RES : Mmh! Yes, She took a lot of flagyl tablets.

INT: Mmh! What do you think are the reasons of people hesitating to register for HIV services?

RES : I think some are feeling shy that people may say she is taking drugs she is infected

RES : I am supporting him, some feel shy and be afraid to be recognized by people that they are living with HIV.

RES : I think the main issue here is fear, example when you get the disease you may experience problems in health, when it becomes worse you go to the health centre for test and you may be told you are already infected, so people become worried as there is no one to counsel or comfort, in reality many people are lost (died) due to such feelings. Even myself when I realized that I have that problem (HIV) i thought its better to take poison and die ...(laugh) later on I thought a man should be strong … I can’t just to die like this .... (laugh)....then I became strong, …. And good luck my mother was close to me, she told me look at that person he is living with HIV, sometimes if you go to the health cervices you may find many people are like you, so I was encouraged.

INT: And how are you feeling now?

RES : Aaa! I am ok to the extent that if somebody sees me now, I look very different from the way I was before starting treatment… I advise people they should not fear

INT: okay I see?

RES : Some people are deceiving others, like for me they told me if you start using drugs my friend , it depend on some one’s body, some get fat and others get thin and others even die. I was afraid, …but right now I am strong even though occasionally I have stomach ache, but am generally okay. One day I had a fever i feel my hand and legs not working properly I thought I wanted to die, I asked them to take me to the hospital and do all the tests, including HIV, I found that I was infected and they registered me into drugs, since I started taking the two weeks drugs I don’t feel any problem.

INT: In another case you find other people have well started using drugs but later on they stop, do you think why? what are the reasons?

RES : Some do not understand how to use drugs, you may find others were sick they started using drugs and feel better then they stop drugs. I think Satan has taken them….. *(others laughing)*

INT: Do you think they are not well informed.

RES : Yes, maybe they don’t have enough education.

RES : I have my friend whom we registered together for drugs but surprisingly i don’t see him for two days now , today I put my card here and say let me go at the place where we work together, I found him and asked what is wrong? He told me he went to take the drugs two days ago, I said to myself that he might be depressed already but when we started using drugs we were given instructions, we learned in the 1st up to the 3rd class that if you start the drugs you should keep on taking until your death.

INT: It means after starting you are not allowed to stop! Mmh!

RES : Yes, even if you start feeling better, keep on using, because if you stop, when you start again those drugs will not work. I just look at him and say why this person whatever I ask him he does not want to answer me, we were taking the drugs on the same day and his condition now is better.

INT: So he has improved

RES 3: Yes his health is good than mine.

INT: So if your conditions will improve like this person will you stop drugs?

RES 3: No for me I won’t ... (laugh).. as we were given instructions…. I will follow instructions, I don’t want to die ….. I have children to care

RES: Mmm! What about others….

RES : For me when I started using drugs I suffered a lot, I felt am seeing a grave, I could not even go outside. I thought it was because of drugs, I said, I want to die due to these drugs, I decided to stop… I told my sister she also agreed with me because she saw my condition , she told me to go to my mother. i suffered a lot I couldn’t even stand up;! When I felt better i decided to come here and then, they gave me another type of drugs now am better.

INT: It means that you took the drugs for two weeks, then you thought the drugs are causing you more suffering?

Res : Yes but now am fine

RES : For me, I started the drugs without getting any problem but after starting the second dose which was for one month the whole body was swollen and rashes up to now my body has scars.

INT: Mmh! What about you my brother at the corner?

RES 1: I think those who are stopping the drugs some goes to the pastors for prayers instead of checking their HIV status and have ended up, just stop drugs.

INT: So they believe in prayers?

RES 1: Yes! If they pray for me my problem will end.

INT: But is it true that the disease heals or disappear?

RES : No, it is just a people’s belief, HIV does not go away by prayers even if you pray the whole night

INT: Are there other people who are using traditional medicine?

RES: Yes, they do (laugh)

RES : Mmh! If you start this drugs at first some people get confused, so if you are close with that person who believes in witchcraft, its better you stay away since you will be afraid and think let me go and try the traditional healer

INT: Has any of you been attended by a traditional healer?

RES 7: Before coming here i went to get some treatment to a traditional healer but i did not see any change or improvement, then my brother said i should come to hospital

INT: Were you told you are bewitched?

RES 7: Yes, I was told somebody has bewitched me, i was given some herbals to use but after using I did not see any changes that is why I decided to come here.

INT: Mmh! What happened after coming here?

RES : I started drugs when I came here so right now I ‘m doing well.

INT: Which month did you register for drugs?

RES : If not mistaken I started in March.

INT: So are you ok now?

RES : Very well! I am very good and even if you bring food here I can take nicely as if it is not me.

INT: Ok thanks, let us go to another question, What do you have to say about the health providers, do they give you the necessary information about your status and how to link into further care?

RES : Frankly speaking the health providers here have welcomed us nicely especially me, they honored me and started the class on the first day, they explained step by step on how to use drugs and asked me not to worry, I finished all three classes I really thank them. Its two weeks now since I started the drugs they are providing good services they don’t hide anything.

INT: Ok, any other comment?

RES : In the side of health providers, people differ in communicating, you may go to see the Doctor and explain your problems you might be treated differently but is not common here.

RES : I never experience bad treatment from them, example I started using drugs in November last year they attended me nicely, I was given the appointment to goon and I take the drugs and never got any problem.

INT: So do the health providers encouraging you?

RES : Yes! They encourage us that is why I am here until now, If they couldn’t encourage me, I could have already given up.

RES : Aaa! No….. they say if there is a problem when using this drugs and get any side effects you should come to explain here (nurse station) don’t go to the Doctor.

RES : Because in the class they told us that if somebody is sick he/she should not go direct to the doctor, he/she needs to come here to our teachers who are teaching classed in order to be registered then you go, Everything is free of charge because others from home they have money they go directly we were told we should not complain

INT: Thank you I appreciate, let us continue with other question, since you are registered at this clinic and you are still in care tell me what motivates you to remain in care despite the challenges?

RES : Generally we are encouraged with the discussion with… our nurses encouraging us that we should not give up, we should proceed with the drugs and they emphasis to take food and how the food can be taken and to take in consideration, all the instructions and the next appointment date.

INT: There fore do you follow your appointment date?

RES: Yes! the same

INT: Good! Also, we have talked earlier some people are stopping coming to the clinic, they dissapper, what do you think is the reason?

RES : As for me what makes me to come is that since I started this services

i never became sick again my health has improved tremendously

INT: Mmh!

RES : Before I was suffering from stomach ache that is why I come for services up to now. I will never stop this services because I count this drugs as a part of my food.

RES : About the issue of drugs even the first time when i came here i was afraid I thought I was alone but other patients were encouraging us that there are other people who started these drugs a long time ago and they are okay, so my sister don’t be afraid the important issue is to be careful with food and adhere the drugs timetable , it should be taken like food Like the way you eat food every day, I said can I manage? They told me I will manage but the way I was suffering and now am okay, I really thank God and I will never stop.

INT: Mmh!

RES: It’s true I will never stop.

RES : Before I was getting fever very often but from the time I started drugs up to now I have never disturbed by fever.

INT: Mmh?

RES: They make me to be health like how I am.

INT: Ok!

RES : Before I was not capable of working, I was not very sick but feeling tired. Since I started drugs I can work up to evening …I can work from 07.00 hours to 18.00 that is the good thing I can say which motivates me up to now.

INT: Let us now talk about distance, is there anybody who is coming very far from here? Do you think transport cost can contribute to a person to stop attending clinic?

RES : It not a problem to me, if my appointment to the hospital is coming I start saving money little by little up to the time of going for drugs you … I have enough money for bus fare to the hospital. Another issue which makes a person to stop using drugs is health improvement some people when they see their condition is good than before they decides to stop treatment. …. you may have the friend who can persuade you by saying you look good…why are you still taking the drugs throw the drugs away and go on with your life! Or you may find another one saying let us go to the church to pray for you and you agree, but if you are careful you cannot stop drugs.

INT: So the issue of distance and costs does not contribute to drop out?

RES: No it does not contribute because a person can be careful with the appointment date and most of people are coming around.

RES: It does not contribute because the centres are near as from here to … is 1,000/- for people staying at … is 500/-Tshs. There is the center at … but they do not provide drugs, they provide drugs at ... and ... So you may find the transport cannot exceed 1,000/-.

RES: They do provide drugs, they have only one day, but i heard they start at … and later on go to …, Aaa! The same nurses going to provide drugs, they don’t agree to go and take drugs in other centre, they are saying you should take the drugs near your home.

RES: You know sister as I talk here you may find others go to …, … or go for drug registration in … town, for those they add cost by their own wish

RES: Yes! They are afraid to meet with their neighbors or somebody whom they know. Those people are available even now.

RES: Others finds it’s better to use money to cross the border and go to Zambia for registration just to hide.

INT: Mmh!

RES: Those who are given drugs have never came here, some of them are drivers who are on the way daily.

INT: Thanks, another question, do you face any problem when getting services.

RES: Mmm!

INT: Here at clinic and if you face problems what are those problems?

RES: When you start using drugs at first you face some minor problems example, I swallowed the drugs at night when sleeping I dreamed somebody is strangling me without saying I am HIV positive ...(laugh).. When you wake up you find that it was the dream.

INT: So you were having nightmare?

RES: Yes!

INT: There are so many people who experience the problem of nightmare

RES : You may dream seeing the grave, or somebody has done something bad to you, they told us at the beginning in the class that you may be getting bad dreams but it will end and also for others may get terrible headache as if the head is going to break.

RES: I once dreamed they have put me into the coffin and take me for the burial. In the morning I asked is this drugs belongs to the devil’s kingdom! I real had bad thoughts that why taking me for burial. The drugs had bad dreams one day I decided to wake up and just sit on the bed.

RES: At first you may have bad dreams or thoughts, you may be seeing bad people even though there is light, (laugh) you may think that am I crazy?.

INT: How long did they last?

RES: For me they stopped after two months

INT: Mmh!

RES: For me I get nightmare every day.

INT: Ok! What about you who you are in drugs only for two weeks now do you still get nightmare?

RES: It happens but not very often! One day I was scared, till my husband said do you want to die? I told him I had a bad nightmare, I dream that I was being buried and I was blocked by the big stone I said to myself do I want to die? I suddenly wake up and found it was a dream. I am very fine now and my husband is trying hard to care for me I was not even eating but now I take everything. The good thing is I stay near Mrs.… who is the nurse ... She is the one who is encouraging me so much.

INT: Okay, do other people experience different side effects of ARTs?

RES: Yes, they affected me I got rashes.

INT: Mmh! What did you do?

RES: I decided to go back to the hospital I explained to them they changed the drugs.

INT: Mmh! Did the rashes stops when they changed drugs?

RES: Mmh! Yes they also gave me a cream to apply so now is better.

RES: When they registered me for drugs I did not get any effects.

INT: Aha! Is there any person who had side effects fro medication, apart from what we have heard?

RES: No

INT: What suggestions do you have that can help improve services in our clinics? to the government or the health providers to improve care for people living with HIV.

RES: Silence

INT: What do you advise the Government or health officials to do in order to improve the services at the clinic or even community members.

RES: On my side nutrition is a problem, the life is too difficult and you cannot take this drugs without food, we can appreciate very much if they will assist us in getting food.

RES: Aa! I request the researchers to continue doing research and get drugs that can cure the disease completely, we pray the research should come up with drugs.

INT: Ok, what would you advise, if you happen to meet someone who has recently been diagnosed with HIV but does not want to register into care, What will you advise him or her?

RES: I will go politely and explain as they explained to me, secondly then I will advise and keep on insisting till he/she agrees because this is a big problem. I even tell my neighbor every day, today she asked me to wait for her while getting prepared when she entered inside, then she come out saying her husband is coming … She said you just go I have postponed, but i believe she will come one day.

RES: My friend was passing near my home the day before yesterday she was very tired, she carried rice, oil and soda when reached my home she leaned in the wall, I asked her what is wrong? She replied, “I am tired”, by then i was going to take bath i put the bucket of water down then i asked her again why are you tired like that? I kept on asking but it seems as if you are sick? She said yes. I said my friend as you see me here its the second week since i registered for ARV, so I advise you to go with me. She said, my sister I am also taking the drugs in Zambia, you see!

INT: Therefore in short, most of you here, have recently started medication and you ready to give advice to your fellows

RES: Yes we are ready

RES: Like me my neighbor was suffering I advised her to go for drugs, She said let me talk to my husband so that we can go together. For me my husband has never stopped me, he said prepare yourself my wife and take this money go to the clinic.

INT: Has your husband already tested?

RES: My husband hasn’t tested he say he is busy at work, but he allowed me to go. If I tell him he does not refuse he says call your sisters and friends go together with them. As you know I am already tested and we will tell even our children to go for testing.

INT: According to this one I know the husband is aware of her status, what about you did you tell your spouse/partner? If you do not want to talk about it is okay, I will understand.

RES: I have told him..

RES: Aaa! I have the wife

INT: Mmh!

RES: Both of us have registered for care and we are on medication, he was the first to register and later she convinced me to come, but it was difficult. I suffered a lot then later on I decided to surrender and come for testing and now we are all using.

INT: Is there anybody who faced problem after telling the spouse? Since I heard there are some marriages ended up in divorce.

RES: I divorced with my husband for the same reason…… he is currently married to another woman who does not know his status.

INT: Has another wife not tested?

RES: Mmh! I don’t know

INT: So in the community the issue of testing and sharing results in couples is a problem.

RES: Many people are facing problems in the community and some lead to divorces.

INT: Okay what about prayers are there people who stop treatment due to spiritual belief?

RES: Yes! They go direct to the front of the pastor with the drugs, for the pastor to pray for them and the drugs are thrown away, sometimes you find the pastor himself is on drugs the doctor is taking for him! (laughing).

INT: Mmh!

RES: But a person is throwing the drugs saying the pastor have prayed for me I will be healed while others are going to the traditional healers.

RES: Yes the traditional healers can trick you. How can they get your money, without lying and telling you someone has bewitched you…

RES: I went to this local herbalist, she gave me some roots ,I took them but they did not help me at all and that is why I thought it’s better to come here.

INT: Thank you so much, here is the end of my questions unless you any question about what we have discussed,

RES: No questions

INT: We appreciate so much for your time in this discussion