**FGD-002**

***Today is tenth of June 2015, we are going to discuss HIV care services at …. Facility, may I request everybody to speak loud, as we agreed we will record without mentioning any names. Be free to share anything that you feel is important in the process of linkage into HIV care, Is every one ready we can start?***

Yes, thank you

***My first question is, Where do people in this area go for HIV test.***

Here in …`

***Yes!***

We prefer testing at … and when this car(the mobile testing Lab) comes here also many people come for checking their health

***Mmh***

Ok, there are other dispensaries or private center’s apart from … Health center or the MMRC mobile lab, which offer HIV test?

Is … Health center and there other dispensaries, Matema, Ntaba, Makwale and that Mission hospital?

***Res: Ok, and why do people prefer those centers?***

For example myself, when i started having frequently fevers i went … for testing, I was found with HIV infected

***And, where do you live?***

I am living in…, I was tested there and when started drugs I was going there everyday so when established dispensary here I found its near, they told us if you want to CD4 count you should go to ….

I started …, after moving to this area, its far and I don’t have bus fare so I started on this dispensary where I can walk,

Me and my wife came for testing here. We started at …, , we were both found HIV infected and we started medication here.

***My brother do you want to say something?***

***My question is why people go for testing to center’s that far from where they live?***

I wanted to tell you that, some people in this century still don’t know but some of us knows, like me am still young and am HIV positive, at hospital after seeing elders, women lined up for testing who am I to fear, so I tested and was found with HIV.

***At the mobile center***

Yes, the doctor said, are you ready? So I said yes I am ready for anything and he said, ok, thanks for your confidence and the result shows that you are infected with HIV I thanked him, he gave me the leaflets and said go to room number ten , they gave me a card and said I should go to room number five where they drew my blood for further tests

I was told to come the next day for the results, so the next day I returned they said, I had very low immunity about one hundred and ninety nine.

***What motivated you to go for testing?***

Thank you… after discovering that my body was different from before, I had frequent fevers, I was getting tired without a reason, before I used to ride a bicycle, but now I can’t, so that I thought I should check my health. I attended treatment adherence sessions for two weeks then I started taking medicine for two weeks and then for month. Since I started medication am fine and when doctor asked if I have any problem, I said I don’t have any problem, so he said I have to check my CD4, again and it is now increasing , I have 278.

So are you now doing well?

Yes, so they changed my medication from morning and night, to night only until i check CD4 again i will continue or I will be back again because we have many activities, doctor said that (we) young people should not loose life with our family while we are still you and the family depend upon us. So when we feel un well we shouldn’t fear....

***Okay lets now discuss, what happens here at the clinic***

Like me I come from very far away and I brought my card early about six in the morning , while others who brought their cards about eleven or twelve but they are the ones receive medicine before me. Some times this is the reason why people shift from this center, if you have money you better go to …. Hospital or somewhere else.

***So do you mean services are not done by the first to come, is the first to be attended and get medication?***

Yes, you may arrive early but you get the medicine late than the one who arrived late and gets medicine early for those who comes at 9:00 will be attended at 04:00 in the evening so same opting to go to …. thinking will get services quickly, you come from far and get such problem.

***mmh***

I wanted to answer your question, for example, why should I be tested here, where … will see me as HIV positive so I should go to… where no one knows me. do you get Me?

Mmh I understand

That is the major reasons for the people to go far away for testing?

Some of the people tested here, but start to take drugs somewhere else, so as not to be seen by their close people.

***Mmh anything else***

This situation has got two side, even our service providers, some of them abuses us, we can’t hide it, for example as my sister said here you arrive early about six in the morning but you get medicine late than the one who come late. There was a trouble here on ...September there was serious problem between the nurses and us. We arrived early at six in the morning and we collected our cards waiting for our turns but someone entered with a card in the pocket at about one in the afternoon, then got their drugs and left.

***Mmh!***

The ones who comes early we were still there just sleeping, some of the elders and children were sleeping on the floor they kept waiting but this time we all reacted, It was I big conflict and chief doctor in charge….. helped to calm the situation. He asked the nurses what was wrong. he said if there no drugs you could have told the patients early that they should come another day and So this is also a reason why people shift from this center.

It was eighteenth they refused to give me drugs, I went again few days before February on the same dates, they opened the center at twelve noon, but today, they gave us medicine early may be because they saw you are here.

When we arrive here they look at us like we are not normal human beings, they discriminate us but government is the one protecting and helping us. So that also is the reason why people shift centres, we once wrote a complain letter and drop it in the suggestion box but it didn’t help.

***Mmh, okay, lets continue with another question. There are some people who get tested then after results, they are given a referral letter to attend further care but they don’t go, what do you think is the reason?***

They don’t want to be seen at the hospital waiting for drugs, its better to say, it was malaria. (laughing)

Some people travel from here to … with bus fare without even eating just to avoid to be seen here at the clinic.

***And what about transport cost, is it one of the reason people fail to enter HIV care?***

For example people from …. (about 60 km rough road) are supposed to come here to be tested for CD4 and is there one boy who failed to get bus fare he was not able to continue coming?

Some people delay for weeks just to find money for bus fare to come here for testing.

The worst is that …for example, I have emergence and send my neighbor with card on the appointment date to take medicine for me, they gave medicine to the one who is present only and the one who sent card has to come personally some other time. That is also discouraging us.

Even me, I with my wife were taking drugs on the same date but they told us that all of us should attend and not sending one person among us even though were together, one could take medication for both of us to save cost but no they don’t allow.

Mmh! Any other opinion?

Some people they don’t even want to be tested, they keep using Panadol when they get very sick. For example, few days ago, one HIV victim died because, he didn’t want to use medication, they found him very sick on the mattress, they brought him here (at the hospital) then he died the next day! he would be alive if he was using medication... silence....

***So, he wasn’t using the medicines?***

Yes, they took all the tablets they found under his Mattress, he was not taking them.

***Why are they doing that? Help me here!***

Some people are just insane…(laughing), Because, when you plant potatoes how can you reap maize? It will be potatoes. This is world disaster.

And anyone can get it [HIV], why fear?

Other people wait until they are sick to be tested and to start using medication,

***How would advise those who do not want to start medication?***

on our side we should not stop to give them advice they will someday come around and tested. Also we should be free to come and take medicine and also proceed to advice them, so one day they can change and accept the reality, as you are giving us counseling.

***My brother there, you are very silent***

Am listening

For example when somebody doesn’t want to be tested, I usually give them education in Pombe shop (local brew shops) where we meet them, that this is normal situation and you don’t have to wait until your very ill to start medication

I tested here, then they told to come after three month, I come but again they told to come after three months until and my immunity reached 300 then told me to start medication

***So, you counsel your fellows to use medicine?***

Yes, we want to save this generation because many people are infected especially at this…. district.

All in all we have to pray for each other instead of laughing, but they will know that later we have good intentions even I was advised by others that here are some things I have to do so that i can live and care my family. Am thanking that brother so much for opening my eyes he told me I have to change my religion to Roman Catholic, so I changed until today am worshipping there. I advice those who they see themselves that, are ok to come ad test. We shouldn’t be discouraged even if they insult us.

I always tell others this is your health and the medicine is free, that money can be used for food in your family you just have to go and get it, they refuse by saying that they were be witched.

***Okay, in some areas they associate HIV with witchcraft, it this happening here at…?***

When I started feeling sick, I was at … (is another region), My in law took me to traditional healer, he just look at me and said I was not infected, he started treating me with different medicine, they said that, there was a woman with the same problem but she were cured, so they gave me the whole bucket of, medicine for drinking and bathing I refused, at the end because I wasn’t getting any better so I told him, I want to go to the hospital.

Some were for drinking some for bathing, after using it I get frequent diarrhea and I found my body becomes thin due to several diarrhea. I said to my relatives am going to die while I see its better to back me home truly I move up to … town, my brother was there and he send me to hospital for testing and they found I Had HIV also I start medication, since I started medication my condition improved.

Myself, the disease start with heavy cough, I thought may be I have TB why coughing like that! They send me to hospital for testing and gave me a dose to use, after using that dose cough proceeded. I got pregnant but still coughing much, they said why don’t we test you HIV, After testing, they found me infected

For me testing, I wanted to confirm, I said, let me test at the mobile clinic from white people and see if they will also tell me that am HIV postive? (laughing)

***Okay,then what happened***

Results were same, i checked CD4 , they said it was low, so they gave me drugs for two weeks, when started the dose I got fever after taking the first drug I felt dizziness and did not see nurses, after finish dose doctor ask me, how do you feel after using medicine? I said I had a stomach ache, they gave me another medication for taking in the morning and evenings, its three months now since I started medication, I don’t have cough even fevers any more.

***Okay any other contribution***

When giving me the card she said i should go on Tuesday and find my fellows to take the drugs i went there that day and was given the drugs, they told me i will be swallowing two times a day and when you finish after one month you will come to take another.

***Didn’t you attend that session of treatment adherence, the importance of stayingin in medication.***

No

***Mmh, did others attend these classes?***

I attended for two weeks.

Yes I attended the classes for like tree weeks, when the time came I was told to start attending the class they were telling us if you have tested you should not give the drugs to other person

You should not say you give to this also because he/she is sick. That drug need to use yourself because the one is sick you do not know their CD4 number you will give the drug and he/she will become very sick so just need to use yourself.

We were taught to reduce sex and you should eat enough food and in the morning at 08.00 when you take the drugs and also use of vegetables.

Always use condom to your wife and they provided condom

***Mmh do you use the condoms it or you keep under the bed?***

We are using (laughs)

We use because I don’t like my wife to die (they laughed again)

***How long did you take from the day of registration up to starting medication, is it one week, two weeks or a month?***

It took 3 weeks

For me it was two weeks

For me it was six weeks

For me it was about 3 months.

Okay Let us discuss about the people who stop medication, what happens, what is the reason?

It is surprising, for example , you may find somebody who is using drugs when he feels better they stop and later they start falling sick again, till he die

***Why do they stop?***

That is what we don’t understand

Let me answer this from another angle, somebody can say this drugs needs you to eat first, if somebody takes the drugs without food you might get reaction. If you say my friend, this drugs needs you to eat, even if you take one or two bananas the drugs will work. Other people are not eating because they don’t have food in their house that is why they become affected.

Why should you harvest rice while you have planted potato? We can just say people are fearing to be seen by people who are going to … everyday to make a queue, that is the worry and not food. So does those who hide the drugs inside just not to be recognized they are taking ARVs

Some people may start using drugs and when their health improves, no more fevers which convince them that they are okay and to stop the drugs.(they laughed)

So you are saying when they improve they stop taking their medication?.

Yes

***Do you face any challenges due to your status in the community? maybe if people knows that you are infected do you get any problem with your relatives or friends?***

There is none for me, I continue with sensitization like now i will tell people that i have been to the hospital for my medication.

Yes, my parents, children knows even my wife we are together in this matter

***And other people who surrounding you knows and you don’t get any challenges?***

No they know, they are many in our place now, its a disease which facing the whole World.(laughing), there was stigma in previous days, currently there is none.

You can be killed with Malaria but not this disease[HIV] they are saying its better having HIV than Malaria, because with HIV you will get better and have good condition but malaria can kill you within a minute, so now its a normal things.

***So there is nothing like pointing fingers or something like that?***

Haa there isn’t, example at our place there if there is development activities I go to the chairman out him that its my day to … to take drugs, so i wont attend. I save my life they give me permission.

Example at our place here … we have formed the group which we meet every 15th, We have the contributions where by when the date reached we contribute 500/- so when we have that money..., and if someone does not have money for transport we give him money, for going and return on the day of his/her clinic. We are many, its over 200 people

***You have told me good things, I wish we could spend the whole day because you are telling me things that are not in other places.***

We benefit since we are contributing money and is circulating from one to another if somebody has taken and returned another one takes so you get the courage that you will have money one day, so people will say you are HIV positive where do you get money? So you need to join the group.

After arriving there you explain your problem if the fund is available you get the loan if its 10,000/- 3 people will get and others will get 15,000/- they return and others take again.

If somebody does not have money, he/she brings eggs we sell, So in case somebody have the clinic far away going for CD4 test and does not have money he/she just talk to the group and they give money he/she just talk to the group and they give money, in that way you are helping each other.

Haa, the infected people are now advanced they are courageous there some groups we did not expect to stay up to now.

***Mmh, Its good, so we are now going to the end of our discussion, what would you suggest or advise to improve the health care services in our HIV care clinics.***

We advice the government to assist us.

***What do you mean?***

It should not leave us for example as we continue having our groups, the government should put its hand through groups to help financially the people who are living with this problem[HIV].

In additional, the government has contributed to us up to here we are in this situation, I thank the government and it should continue to support us.

For my side, I am asking the health personnel to change, they should care us, as they are cared by the government. The government has seen us that is why they are employed by the government to help us. If the Government provide something it should come direct to us the infected people. So they should stop harassing us.

Mmh,

In Fridays we suffer a lot, they came here and start cleaning at 10:00am up to 01:00pm, they told us to come very early but you will be surprised they start attending us at 01:00

You will hear them saying we can’t see your file, so even if you arrived early still you will leave late. I wonder why can’t they arrange files according to dates? They can arrange all files for patients who are coming on 2nd and also putting aside those who are coming on 3rd, that could be easy rather than now where we arrive early but getting late due to files issues.

Okay thank you very much, for your participation in this discussion, we learned so much in today discussion, we will make a report after finishing data collection and give feedback to the relevant people in health care services at the district level.

Thank you.

End discussion 11. 43 am