**Interview details**

|  |  |
| --- | --- |
| Participant ID | HWKAP02 |
| Municipality | Kapilvastu |
| Health organisation | NGO |
| Years of experience | Over 5 years |
| Years in current job | 1 |
| Start time | 16:04 |
| End time | 17:26 |
| Interviewer | Bibhu Thapaliya |
| Date of interview | 23/01/2023 |
| Transcriber | Merina and Anushka |
| Translator | Merina and Anushka |

**Background**

# INTERVIEWER:

Can you tell us about the institution you are working for and your position?

# PARTICIPANT:

I work as a counsellor for an NGO. This includes breaking the cost barrier for antiretroviral therapy, with the aim that no patient should be denied medical support or diagnosis due to lack of money or transport. In addition to that, we also help with screening for new cases. We have a peer educator that we send out to the population at risk. We also help with reporting of the hospital.

# INTERVIEWER:

You said you are a counsellor. Are you a medical practitioner?

# PARTICIPANT:

Yes.

# INTERVIEWER:

Can you tell us about your qualification?

# PARTICIPANT:

I am a Health Assistant (HA).

# INTERVIEWER:

Where is the institution you are currently working for? Can you tell me the exact location with the ward number?

# PARTICIPANT:

Currently, it is at Thapathali in Nepal. I don't know the ward number.

# INTERVIEWER:

Is it in Kapilvastu?

# PARTICIPANT:

# The organisation is not based in Kapilvastu but we work with the hospitals and stay there.

# INTERVIEWER:

So you are based in Taulihawa Hospital?

# PARTICIPANT:

Yes.

# INTERVIEWER:

Where is the main office?

# PARTICIPANT:

The main office is in Thapathali.

# INTERVIEWER:

Does this mean that AHF is an NGO that works with hospitals and is based at Taulihawa Hospital?

# PARTICIPANT:

# Yes, we are based in the hospital. This is also the case in other districts; all are based in hospitals. There are other organisations working in the field of HIV as well, such as FHI 360. They have separate offices and keep only one staff. In the case of FHA, we have staff in all districts working in hospitals.

# INTERVIEWER:

Which organization directly coordinates this?

# PARTICIPANT:

We approach the National Centre for AIDS and STD Control for coordination of the census review of any location and implementation of the FHA work. Once they agree, we coordinate the work in the hospitals at the local level.

# INTERVIEWER:

How long has AHF been working at Taulihawa Hospital?

# PARTICIPANT:

Since December 2017. That's more than 5 years.

# INTERVIEWER:

When did you join?

# PARTICIPANT:

# It has been more than a year. I joined in 2021, on 1 December.

# INTERVIEWER:

Do you have a room or an office in the hospital?

# PARTICIPANT:

We work in the ART clinic.

# INTERVIEWER:

We will talk about the ART clinic later. What kind of advice do you give as a consultant?

# PARTICIPANT:

It includes HIV testing, prevention, and adherence counselling. Adherence counselling is about taking medication. We also provide advice on starting ART. Other counselling includes risk management and co-infection.

# INTERVIEWER:

Apart from that, do you also provide psychosocial counselling, which is not related to the medication aspects, concerning social behaviour and discrimination?

# PARTICIPANT:

Yes, we provide comprehensive counselling, including psychosocial and mental support. We also do advocacy. We are charged by the AHF with advocacy, so we also do that in many cases, if necessary.

# INTERVIEWER:

As you are a woman, should women provide advice only to women or also to men?

# PARTICIPANT:

We counsel males too.

# INTERVIEWER:

Whom do you find in greater numbers, men or women?

# PARTICIPANT:

Here it is mainly men who go to India to work because of the poor economic conditions. That is why more women visit us on a regular basis.

# INTERVIEWER:

So more women are coming here?

# PARTICIPANT:

If both husband and wife test positive, it is mainly the women who come for medication, as the men are usually looking for work.

# INTERVIEWER:

Explain to me again if I am not clear. People who go to ART centres already test positive, right?

# PARTICIPANT:

There are also other NGOs in the ART centre. There are two organisations for the FHI Epic programme in Kapilvastu. These are Nabajeevan and Namuna. Namuna prioritises sex workers to include cases from at-risk populations. They also have other activities but their priority is sex workers. Nabajeevan focuses on populations such as MSM (men who have sex with men) and TG (transgender). Nabajeevan and Namuna have sufficient staff to work in the field. They visit high-risk populations and screen cases by self-testing.

# INTERVIEWER:

This is in the context of Kapilvastu, right?

# PARTICIPANT:

Yes, it's like that in many other places in all districts. They do self-tests. If it is reactive, they do the test in their organisation's clinic or do a confirmatory test. If it is confirmed as positive, then a reconfirmation is done in the HIV Testing and Counseling hospital laboratories and only then is the case registered. That's one way of doing it. On the other hand, we register the cases that are diagnosed as positive in the regular laboratory tests in the hospital.

# INTERVIEWER:

So the flow rate is high?

# PARTICIPANT:

Yes, there is a flow of patients. In the current scenario, not as many cases are diagnosed in hospital laboratories as in organisations.

# INTERVIEWER:

When symptoms first appear, whether it is HIV or other diseases, people usually want to go to health facilities first, especially public ones, because of the low cost of services. How do they know about these organisations and how do they reach them?

# PARTICIPANT:

Field workers have a target so they will contact people at risk directly. However, diagnosed patients also inform them of any suspicious cases in their community, for example a person returning from India. Field workers liaise between health posts. They coordinate with the health workers and suggest that they inform them if they have signs or symptoms. When they are informed, they go to the suspected patients. Currently, testing is not available in many places. Although kits are provided, they may not be available due to a shortage. In such conditions, they go for help.

# INTERVIEWER:

Are the field staff part of AHF?

# PARTICIPANT:

There is only one AHF staff member working in the field. Our staff is only mobilised when there is a positive case that requires a confirmatory test. Otherwise, they are involved in other work in the hospital such as registration, reporting, scheduling clients and following up on calls to patients for medication. However, staff from other organisations are fully involved in case finding and make home visits to check the patients' health status, cross-check medicines and whether they are taking regular medicines or not. They make home visits without informing the patients and check the medicines and their bills to ensure that they are taking the prescribed medicines.

# INTERVIEWER:

As far as employees from other organisations are concerned, do they come from this community or from other districts?

# PARTICIPANT:

It's just the people here. In the field of HIV, jobs are usually reserved for people living with HIV. Thus, most staff are HIV-positive, only some are not. Staff who do not have HIV are employed to counsel risk groups and bring FSW clients to preventive treatment. People living with HIV are employed when there are problems. For example, when there is a high chance that HIV-positive patients will not enrol. In Kapilvastu, I knew of one case who did not come to us even though he had been diagnosed a long time ago. We all made many home visits, but we could not wrap him up. In such cases, peer educators are mobilised because it is more effective for patients to be educated by someone like them than by us. This can be an important support.

# INTERVIEWER:

As you work in AHF, does the organization give you training?

# PARTICIPANT:

Yes, it provides us with training. Shortly after I joined the AHF, I went through a training on clinical management, called CMT training. As far as counselling is concerned, it should be provided by the government, so the NCSC has not provided counselling training. We hope to get it. So far, the only training I have received is CMT training.

# INTERVIEWER:

Is this training organised by the government?

# PARTICIPANT:

Which ones? Training in counselling?

# INTERVIEWER:

Yes.

# PARTICIPANT:

Yes, there are such provisions, but they do not have sufficient budgets, so they have to collaborate. The government should manage the time and other problems and provide such training.

# INTERVIEWER:

Does the government also provide such training to health post workers, such as ANMs?

# PARTICIPANT:

Prevention of Mother To Child Transmission (PMTCT) training?

# INTERVIEWER:

Yes.

# PARTICIPANT:

PMTCT training is conducted frequently at the district level. They are conducted several times a year so that new staff who have not received training can easily benefit from it.

# INTERVIEWER:

How many training courses are provided per year?

# PARTICIPANT:

Training is provided on an as-needed basis. Previously, when I worked on the TB programme, it was based on the DHO. They have to include at least one representative from each health post. So there are usually 5 or 6 PMTCT training per year.

# INTERVIEWER:

In PMTCT training, is there a topic on STD counselling?

# PARTICIPANT:

I think so. I have not participated in such a programme so far, but I think it is included in the package. As there is a risk of STD transmission, it should be included. But I'm not sure, I couldn't attend.

# INTERVIEWER:

Speaking of STDs, how prevalent do you think STDs are in Kapilvastu?

# PARTICIPANT:

Since I joined the organisation, we have found only 5-6 cases of VDRL-positive [syphilis] patients. The counting is done by the Kapilvastu hospital laboratory. Treponema Pallidum Haemagglutination [TPHA] should also be considered.

# INTERVIEWER:

What does TPHA mean?

# PARTICIPANT:

This is another test for syphilis. I don't know much about this lab test. The VDRL detects syphilis but the TPHA is needed to confirm it. So you have to do the TPHA. The chemicals needed for this test are not available here, so the test cannot be done. Recently we had a client with a serious condition. The VDRL result was reactive and we needed a TPHA. But as it was not available here, we sent the case to Butwal. I think they did the test today. Otherwise, there were only 5-6 cases in Kapilvastu hospital according to the data.

# INTERVIEWER:

As you can see at the community level, what do you think is the reason for this? Is it because they don't have access to the institution? Maybe there are patients who have not yet been diagnosed. Is the low prevalence due to the fact that patients do not go to institutional services or due to the actual absence of disease?

# PARTICIPANT:

I don't think it's due to the lack of diseases. I think it's because people don't come for services. Because here we have a scenario where patients only go to the hospital when their condition is really serious. For example, with STDs, if patients have severe back pain or abnormal discharge or something serious, then only they feel the need to go to the hospital. Otherwise, if the problems are normal, they don't even mention it. Moreover, the OPD is often crowded, so when the doctor asks them what their problems are, not all of them talk about them. For this reason, screening and diagnosis cannot be done properly. On the other hand, there are many cases of VDRL tests on people who are suspected of being HIV positive. They prescribe serological tests, including HBsAg. If a patient does not talk about their problems, the screening and diagnosis cannot be done properly.

# INTERVIEWER:

People come to the hospital when they can no longer tolerate their symptoms. To what extent is the problem excessively stigmatised in society? Here people think they can't talk about these problems. It is like a taboo in society. They can't even say the name of the disease. We can see this in many people. They are ashamed and afraid of being judged for their illness. We have a lot of evidence to suggest this. How widespread do you think this thought or attitude is here?

# PARTICIPANT:

This is a very common phenomenon. Although we maintain intimacy about it, they do not share their problems openly, perhaps because of a lack of self-confidence. This is more often seen in women. Some can tell us clearly about their problems and we screen and diagnose them accordingly. Others do not say anything. It is even difficult to determine the risk group and the initiation of the risk behaviour. Moreover, they constantly change their statements. Not even STDs, also in the case of tuberculosis, which is not so serious, they think it is the end of their life. This kind of taboo is present here. We often call it a lack of awareness, but I don't think so. There are enough awareness programmes such as campaigns and school health programmes. What I think is that we are not able to eliminate these strict beliefs among them. Even if we raise awareness among some patients, others are there to tell them that this is the end of their life. That's why people don't talk openly or even come to visit us. It is very common here.

# INTERVIEWER:

Do you know what is the counselling process in Taulihawa Hospital?

# PARTICIPANT:

After HIV is diagnosed, initial counselling is given by the hospital doctors about the disease, the drugs and their lifelong use. Then, as their state of mind is somewhat prepared, they come to the ART centre, where we briefly counsel them. Then they go for counselling by the NAPN (National Association of people living with HIV in Nepal) which provides advocacy and other support to people living with HIV. After our counselling, if there is no co-infection and antiretroviral treatment is started, we send the patients for a stay of 2 to 4 days, where they receive additional counselling on many other topics. So I think patients get enough counselling at different levels (field, hospitals and organisations).

# INTERVIEWER:

Do you think there is more counselling for HIV than for syphilis and hepatitis B or is it similar for all STDs?

# PARTICIPANT:

During counselling, we suggest safe behaviour because there may be other risks in addition to HIV. We mainly focus on condom use. As there are many other STIs besides HIV, we also focus on them.

I have been here for a long time and I have observed that people here have preconceived ideas. They don't accept taking condoms with them, even if I ask them to take them and use them. The male patients even say openly: "Oh my God! What am I going to do with this condom now since I am already infected with the disease? I tell them that the condom is not only for HIV, but also prevents other infections. When I say this, some of them take it lightly, others adapt and others disagree completely.

We advise them on all the preventive and precautionary measures, but they have a predefined concept of the usefulness of precautions.

# INTERVIEWER:

Don't they think they can transmit it to others?

# PARTICIPANT:

If both partners in a couple are infected, they do not use condoms at all. In the case of a serodiscordant couple, they usually use condoms. A person with a negative attitude thinks that everything that is supposed to happen has already happened. But the main goal of an optimistic person is not only to prevent HIV but also other infections.

# INTERVIEWER:

Does it mean that both partners of couples come for counselling?

# PARTICIPANT:

If it is a case of mediation, we call both partners to advise them. Otherwise, we counsel anyone who comes to us for advice, whether it is a man or a woman.

# INTERVIEWER:

Do pregnant women come?

# PARTICIPANT:

A few days ago, a woman who was under treatment gave birth to her baby.

# INTERVIEWER:

How many pregnant women consult in a month?

# PARTICIPANT:

Not many that I know of. Since I have been Kapilvastu, I have only known her and two cases of Maharajgunj, that's all.

# INTERVIEWER:

Do they tell you how they got infected?

# PARTICIPANT:

These are old cases already on antiretroviral treatment. But there is one case where she was diagnosed during pregnancy. She went to the hospital for a check-up and was diagnosed there. We looked for her everywhere. We even asked the field staff to help us, but we couldn't find her. We had to ask for help from people who worked in the field of TB and knew many people there. From there we were able to find her home address. After that, even her husband was diagnosed with HIV. She took antiretroviral treatment for a while but stopped after a while.

# INTERVIEWER:

Did she say why she didn't take ART?

# PARTICIPANT:

I've asked her again and again. The main problem is that I don't know how to speak Awadhi. I felt that even if I explained, they didn't understand what I was saying. We had a communication problem. I could only help if someone understood Nepali. We asked for help from a lot of field staff to find her. The problem is that they have this idea that taking medicine is useless because nothing has happened.

# INTERVIEWER:

Even after the blood report shows they are HIV positive?

# PARTICIPANT:

Yes, because they think that taking medication is not worth it since they are healthy.

# INTERVIEWER:

Is it because there are no apparent symptoms in their bodies?

# PARTICIPANT:

Yes, that's exactly why. Until signs are visible, complications arise or they are affected, they will not continue taking medication. This shows their self-neglect and ignorance. They think that since no symptoms are visible, we as health workers may have lied or the reports may be wrong.

# INTERVIEWER:

Where were the pregnant women referred from?

# PARTICIPANT:

From the nearby health post. I have already mentioned that test kits are not available in many places and that diagnosis during pregnancy is difficult. For this reason, they are only diagnosed at the time of delivery. I have been in contact with many places where test kits have not been well provided and where it is not possible to test during pregnancy.

# INTERVIEWER:

Do you think that health posts with a laboratory routinely test pregnant women for HIV, syphilis and hepatitis B?

# PARTICIPANT:

A few years ago we had to work on HIV because of the risk of co-infections for people with TB. When I collected data, it showed that routine check-ups were being done. But sometimes, because of a low supply of test kits, they were not able to diagnose it at antenatal check-ups. If there is a good supply of kits, then they will do it because they have to report as it is mentioned in their reporting tool.

# INTERVIEWER:

Do they have to pay for anti-retroviral therapy and counselling?

# PARTICIPANT:

No, antiretroviral therapy is free of charge. When the test kit is positive at diagnosis, we opt for zero billing, i.e. free. As the provincial government has decided to pay for the test kits and has allocated a budget, we opt for zero billing.

# INTERVIEWER:

Even the counselling session is given by AHF for free?

# PARTICIPANT:

Yes, it is free of cost.

# INTERVIEWER:

How long is a counselling session?

# PARTICIPANT:

Minimum one hour as we also need to record additional information. The session may exceed this time depending on the situation. We start with a brief history and note what happened, how it happened, how long the therapy is to last, etc. We do this unless the client does not understand the information we have given. We do this unless the client does not understand the information we have given them.

# INTERVIEWER:

Do you remember anyone who came because of a planned pregnancy?

# PARTICIPANT:

No, not since I've been here. So far, the delivery of the baby of the woman who was on ART was the only case.

# INTERVIEWER:

And what happened to the baby?

# PARTICIPANT:

We have sent the baby's PCR (Polymerase Chain Reaction) test. The results are not in yet. I think the chances of the baby contracting HIV are high because the mother's viral load has been elevated several times. In her previous pregnancy, one of her children died and it was rumoured that the child had HIV. There is another child of hers who is about 3-4 years old and is on treatment now. The mother's health is not very good either. After the delivery of her newborn, I have doubts that the child could be infected too.

# INTERVIEWER:

So the woman diagnosed was infected with HIV for a long time?

# PARTICIPANT:

Neglect, she neglected everything for a long time. It hasn't been that long. I need to see the data but it's been about 4-5 years since she was infected.

# INTERVIEWER:

So, during these 4-5 years, did she give birth?

# PARTICIPANT:

Yes, she might have given birth to twins last time, but I'm not sure. I took data from the staff but I'm not sure if it was twins or one pregnancy after another. But one of the children has died and the other is also infected from what I had heard. Another child is on antiretroviral treatment.

# INTERVIEWER:

Given that she is in the high-risk category and is likely to give birth in the next few days as well, is there a difference in the way you approach her compared to others?

# PARTICIPANT:

Yes, the fact is that not only she but also her husband and daughter have a high viral load. That's why we went to her house several times.

# INTERVIEWER:

What does high viral load mean?

# PARTICIPANT:

If a person is on treatment, we check the viral load every 6 months with a blood test. We send the blood sample to the National Public Health Laboratory (NPHL), where they check the viral load in the blood sample.

The viral load indicates whether ART is working or not. It indicates the amount of viral load in the body. For example, if a person starts ART with adherence advice to take a drug at a certain time. For example, if you take a drug at 8 pm today, tomorrow you should also take it at 8 pm, and your nutritional status should be maintained. We advise them with all this information, and if their health condition deteriorates, we ask them to come to the hospital as soon as possible. Our main objective is to ask them not to interrupt their ART cycle. The viral load report shows whether the client has understood our advice and whether the medication is effective or not.

In some cases, many clients come to us and say that they have not missed a single medication, but the report indicates that the viral load is high. We then start looking for other factors that may be associated with a high viral load, such as food intake or nutritional status not being maintained, co-infection, etc. They also complain about a loss of appetite, and that they are not getting enough food. Also, they complain of a loss of appetite, and this could be a factor contributing to a high viral load. So we try to identify the situations in every possible way.

A closer look at the same case and history shows that her husband was seropositive with a high viral load. His first wife, who was also HIV-positive, may have died and that their child was also infected, which is a clear case of vertical transmission.

# INTERVIEWER:

# Is this his second marriage?

# PARTICIPANT:

According to him, this is his second marriage, but according to the villagers, he has been married more than twice. However, he did not give details of his previous marriages.

His first child, who was infected through vertical transmission, initially took ART in Butwal, but recently started taking it here. Of her other two children, one has died and the other is registered with us and is on ART, but his viral load is high. And what happens is that every time she fights with her husband, who is a drunk, she ends up not eating anything and refuses to take her medication, and doesn't allow her daughter to eat either. This has happened several times and because of this, their viral load is always high. Given this situation, we counsel them, but because of her argument with her husband, she does not eat nutritious food, does not take medication and does not allow her daughter to do the same. As a result, their viral load is consistently high when tested three times and the baby is at high risk of vertical transmission.

# INTERVIEWER:

Since you are taking details of patients such as caste, religion, ethnicity, etc., which caste or ethnicity do you think the people at high risk of developing HIV belong to?

# PARTICIPANT:

People belonging to the Madesh sub-groups are the most vulnerable. In the Madesh group, some of them belong to the Dalit category, which makes them more vulnerable. I think it is mainly because of economic deprivation, with less or no sources of income. As a result, they are not able to feed themselves properly and without proper nutrition, medicines are not effective. Another reason is the migrant population that comes and goes in India, which increases the exposure.

# INTERVIEWER:

Thus, it is mainly the lower class and those who depend on a daily wage who are most likely to be at high risk.

# INTERVIEWER:

Yes and also FSW.

# INTERVIEWER:

Any pregnant female sex workers?

# PARTICIPANT:

Not these days. We were able to track down a sex worker, and even brought her antiretroviral treatment. She took her medication for a month but didn't show up after a while. We counselled her for two hours and convinced her to take the medication. I even thought she would continue to take her medication, but she didn't. She made excuses like she lost her medication. Now she wanders from place to place, including India. However, I don't think she is pregnant so far.

# INTERVIEWER:

Are there women drug users who might have HIV?

# PARTICIPANT:

No, some men who are drug users have contracted HIV. I think we have two men, but no women.

# INTERVIEWER:

# Does this mean that there are not many drug users around?

# PARTICIPANT:

No, not according to our data and diagnosis so far. The majority are spouses, then FSW and vertical transmission.

# INTERVIEWER:

For those who are regulars in ART, how often do you give them advice? How often should they come?

# PARTICIPANT:

One box contains three tablets. They come once a month for ART. But if they have problems in between, they come for counselling. When we organise programmes, for example, on the occasion of the ICD celebration on 13 February, I have invited all serodiscordant couples to discuss. So we have regular meetings, whether it is for ART, discussions or related activities.

# INTERVIEWER:

# Once a person starts antiretroviral treatment, he or she must continue it for life. Does this mean an unlimited supply for the hospital?

# PARTICIPANT:

There is no unlimited supply of ART in the hospital. Initially, a patient received three months' supply of drugs, and this is still the case today. This means that a person is supplied for three months. For example, if we have 464 active clients, we ask for a sufficient supply for active clients for three months.

# INTERVIEWER:

Does this mean that the patient has to go elsewhere to get medication after three months?

# PARTICIPANT:

No, we require the supply for a period of every 3 months with a continuous supply.

# INTERVIEWER:

Is ART a costly process?

# PARTICIPANT:

ART is a completely free process. If a patient goes to the private sector, they have to pay a certain amount of money, and it is not possible to sustain themselves in this way. But if you go to a public health facility and you are diagnosed positive or even reactive, the treatment is completely free of charge from that point on. All they have to pay is the transport costs to get here, and if the client is from a lower class, a single woman or an orphan, we even offer them a small transport fee.

# INTERVIEWER:

Are the transport costs also borne by the government?

# PARTICIPANT:

No, by the NGO.

# INTERVIEWER:

How are transport costs given?

# PARTICIPANT:

It is distributed according to the distance and situation; we give an amount ranging from Rs.100 to Rs.500. In exceptional cases, we give Rs.1000.

# INTERVIEWER:

# Has the government provided incentives for transportation so that the cost isn’t issue for them to receive the ART service?

# PARTICIPANT:

No, not yet. Nepali government provides with regular ART supply. None of the HIV infectant has ever returned empty handed without receiving ART. Other equipments such as kits and medicines are too supplied by the government. Laboratory service is provided, also the medicines are covered if people have health insurance. However, there is no transportation cost provided.

# INTERVIEWER:

# So collaboration between the government and non-governmental organisations is important?

# PARTICIPANT:

Yes.

# INTERVIEWER:

For those who come for ART, how often do they have to have a blood test for the viral load?

# PARTICIPANT:

If they started ART today, then once every six months for a year, then once a year.

# INTERVIEWER:

Are they willing to do it again and again?

# PARTICIPANT:

Yes, they are. Once they are on treatment, once every six months for a year and then once a year, they should check their viral load regularly. Another baseline test is a VDRL (venereal disease research laboratory) test, HCV (hepatitis C virus) test, anti-HCV test, complete blood count (CBC) and other related blood tests such as SGPT (serum glutamic pyruvic transaminase) and SGOT (serum glutamic oxaloacetic transaminase) if they have other problems. These tests are done every three months.

# INTERVIEWER:

Does baseline testing mean the first test you do on your first visit?

# PARTICIPANT:

Yes, we repeat those tests every three months.

# INTERVIEWER:

# To see if there is another infection or not?

# PARTICIPANT:

Yes, to monitor if there's any other infection or not.

# INTERVIEWER:

# Speaking of taboo, what we were able to identify in the health post during the interviews was that people did not object to blood tests, but if they were informed that blood tests were done to identify sexually transmitted diseases, they normally objected.

# PARTICIPANT:

Yes, they will object.

# INTERVIEWER:

Is it because of the word "sexually transmitted diseases"?

# PARTICIPANT:

Yes.

# INTERVIEWER:

Or is it because of fear of the result is positive? What do you think might be the reason?

# PARTICIPANT:

As you said, it's all due to stigma and taboos. Here, once someone has got a disease, nobody wants to go near it. Also, they are embarrassed by their inner thoughts such as "What am I going to do if society looks down on us? That is why they choose not to disclose their illness to others.

So much so that if you organise a campaign to test blood for dengue, diabetes and malaria, they will readily agree to a blood test, but they will hardly agree to the same blood test for sexually transmitted diseases. They would rather run away or scold you, but will not agree to a blood test. This is all due to taboos.

The stigma here is that if you have contracted the disease, your life is over. How will I show my face? How am I going to get around? Because of this mentality, people don't open up easily. But in some cases, I have even seen people coming to us based on the signs and symptoms they heard on the radio. They come to us and say, 'I heard symptoms on the radio, so I came for a blood test'. I found two men, one was negative and one was diagnosed. The one who was diagnosed is in critical condition and is even suspected of having cancer. So your perception of the disease is essential.

Now, if you go into a community where even the smallest problems are magnified, it's almost impossible to do anything.

# INTERVIEWER:

Are women shyer than men?

# PARTICIPANT:

Yes, they are. First of all, in the Madhesi community, a young girl who has just got married is not even allowed to go out. Secondly, they have the mentality that women are supposed to stay inside the house, and whatever happens inside the house should stay inside the house. Therefore, women do not come out freely.

# INTERVIEWER:

Is this phenomenon also prevalent in the Muslim community? I mean there are Muslims and Hindus in the Madhesi community? Which of the two is more prevalent?

# PARTICIPANT:

I would say mix because in some Madhesi places, they speak with such enthusiasm and frankness, and they will give you all the information you are looking for. But if you go to a neighbouring area, they will not tell you anything. Similarly in the Muslim community, they will tell you everything in some places but not in others. It depends on their environment and their cultural upbringing.

# INTERVIEWER:

Is the trend of banning women from leaving the house for a year also widespread in the Muslim community?

# PARTICIPANT:

I don't know about the Muslims, but I got to know them because they are more numerous in the Madhesi community.

# INTERVIEWER:

There is a strong link between women community health volunteers and the community, especially pregnant women. They have more faith in what women community health volunteers have to say. How would it be possible to talk about sexually transmitted diseases with women community health volunteers?

# PARTICIPANT:

It depends on the situation. In many places, a woman will approach an FCHV in the same area, with the intention that she can help her present her problems at the health post and make it easier for her to receive services. But most women can express their other health problems but not those related to sexually transmitted diseases. So it largely depends on how flexible she is in talking to others.

# INTERVIEWER:

To what extent are people who come for ART supported by their families? And do couples who come for counselling come alone or as a couple? And if it is a woman, is she well supported by her partner?

# PARTICIPANT:

If both partners are HIV-positive, it won't be so difficult, because they have this mentality that we both have and that everything will be fine if we take medication regularly. But in this case, it is quite possible not to inform the family for fear of stigma. Also, in many cases, if one partner is HIV-positive and the other is not, they won't tell anyone.

# INTERVIEWER:

In such cases, is there a protocol for getting the partner to consult, or does it depend on the person?

# PARTICIPANT:

We cannot force them if they do not want their partner to know. We are there to defend their interests and if there is a breach of privacy, we can also take legal action. If the patient is flexible and allows us to advise their partner, then the appropriate steps are taken. But if he asks us not to disclose his problems because they may affect his personal life, we advise him to take his medication and use condoms regularly. The main thing is that he agrees with us.

# INTERVIEWER:

Is every piece of information, including name and address, kept confidential?

# PARTICIPANT:

Yes, it is true. In HIV counselling, it is important to maintain confidentiality. Even if the counsellor is under my wing and works in a hospital, confidentiality is maintained so that even the staff of another hospital will never know whether he is HIV positive or not. Except for ART, no one will know whether he is HIV positive or not.

# INTERVIEWER:

Do you think that if a pregnant woman shows signs and symptoms of HIV, ideally her family should be part of the testing process or not?

# PARTICIPANT:

What I think is that it depends on the family and their point of view. If they are educated and supportive, then it won't be a problem if we include the family. Otherwise, in my opinion, it would be better if the blood test is done only for the suspected person. Because if the report says she is positive, we should offer her psychological support, to help her prepare mentally for everything. But if his whole family is exposed, it will not give him enough time to prepare mentally. Therefore, I think it is better to screen without involving the family members rather than including them.

# INTERVIEWER:

Let's talk about health workers. We have heard about the prejudice against patients in health posts based on their health status, even in hospitals. Do you think health workers behave in a normal way, especially towards people with sexually transmitted diseases?

# PARTICIPANT:

It's a difficult situation, especially after diagnosis. We've been advocating for so long that if a patient is facing some form of discrimination from staff, we've even had discussions with them for our patients.

So much so that if a person is diagnosed with TB, they will not be admitted to the hospital. Isolating a patient from the point of view of medical management is a good thing, but not admitting them at all is a mistake. This is a minor scenario in the case of TB. Even in the case of HIV, they would not admit an HIV-positive patient. They would still refer him to another health facility. I kept pleading with the health professionals and doctors that it was not possible to keep referring the patient. So the scenario is a bit different and they are now admitting HIV-positive patients. But for that to happen, we have to be present with the patient in the health facility for admission. We understand that they have to take precautions as the medical staff. But by not trying to admit patients despite all precautionary measures, rude behaviour is significantly present.

# INTERVIEWER:

Rude behaviour is very important on the part of which health professionals? I mean nurses or senior doctors?

# PARTICIPANT:

With the exception of a few senior staff, these behaviours are generally observed among young staff.

# INTERVIEWER:

Does this demotivate patients to use institutional services?

# PARTICIPANT:

Yes, extremely. Sometimes clients even refuse to enter health facilities. As I said before, a person infected with HIV has to do basic blood tests every three months and also check the viral load. On top of that, there are even health insurance facilities for HIV-positive people, but even these clients are reluctant to come because the health staff do not treat them properly and send them from one place to another. So they are demotivated.

In extremely serious cases where a client stays at home despite being co-infected, I will tell them to go and get admitted and I personally pay for a visit. Despite this, if they refuse to admit the patient, I defend my patients, even if I have to argue with them. Otherwise, when a client goes to the hospital, regular screenings, blood tests and routine examinations are carried out. However, the situation is improving compared to the past. It is not that they are not cooperative at all. In serious cases where the patient's life is threatened, they have cooperated with us and even given discounts to needy patients on a phone call. Compared to the past, the number of referrals has decreased and the admission of patients has improved considerably.

# INTERVIEWER:

So this means that comparatively speaking, the situation has improved significantly?

# PARTICIPANT:

Yes, the situation has improved significantly. I don't know the scenario of the health post, but in the hospitals, the situation has improved a lot compared to the past. When I came here, the referral of patients was very high, but the situation improved considerably. This is also thanks to our medical superintendent who supports us. Our medical director is very supportive. If he hears about such a situation, he makes sure that the appropriate measures are taken. A few days ago, while I was off for my exams, a client arrived with a leg injury. The OPD [Outpatient department] doctor did not dress his wound. However, our medical director came the next day and cleaned the patient's wound himself. He wants to make his staff feel that he is there even if they are not ready to work. This will eventually make the staff work and do their job at any cost. Compared to the past, there are notable changes. The rude behaviour of the some staffs is still prevalent. As a result, patients are demotivated.

# INTERVIEWER:

Can you provide example?

# PARTICIPANT:

Community Medical Assistants (CMA) and in some places Auxiliary Nurse Midwives (ANM) and nurses.

A few months back, an HIV-positive pregnant woman, was admitted in the general birthing ward. But they receive their ART there. A staff nurse tried to refer her to other place saying the disease could be transmitted to others. It’s ideal to manage the environment in the hospital for them to be treated than to refer to other health facility. It’s good to refer patient to other places only when their condition is not treatable here or the investigations cannot be carried out here.

# INTERVIEWER:

Is the hospital administration cooperative enough to keep the counselling centre?

# PARTICIPANT:

Yes, they are.

# INTERVIEWER:

As this is not a governmental organisation but an NGO, is there a partnership between the hospital and the NGO?

# PARTICIPANT:

I would say it's collaboration rather than partnership. We provide support for registration and reporting and guidance for ART-based work and any government-level work done in hospitals.

# INTERVIEWER:

Do you mean technical support?

# PARTICIPANT:

Yes, technical support.

# INTERVIEWER:

So do you have to follow and read protocols while giving counselling related to health and ART?

# PARTICIPANT:

Yes, we have to, because we cannot give information or advice at will. We have to follow certain protocols for that and we do that because we are here to support and strengthen the Nepalese government services. So we follow the protocol accordingly.

# INTERVIEWER:

We were informed of the existence of a triple blood test that includes HIV, syphilis and hepatitis B. According to the government protocol, it is mandatory and part of routine testing, especially at the first ANC visit. But in many places, it has not been implemented, even where laboratory services are available. Given this, how important do you think it is to implement blood testing for sexually transmitted diseases during pregnancy? Why do you think it is important for the health of the mother and child?

# PARTICIPANT:

If the disease is diagnosed at an early stage, the main thing we can avoid is the vertical transmission. I would say it is negligence if one person has the disease and passes it on to another person. Whether it's through organisational support like ours in situations where the government supply is interrupted, pre-screening should be done. It will affect the census in the future.

# INTERVIEWER:

Some people are not aware of blood tests, especially for sexually transmitted diseases. Counselling should therefore be mandatory, especially for pregnant women, to prevent vertical transmission. Not all organisations are able to offer counselling for an hour like yours. Why do you think health posts and public health institutions do not take the initiative to provide counselling services? What do you think are the challenges facing health and public health institutions?

# PARTICIPANT:

From what I have seen, in the health posts, if we talk about antenatal screening for sexually transmitted diseases during antenatal visits, then when the flow of patients increases enormously, they don't have even a single minute of respite.

# INTERVIEWER:

So due to a lack of time?

# PARTICIPANT:

Yes, because of a lack of time. And because there is a lack of time, they won't be able to do anything else after that. Another reason is that once a patient comes for a visit, they are in a hurry to leave and because of that, we, the health workers, are not able to give them all the required information. So, due to the lack of time, the counselling to be given to the patients is compromised.

# INTERVIEWER:

Do health workers feel shy or uncomfortable talking about sensitive topics?

# PARTICIPANT:

If I talk about myself, I don't feel embarrassed when I talk about these sensitive topics. Even as a team, we are not embarrassed at all. In my experience, I haven't found anyone who has had this experience. There may be a few who may have felt shy. I can't say much about them, but since we are here to provide services to those who need them, there is no need to feel shy and embarrassed about it. I don't know if there are any health workers who are shy when giving information or advice.

There is much more difference between students and health workers like us. Anybody would feel shy [laughs] at first. But after working for so long, the chances of feeling shy are much lower.

# INTERVIEWER:

What would you suggest as an appropriate training programme for the community to accept without any hesitation, shyness, anxiety or fear of the whole situation?

# PARTICIPANT:

First of all, it would be extremely beneficial to bring any awareness programme, and the community adapting to it is an improvement in itself because it can improve its behaviour. Locally people get more open to FCHVs. So, the involvement of FCHVs, workers from the health post level, and expertise will be better. If community participation is high and a lot of questions arise then expertise can help in answering their curiosity.

# INTERVIEWER:

What is the prevalence in the community?

# PARTICIPANT:

I only have data on active patients, although there is data on those who have died, been lost to follow-up or transferred. There are 465 patients in Kapilvastu and 734 patients ever enrolled after being diagnosed as HIV positive.

# INTERVIEWER:

This is the data from Taulihawa's hospital.

# PARTICIPANT:

Yes, 734 enrolled patients.

# INTERVIEWER:

Since when have these 734 patients enrolled?

# PARTICIPANT:

The data has been maintained since AHF started here, but the total number that has registered so far is the number of people who have started their medication. I don't know when ART started.

# INTERVIEWER:

Do you know how many females are enrolled?

# PARTICIPANT:

We have 224 active women. Of these, 15 are women with children. As far as vertical transmission is concerned, 65 active patients are children born to infected mothers.

# INTERVIEWER:

Do you mean children under 18?

# PARTICIPANT:

No, we consider children under 14 as children.

# INTERVIEWER:

Are these data collected from clients who come for antiretroviral treatment or at the sites where institutional delivery takes place?

# PARTICIPANT:

4 clients on ART were diagnosed during early infant diagnosis. Otherwise, these are the data that were confirmed after the confirmation of vertical transmission. Many are old cases, so I don't have much information on how they were counselled and received other services. If the adherence advice is good and the viral load is below 1000, then the chances of transmission are zero. We even give advice on transmission through breastfeeding after delivery, but I have no idea about how was this counselling in the past. Since we started advising and organising several programmes, the rate is comparatively low.