**FGD- 001**

Discussion start at 10:08

Facilitator’s words- bolded and in italics

Introduction

As we discussed during our introduction that today we are to discuss the health care services to HIV positive individuals from the time of testing through registration into care to the stage of starting using ARV’s. Even if an individual has not started using drugs (ARV’s), we will discuss about the other procedures at the CTCs

We have agreed to use this audio recorder because our conservation is important, and i cannot write everything down, and for these reasons all information are very important so I must get all information correctly without missing anything.

***Is there anybody who is having problem using the audio recorder or is there any question to ask me before starting discussion?***

No is fine we can start

I would like to ask…. mmh! Are we going to talk everyone with his or her problem or ......

***Ahh. Don’t worry you will see the questions are they will guide you, i will ask you the questions, be free, in case I ask you the questions you don’t like to answer, you just say i don’t want to answer that question and I will continue with other questions****.*

(coughing...) and sorry guys am having chest pain and cough, and i was riding a bicycle so .....

Others: Sorry, sorry, it is okay

***My first question is where do most people go for HIV testing in this area?***

Most people test in … hospital, some people test here at … and also at …, although now no people go to ...

Most people go to the …. hospitals and here (meaning …)

After testing here, where do you go for further care?

They give you a letter to go to the district hospital for CD4 count and medication

For me I tested at … and later on after starting treatment I came here to join other people living with HIV in this NGO

Since am a peer health educator in this area, I can tell you the details, we normally provide health education in different areas like, local brew shops, markets and other gathering areas… so we tell people the importance of knowing your status, … some people fear but we encourage them, then those who want to test we bring them here…they test and then they are referred to … for CD4 and treatment.

***Okay! are there people who come for testing but are reluctant to entering/ joining into further care in this area and what are their reasons?***

Part 1: Ooh yes…. They do not like going to the hospital, some fear other people will see them at the clinic and they will know that they are infected, that is why we are obliged like me, If I brought some one here for testing, if he/she is positive, I sometimes take the letter from here and I accompany the person to the clinic at … hospital, I take them trough all steps, CD4 check, seeing the doctor up to starting medication, then I give feedback to this site.

***Mmh!! Okay so peer health educators escort the clients to enter care***!

That is right we escort them and we advice them, like me , I just tell them that am also attending the same clinic and am taking my medication from the same hospital , so they should not fear, they are not alone, there so many people in… living with this condition (HIV), this gives them encouragement and I tell them to be relaxed and have faith.

***What about others, what do you think or do you have to say about this, it is only … who has been talking much about this question. (…silence)***

***My sister what do you think are the reasons for HIV diagnosed people not entering HIV care? There are given a referral letter but they do not what to go*** !

Most people fear stigmatization and we tell them not to be afraid, you can see.... us your fellows here are taking medicine, go and start medication so as you can rise up your children! Person agreed and went to the clinic.

For those who don’t like to go, do you think what is the reason?

They are afraid that people will laugh at them, incase somebody see him/her at clinic people will know that he/she is infected.

***My brother what do you want to say about this matter?***

A high percentage of people at the medication area you will be surprised are hiding themselves.... eeh! interruption …sometimes nurses call names up to five times, we tell them that they have gone to take tea so as nurses do not become angry, if I know where the person is, I go and tell her/him that it is her/his time to go, i talk to him/her that let us go to take medication and leave together.

People are hiding ..........., they sit at reception area or other places due to fear of being seen at the clinic by people who are going to see their patients at the ward.

But they are scared at nothing as nurses are saying themselves that even themselves are taking drugs at their office so what are you scaring about? Actually the nurses are encouraging us.

***Mmh! So are nurses encouraging you?***

Most: aah! They are encouraging so much.

***Is there anybody who has experienced unpleasant treatment from the nurses or staying too long at clinic waiting for services?***

it is not so, nurses are very polite and helping us a lot.

And the matter of staying a long time it is because we are too many so we consume a lot of time, but it is not because of nurses,. Its true they are treating us very nice and their language is not bad.

***How about the distance, if somebody lives far away is transport cost the reason of people not to join?***

For example you will find nurse have come with the patient card which shows is from … (about 30km from here) they call him/her and ask why he/she is afraid to be treated there at ...

“They are scared if they are treated in their home centers they will be seen, so ... a person says am going to … for shopping but he/she is going to the clinic”. (…laughter…), Since the nurses do not like congestion they advice them to be treated at the centers near their home.

***Aah: so if for example you go at seven o’clock in the morning at the clinic what time you will done and ready to go home?***

If you come at 7 you may leave at nine or ten o’clock in the morning (3-4 hours).

They are starting with education first after finishing cleaning then services goes very fast and after finishing everybody is leaving they don’t get late.

***What do you think makes it easy for people to enter into HIV care?***

In previously time the CD4 test was done in … (referral hospital).

For those who find their CD4 is high are not yet required to use drugs. They are usually given education and they come back again later one.: But are they attending education classes

***Oh! They are not coming because their CD4 still high,***

They are told to come back after 3 month.

For example my friend was suffering because had frequently fever I advise her to go for testing but she was not ready therefore day after day I was passing to her place she asked me where i was going i told her that today is my date to go to the clinic to take the drugs. She told me to pass by to her place after taking the drugs, she told me why i have the confidence to tell her then i explained to her that because you are my friend like my relative so i can not hide. So when she started suffering from frequently fever I went to counsel but she was not ready, last month she suffered from … at the chest near the breast pass through the stomach up to the back borne, i followed her and say …you see i told you not to hide me am you relative if you hide me who you will tell so she gained confidence and ask me to take her for testing when i take her they told her CD4 was high but asked her to attend classes in case she will attend classes for three weeks in case the CD4 has gone down she will start taking drugs without attending classes because she has learned already.

So her problem was fearing to attend classes because people could see her

I remember it was Thursday firstly we were provided education immediately i received a call that i am a chairperson in our group of peer educators then we said you may come we are ready and reach at a guest house near the road truly even the nurses happy This mother and Doctor … they all become happy to get many people in extend that other people found here were surprised of us by asking us what are you doing here, we provided education to the and entered inside for check up without worried they got many people.

***Now let us talk about people who are tested, they go for CD4 check and they are supposed to start medication but they don’t , what are the problem or reasons?***

Their problem is same as we have talked from the beginning, that if i go there (at the clinic) people will see me waiting for ART, “they just stay at home until they are seriously sick is when they come to start the medication” when they are sent to the hospital which results into a big problems

***So if and individual do not feel sick also is among of the reasons for not taking medication?***

Yes… also several times it happens even when a person starts treatment when they starts feeling better and becoming fat again they stop treatment…

you can see someone she/he wants to get married and has not told the partner that I have this problem(HIV) and so they stop medication

When the problem arises the partner is also infected they will go for testing again, pretending to be the first time testing. There was one woman who stopped medication when she married, she feared the husband will see the drugs and asking question, but this problem led her to lose her life yes…she was afraid to tell her partner that i have this problem the husband may divorced her

***You have answered my next question about people who starts to use ART but then they stop, so wanting to get married is one of the reasons?***

Others stops for the reason of marriage, and others stops when they see they are fine and no longer sick…They forget totally that they may get a big in problem than before...

“They decide just to stop because now my health condition is back to normal there is no need to continue with medication… while we are told to continue with the medicine until the end of our lives”.

***Brother you have been quite for long what is your opinion in this?***

In general is like that ... they may tell you there is a traditional medicine to cure, you go and try… you will be surprised that you feel better … you think has the medicine cured me… and the traditional healer will say after you finish that medicine your totally cured.

Yes, Traditional healers… a person went to take that medicine and after using that medicine he/she told you that your totally cured

And another thing contributing most is religious beliefs, “they are saying i have already prayed and deliverance, you do not need ARTs... there are many people died as a result of that”

***That you will be cured by prayers?***

Yes

One of our colleague died because he throw away the medicines, saying God saved me i am cured while it was not true the disease erupted now he is dead and we buried him

***The one you buried was he from here?***

Yes, he was from here...

***This means you were taking drugs together with him then he stopped***.

Yes…he said, My fellows in church have prayed for me and cured. Jesus cured me and he even advised me to throw away all medicine and go to his church but I told him no I continue with the drugs.

***When this person died how did the church members feel?***

They said it was just bad luck, I always advise them to take drug while continuing with prayers, praying to the lord to cure us and not to stop taking the drugs but …..eeh…everybody with their faith.

***What motivates you to continue using your medication, or tell me what made you to continue using these services?***

I thank God because since I started treatment, am doing well even my family lives happily with me I continue using drugs and raising up children even those educators who are living nearby us visit and encourage (Home based care) us and we get a courage of even going to educate our fellows who have never tested, we educate them and they agree.

***Can you explain to us how your family encouraged you?***

Yes, when I started suffering at first time I decided to ask my elder brother to escort me to do the test. We went to test and I was found HIV positive, there after they gave me a card and asked to come on Wednesday to provide blood for CD4 count, I went gave blood, they gave me an appointment date to come for the results.

How long did it take?

After one week I returned to take results, and I my CD4 count was low, then I attended adherence classes for three weeks , they gave me drugs to be taken in two weeks for a trial if it will give me the reaction or not, I thank God that drugs did not give me any reaction, they gave me another drugs to be taken in a month now I get courage from my relatives which lead me to be open to them that I have found with such problem [HIV], they encouraging me. so I became teacher now for educating my fellows until now I continue to use drugs well and home based care are coming to visit me. Current I am okay, working and up to now I am alive!

***Mmh , what are others have to say ?***

I myself after the death of my husband I went to test and found that an HIV positive.

***Did you think that your husband was suffering from the disease(HIV) or you just went for testing***

Ah Ah!......I did not know until .... I suddenly became frequently sick, so I decided to check my health

***How long did it take you to start the drugs after being tested?***

I think is about the 3rd week. I took 3 weeks learning and later on start the drug.

I realized later ... my husband left one child with me but his relatives took that child and ask me to go to my parents so they can take care of me. But after being tested and found with HIV i asked them to take the child to the Hospital for HIV testing because i am HIV positive. They agreed and the child was tested. Thy said the child is also HIV positive but her CD4 is high and is continuing with only Septrine. But when i visited her later on i found her not in good condition i told his uncle to take the child again to the hospital for further investigation and now they have started giving her drugs.

***How often do you see her?***

She is visiting me during school holidays,

***Is there anybody who took two up to 3 months before starting the Medication?***

For me i did not take long. I was sick my daughter asked me to go to the hospital for test, i was tested and found HIV positive and they asked me to start attending classes for three weeks.

Mostly Is it within 3 weeks up to a month you will be already started the drugs.

They started giving two weeks medication and later on gave me a dose.

***Some people do stop taking medication due to getting side effects, did anybody experience this in the group?***

You can change if you are getting side effect, In general if you get problem you go back to explain to them and they can change.

If you are using drugs and get problem you should go back to tell them and they can advise you or change the drugs...there is a way the nurses help people, if you decide to stop it will be your own decision.

I was married and because of the disease my husband divorced me. I was sick then... I started getting the symptoms I was bleeding without stopping up to the stage my neighbors said I’m bewitched, I told them I cannot be witched since I am not rich. I said I am not wealth enough for somebody to be jealous of me. Let me tell you, when I was sick I started quarrelling with my husband at night he wanted to do sex... I told him I cannot do, he told me to leave him and I told him there is no problem.

One day, I got courage to go for test and nobody advised me but I had the dream the voice asked me to go for test because my condition was not good , I was bleeding for about 3 months, I looked pale or white like somebody who is using cosmetics even my eyes was white, He was not coming home even for the whole week, he was not giving me any money, my mother was bringing food for me. I worked up, I went outside I did not see anybody I entered inside something stimulated me from my leg up to my heard. I asked myself where does this sound coming from, I slept again I held the voice that I should go for test, I waked up with confidence since my mother is born again workshop at …Church she was living not very far from my home. I went there it was Saturday i told my mother that I have something to tell you, my mother welcomed me to her bed room. I told my mother that at night I heard the voice two times which never heard before. I explained everything to my mother. She asked me what have decided, I said I want to go to the hospital on Monday for testing.

In evening time I returned home. When my husband returned I told him that I have the privacy with him inside the house, he came in then I told him because always I am sick I want go for check up, he said did you call me inside because of those issues: He insisted that he does not want to listen those rubbishes and he said if you go for testing and found with HIV positive you will die because of fear.

I tell him that I shared those words with you because we are one body but you are giving me wrong advise, I have decided to go for testing that is why I told you. He said he does not want to talk with him about that issue, and if you go for testing don’t give me the results. I told him that I have understood him and will not go for testing, he said if you don’t go for testing its good and he left for work. On Monday I worked up and went to the church to worship, I was the 1st to arrive at the hospital. After arriving I saw one lady, when she saw my condition she asked me if I was accompanied by anybody, I told her that I have come alone. She feared that I can fall down and be taken to the ward because I have come alone no one to help me in case she become unconsciously.

I am the daughter of somebody you worship together at … Church. She said , Really? …She tested me and asked if i was ready to receive the results …She said it’s true you have HIV positive. She said I should come early start attending treatment addherence classes while taking drugs because I had low CD4. So it is the source of divorcing with my husband and now I have rented a house living alone.

***When you went home with the results what is your husband’s reaction?***

It reached the stage that person was forcing me to do sex with that condition I had, I decided to leave the place and told him that, I go to my mother as she want to take care of me because he refused to hear my results. At first he came with the owner of the house we rented after seeing my condition he stopped coming and the owner of the house he chased him away because the neighbors were staying with them were coming every time to see me. So he moved from that house and married another women. I was just hearing all the news while i am in bed.

***Does he now know that you have HIV?***.

He knows since i once called his new wife while standing at the line at the hospital and also her condition is not good i called her at my house because she was my friend, at first she refused she wanted to fight with me. I called two ladies from her street and tell them that they tell her the matter. However, I saw her condition was getting worse she had a swollen legs so I advised her to go for testing. She said its better to die than being tested. I told her you have already have 3 children from your previous man and now you have married... In reality you will leave your children and bring problems to your mother.

***Mmh okay, what about you my brother here what made you the test and how long did it take to start the drugs though ... many people said within the month.***

I was frequently sick, if I go to the hospital today I get treatment and go Home then the day after I become sick again, but I got shock when I found with TB. The nurses at the hospital were advising me to do full examination including HIV. I told them I am ready tested and found with HIV positive. I felt better after starting drugs.

Mmmh!

I took my wife for testing and good luck she was HIV negative. I was given counseling and told on how to prevent her from getting infected and fortunately my wife did not run away from me. So we are together up to now.

My Next question, people are testing and have the spouse living together, and do not disclose their HIV results to the partners do you think what is the reason?

There is one sister our neighbor she was infected, before she was also frequently sick she went for test and were told to have HIV positive. She went to tell the husband and he said, he does not want to hear that news, she came to me and explained what her husband say. I advised her to go and tell doctors that the husband is refusing. She said she is afraid, and better she continue using the drugs. I told her if she is afraid and said the husband can even tear the card its better she brings to me and I can keep for her in order to continue using the drugs. Right now is continuing using drugs and she is keeping the card in her bag but now the husband knows that her wife is using drugs and is no more hiding the card.

***Did the husband go for HIV tested?***

He said, I cannot go if am not sick. They are waiting to go when they are sick, others are speaking openly .

There was one sister who was staying with somebody’s husband. She said they were living together but the man was deteriorating the lady did not know that the man was HIV positive and was using drugs, but the lady was getting recurrent fevers. I told her to go for test which does not cost anything within a minute you test and come back. She said she will go, one day the husband something swollen in his body - Lymphnodes. The lady said my sister I am worrying and asked my husband why you have swollen nodes. She then discover that he started drugs a long time ago.

After a while the lady became very sick and her neighbors took her to hospital and after arriving they tested her at …and was HIV positive. They gave her the drugs and asked where is the husband he is supposed to be caught up why he did not want to tell you. The lady said he has ran away outside the country. He was working with … company. God will help her as she continue to take the drugs.

***Do have groups where you meet with each other or you only meet where you take the drugs?***

Yes, like us we have the group which we meet to educate each other and discuss many issues and we go away (we give anything we have as contributions).

***Do you encounter any challenges or problems due to your status either to your family or community in general?***

Example I stay with my brother who is married they take care and help me very well

There is no problem, even neighbors because frankly speaking when there is any difficulty job I just tell them that I don’t feel well and they do understand. I am free to send my brothers son and even if I get sick they give me the drugs as they know where I keep ..even my brother knows where I keep the clinic card.

I also want to contribute that I am free because if you hide you will be stigmatizing yourself because if someone said I am using the drugs I cannot take the person to police …I know it is a normal things, I also have this problems.

I don’t pray for him to get or his relatives to have the condition like this . I am free I don’t fear anything that is why I was doing the business of selling food. Sometimes my customers asking me where were you yesterday? I just tell them I went to the hospital, it was my clinic day. They were laughing and said you are very free, and also I have confidence.

I was suffering from TB my husband died in 2009 I stayed alone for a long time with my children. Fortunately my children have grown up whom I depend on them I left them at home but I was in …my husband was working there. I stayed in …till I started being sick, I said to myself that may be it is because I was not used to work hard. Many people were seeing me sick. I took care of him till he died. ...We used to be admitted at … hospital but I didn’t know if he has something like this he never tested HIV. We were checking normal fever. They were just saying its fever and liver problem till he died. When I came here I started becoming sick , I was just saying its fever but my neighbour knew earlier than me, she said go and test your blood you might have major infections. I worried, she kept insisted me and told me that she will accompany me I agree. Let us go there we found that lady. She tested me and say can you see now the condition were getting worse, and having black spot. I said when my husband was sick I did not think of testing that is why I did not get courage to test. But I trust myself since my husband died I am with my children only.

***Therefore in short, your family relatives and neighbours have accepted your status!***

Yes even in the hospital said I should write the name of my closest person I have written my son. …I have written my brother who sent me there.

***Now I would like to hear your suggestions, on how to improve HIV care services in our area, what do you advice the health care personnel or anything?***

Stigmatization somehow is still a problem, it’s not completely ended or someone can stigmas herself., so people need more education

Some are stigmatizing themselves fearing that if somebody will see me will spread the news to my boyfriend/girlfriend he/she will leave me, so they are fearing to be left by the boyfriend/girlfriend while it’s a common issues nowadays.

***Okay what about the health care providers?***

In the reality the service providers are helping us very well. Example you may go to take drug and if they see you not in good condition, they can give you priority and they attend you quickly so that you can go home and rest… and they ask you what is the problem, if she/he is sick they give you HIV drugs together with other drugs, you will be given if they are available at the clinic but if not there they will ask you to buy it.

Also we appreciate the nurses because they were teaching us to love each other and at first the person can go to the clinic for the first time may be she/he is very sick we were not giving them priority, nurses said you started drugs a long time ago, your condition is good so if you see your fellow whose condition is worse you give him/her priority in getting services then you follow because you are strong. So I like the service providers.

***Mmh you are saying you don’t have any problem with the service providers, would you like to suggest any thing that can help improve services at the CTC?***

I told my sister that I think the government should contribute some money example we are living with HIV you may find other people do not have any income or capital, you can fail to get any money which caused somebody to .... go to do casual work in the farmer from 08:00 up to evening is hard for us.

If you go to test CD4 you will find has dropped, (the sun contributes very much to weaken the body, … and the child needs exercise books and to eat. Example we are divorced we don’t have any assistant. The child is looking for you for all school premises contribution uniform, soap, house rent, we are really having problems.

A person might be staying alone and living with HIV, the problem is there some contributions to pay for children and they are requiring going to school while we don’t have a job.

***Ok I hear you, but let’s leave this for another platform to discuss or ask to people who will be I a position of addressing this matter, let me ask the last question Is there any person who started using drugs but her/his condition continue to be worse?***

No, I am proceeding well, example me there was a drugs which I was taking one in the morning and two in the afternoon I’m also doing very well.

Okay, thank you very much for participating in this discussion, I got a lot of useful information in this discussion. Thank you everyone.