

CHAPTER - VI

CASE STUDIES/FOCUSS GROUP DISCUSSION

Chapter Six

Case Studies and Focus Group Discussion

Case Studies:

This chapter represents the case studies and focus group discussion made during the period of field work to get more depth of information and cross verifications.

Case Study. No. 1

Sabitri Devi (name changed) is a 37 years and was married at the age of 19 years and got two daughters. She eloped when she was reading in Class VIII with a petty businessman. She did not know that her husband used drugs before. Her husband thus passed away five years later. She had no knowledge either, how to survive as there were no means of earning, being from a poor family. She is Hindu by religion and belongs to general category.

After her second child birth he died. That's when she was just 24 years. Her mother – in – law separated her children. Her children were living with her mother – in – law. She was not allowed even to meet her own children. Her in – laws wanted to drive her out of the family, blaming her that she was responsible for the disease her husband had. She does not get any chance of meeting and being with her children.

Then a day came when her grandmother sold her homestead land without her knowledge. She came to know only when the other party came for demarcation of the said homestead land. She did not have anybody to rely upon. She cried the whole day thinking what had she done to her life. She slowly gathered strength to discuss the matter with her neighbor and well-wiser about her life style. Heeding to their advice, she approached an NGO's for help. Her plight had drawn the NGO's attention, and they helped her by filing a case suit to the court. She succeeds the case and is

still living at the same homestead land. However, her in – laws family members still discriminate her. She still lives alone with moral and physical support from her parent’s family. She has been suffering from illness and economic – crunch while being a victim of social discrimination too as she is a widows living with HIV/AIDs. She used to go out and work as a domestic helper in order to support herself and also to erase the memory she is living with. Today, however, she took up embroidery as her source of income. Using her talent and strength she could earn Rs. 500 – 600/- from time to time. Meantime, her elder daughter realized her mothers’ need and voluntarily came forward to live together. Her younger daughter died of AIDS.

Case No. 2

Mina (name changed) a young beautiful Nepali girl aged 35, eloped with this Meitei husband belonging to another community has been trying to stitch together her shattered life with the only hope of bringing up and educating her only son whose life is also threatened.

After the death of her husband in an unfortunate incident, and soon after she gave birth to a son, Mina was chased out from her in - laws house. They claimed that she had no right over the child. Nowhere else to go, she went back to her parental house, but her own parents refused to give shelter as she had eloped with a man from another community against their wishes.

With the help and advice of a benevolent woman, Mina started running a small shop. Apart from the suspicious nature of the people to rent out room to a young widow who is still in the prime of her youth, many lecherous men tried to lure her to fall into their trap. It was at this time, she approached a man who frequently came to her shop to assist her in many ways.

“I did not have the money; deep within me I cried in pain, I console myself by thinking if ever I get back my own child. Sometimes I remembered the harrowing experiences that I went through. As the society would not allow a hapless woman like me to live peacefully and my son to grow up normally, even after years of keeping memories and worshipping the mortal soul of my late husband, I thought it would be better to have a man in the family,” she said. Subsequently, she married a man who was a regular customer to her shop and always has taken care of her and her needs. However, she did not know that the man was a drug addict, and passed away not long after. Much later when her second husband passed away then only she came to know about her HIV status. She was only 26 years then. She thought and felt that it would be better not to live any longer, with full of fear of social stigma and discrimination. For long months she did not even open up her shop. However, in an awareness programme conducted in the locality near her place by NGOs, one of her close friend staying nearby contacted her and forced to join the programme. The programmes subsequently changed her life. She found a world to begin her life anew. She felt motivated to live for her son. She re-opens her shop and had taken regular treatment. Her health status seems to be poor but however, she is satisfied with the ART. As her life goes on, she still fear to face the stigma and discrimination from the community.

Case No. 3.

Bina Case (name changed on request) “After I was chased out from my in-laws house, I have been spending most of my nights either at the hotels of my friends or on the verandahs of shop and gullies in the bazaar”, says 35-year old Bina. Talking about herself, Bina recalled that she had been married off at a very young age by her stepmother and father when she was only 20 years. Her husband started to get sick two years after their married. As he was not showing any sign of recovery, their family doctor

recommended having an HIV test. The test came out positive and his prognosis looked bleak as he was too ill. She had no counseling before and after the test since she had no knowledge about HIV/AIDS. When the doctor told her that she too had HIV and there was no cure, she was shocked. She thought of committing suicide and started hating her husband, her parents and everyone. But later on she realized that it was of no use crying over spill milk, and she came out on her brave front.

Her husband died eight years later. And soon after that her in-laws started ill treating her, even though their marriage were arranged. Subsequently, she was chased out and therefore had to return back to her own parental home. After coming back to her parental home, Bina started working at Kakhulong village, in assisting brewing local wine to earn money for her sustenance. “While searching for a means to earn at least some money for my sustenance, I took up brewing wine. For brewing one pot of wine, I was given Rs.30 and in a day, at the most three such pots could be brewed”, she informed.

But on the flip side she got along with others in the same profession. Bina started drinking to forget her past. As the meagre income she earned was not enough she changed her profession to fish selling. She borrowed money from her very close friend to start the business promising to pay her back.

Bina, now moves back to her parental home. She is surviving with the little profit she earned in selling fish. She has also stopped drinking, which is very difficult for her to do but she has managed to do so. She is still healthy and strong and under ART. She is of the view that most of the widows of Manipur have become so, in their efforts to find a road to save themselves from poverty and stigma in their families.

Case No. 4

Rita (name changed) is a 30 years old. She is Christian by Religion and belongs to Scheduled Tribe. She got married at the age of 18 years when she was reading in class ten. By that time she had no idea what marriage meant. She was unable to say anything to her parents, since it was a love marriage. Only later, after marriage she got to know that her husband was an Intravenous Drug User (IDU), even though they both knew each other since childhood being from the same locality. Her husband was good for nothing. He only kept asking for money from her and his mother to satisfy his thirst for drugs. But since she did not want to pick any argument she used to give whatever he asked for.

She had already been going through the taunts of her in – laws after her husband died. It only worsened after she disclosed her HIV status. They blamed her for infecting their son. *“I was upset about his death but was scared for myself too. I was depressed and got tense too.”* said Rita. Her in – laws lived nearby but do not talk to her.

Subsequently, she decided and returned to her parental house along with her 3 children. But, her families were too poor and did not have time and resources to help her. Her only son and the youngest amongst her children also died with AIDS. However, her mother was very supportive.

Later on, she came in touch with the women’s wing in NGOs. She was invited to work as a peer educator after hearing her plea. *“I decided to go out and work for the women who were ignorant like me and wanted to educate them”* said Rita.

When she decided to join the NGOs and work as an educator she felt enlightened and said, *“I feel I am doing something good and meaningful for them.”*

She came across many widows who were driven out by their in – laws, forfeiting their own property rights. She felt pity for them and bore the brunt too. She feels everyone has to die someday and no one lives forever.

However, the life that such widows lived was not fair. There were times when she used to think there was no hope for her anymore and that she would die soon. But now she has the courage to fight on and can live for a longer time. She wanted other people living with HIV/AIDS to live happily with mental peace. Her only dream is to remove discrimination and carve out a good life. She wants to encourage the other women to come out too.

Case No .5

Kamla Devi (name changed), a 32 year old with no education has one child. Her husband was a truck driver by profession who used to carry loads from different places of Assam. His job required a journey for 2-3 days. He was the only bread winner in the family and hardly stayed at home.

As life went on, his husband health started deteriorating day after day. He finally became too weak to work one day. She took him to the doctor. The doctor advised to go for a blood test and so they heeded to his advice. The result turned out to be positive. The Doctor told her that he had already reached the AIDS stage. When she heard and saw the report, she felt nervous. She started thinking that how it happened and all other possible ways. However, to confirm she again asked for further test which again turned out to be positive. Suddenly her tears rolled down and began to cry aloud. She brought the report home and suspiciously asked her husband indirectly as to whether he had any affairs with any women.

He said surprisingly, how could it be, but she informed him about the reports. He got shocked and said "how can it happen to me". He too cried out loud, and narrated about one incident which had happened while on his journey, that he once had visited a brothel and slept with a prostitute. He believed that the disease might have been transmitted from that incident. He was not aware that she was living with AIDS. He admitted that that had happened out of lust.

Hearing her husband's episode, she felt distraught and felt with tears in her eyes. She couldn't scold him for he was in a very bad condition. She controls herself but still her thought filled with fear and trauma. She approached an NGO's working on HIV/AIDS. She narrated the whole story and they advised her to go for test too. Coming from a poor family, whose husband was the only bread winner she could afford for the test and even for the cost of her husband medicine too.

After a few months, her husbands' condition worsened and was hospitalized. However, it was too late and of no use, all her efforts went in vain.

She cried and sometimes wanted to commit suicide too. She said: "*I have not told anyone at home about my status. I have my own parents and a child. I do not know how they will react soon after his death. I thought of not telling to anyone*".

She was afraid to live on, thinking for his son expenses. She did not have any one to ask for help. By the God's grace she met a woman who helped her to work as care keeper in one NGO. She was paid a sum of about Rs.1000/- per month. With the little earning she was feeling happy and contented.

However, slowly her neighbors' began to know about her status and started talking about her. She did not care much about their gossip. But one fine day, while her son was playing with other children in her yard, her neighbor discriminated her son saying not to mingle with their child anymore saying he must be living with AIDS. She overheard these from her room and ran out and had fought with them saying "*what wrong have my son done?*" in tears. These made her more painful and also felt that that was the saddest part for her unlucky son.

The above case studies tell us many things. They tell us that HIV can spread itself through various modes. They describe the hell that PLWHA go through. They also show us that PLHA face the world

differently, and experience the social, psychological and physical aftermath of the revelation, in varied manners.

AIDS is not a single disease but a syndrome that may involve several pathological states and be transmitted in various ways, affecting people with diverse disease, life histories and identities.

No other disease in the study of medicine has had such a major impact on various sectors i.e medical, social and economic. As a social problem HIV/AIDS is a phenomenon provoking reactions of panic, revealing social fissures, inequalities and the discrimination and stigmatization of marginalized groups in society. With the spread of the epidemic, individuals, families, communities and nations have to face deaths on a scale unprecedented in modern times. In countries where rapid social family and social structures, change these costs could be enormous, affecting fertility, gender roles, household patterns, etc and perhaps offsetting many of the gain made in these areas recently what a person does, who a person is and where a person lives can specify what hazards are most likely to exist in that individual's life.

This focus of this study was on the social dimension related to HIV/AIDs which have received relatively less attention till now. The specific objectives of the study were to examine the socio-economic impact, to understand the knowledge relating to HIV/AIDS, to find out the kinds and methods of treatment they are receiving, to identify the sources and types of support widows and their children are getting, to document the stigma and discrimination faced by widows and the children at family, community and workplace, to study the need and plan for the livelihood of them and children.

The above cases are representing the similarities and differences of their life experiences. The impact of the case study has already been compared and discussed in the earlier chapters.

Focused Group Discussion

Group: 1

Agency: Social Development Organization (SODO)

No. of Participants: 7

Duration: 1 1/2 hours

1. General information (Background and transmission)

One participant said, *"I believe that it can be passed and infect a child at the time of birth through blood transfusion and can also be spread to a sexual partner through intercourse."*

Another participant expressed, *"As for me honestly speaking, the disease was transmitted from my husband. He was an IDU and I'm not aware of that in the earlier stage. And I don't even think that such disease would have existed in human body."*

Another participant said, *"Earlier I don't know what AIDS is. I think I got the symptoms when I had frequent fever, loose motion and even starts loss of appetite. Then I approached Doctor who advised me to go for a blood test, after learning my husband status. My husband did not inform me about the virus that he is living with. Through the diagnosis I come to know that I am positive."*

2. Day- to-day life (How do you spend your time and what is your perfect way to spend your life?)

"Whatever I earned is to live and eat. Sometimes, I went to cuts woods for selling or take up farming. From the little day – to – day earning I look after my children's need. So I spend my days working for a daily wages. My days are always too tiresome and as my health condition is deteriorating, sometimes I stayed without eating thinking for my children. Sometimes I sit and cried thinking of my condition. Being poor I am not able to meet all the requirement of my children to their satisfaction" lamented one participant.

Another participant said, *"Since I don't have any child to look after, in one way am happy. However, most of my time I feel my life is miserable living*

all alone. I got a small kitchen garden where I grow some vegetables. Thus I spent my days selling the products grown out of the garden.”

The participants seem more conscious about income generation activities as one participant was saying, *“there is no one in my family who is earning and I don’t want to spend my life leisurely as well. So I used to get a job of doing domestic works, like washing dishes in marriage, birthday and other such programme. I am paid about Rupees One hundred or more for such works in a day. With this small earning I am supporting my children and the family as well”.*

3. Supporting systems (Who were the people who look after you and your family?)

“I received none from anyone.” said one of the participant.

Another participant said, *“Sometimes, I got help from the NGOs side, but though they helped me in many ways, I have to bear the medicine expenses.”*

Another participant adds, *“I got support from my parents in terms of financial needs whenever I ask for. But the question is for how long?”*

Another participant said, *“Since everybody knows my husband immoral act and his ways of living, even in the health centre, they ill – treated me. The community people know very well how I am surviving. There is nobody who would support me even with a single kilogram of rice. I don’t want to approach to anyone for any support. I feel so down, even in starvation I did not want to tell anyone.”*

“I don’t feel like asking any extra clothes even from my sister – in – laws. Shyness lies within me.” said one of the participant.

4. Needs you required (Like for children academic purpose or for your family)

One participant said, *“As long as I live, I want so many things to be fulfilled. I have got skills but there is no earning process. When I wanted to earn, I need money to start. So money is very much required in my life.”*

Another exclaimed that, in their nearby areas or their own locality there is no other NGOs except for this one (SODO). This NGO helps them a lot. So she feels the needs of many more such NGOs. She suggested they would require a NGOs coming out for nutrition support, education for children and for any other materials support. She learned and heard that in the Imphal central there are good NGOs, who provide education to such children. She adds, "Here, in these areas where mostly Muslims inhabited, there is only one NGO who is supporting the People Living with HIV/AIDS (PLWHA). Therefore, most of the things we required are lacking."

5. Opinion regarding treatment (Discriminate by anyone anywhere where you seek treatment)

"NGOs were helping us in ART. There are some people who encouraged us and also some who also harassed us saying, 'how long they will live, who knows they may die today or tomorrow. The way they are living today is because of their husbands' behavior.' Such comments or gossiping is frequently pass upon us." said one participant.

Another participant adds, *"Since people thinking is different, there are different outlook. Some makes fun of us and ill – treated us, but till now I find there are some people as well who understands us."*

One commented, *"Why is all this happening? Why is all this comments upon us? Are not they from the society? They don't know what AIDS means."*

Another participant said, *"Among our Muslim tradition purdah systems still exist, so nobody comes out to help us who are dying with this deathly disease. I also feel transmission is increasing in great number."*

Another participant quickly adds, *"Whatever we share they don't feels like listening to."*

Another one expressed, *"When I first come to take ART in the hospital, I feel awkward and scare, so I covered my face thinking if there is anyone whom I know. I enquired curiously to the nurse of the hospital, as to whether all*

the people coming here are positive people. She said yes and they all have come to get the ART (medicines). She encouraged me a lot. Then only I started feeling happy and content thinking that I am not the only one."

6. Face any problems (Like anyone disturbing in your personal matters)

One participant said, *"Till now I was not discriminated by anyone since nothing is written on my forehead. Another participant adds, "Since am selling vegetables in the market, the person who sat next to me does not know about my status, so there is not such discrimination."*

Another participant said, *"One thing is disturbing me in my life. The only problem I face is the financial or money. I wish I only earn a lot."*

7. Taking care of children (Suggestion for your children's care and development)

One participant said, *"Before I die, I want my children to get a good quality education support, so that in their future they get a good job and live happily."*

Another participant said, *"Since my youngest child is affected out of the five siblings, I wanted her to get all the support. I can't say and also know when will I die, still I want my child to live a little longer."*

8. Association in groups (How do you feel being together)

As per the Researchers' observation, there is no other NGOs beside this NGOs (SODO). The NGOs help them in providing medicines and some other materials but there is no such grouping work or any other such training or Self Help Groups is form.

One participant said, *"We want to form a group so that we can spread awareness to every nook and corner of the society, so that there is no further spreading of the disease. Since we do not form groups we do nothing."*

One participant said, *“Living in a group among ourselves in the locality/areas will be much better for our Muslim Society. As we all live in Purdah system we move backward.”*

Another participant expressed, *“I’d enjoyed being in group, going out together, or working together, or spending time together. But our customs forbid us to do so.”*

Group: 2

Agency: Don Bosco Mangal

No. of Participants: 6

Duration: 1 hour

1.General information (Background and transmission)

One participant said, *“Since he is an Intravenous Drug User (IDU), he gifted this virus to me. Even after getting married he did not inform me nor disclosed to his family about his status. Due to my ignorance, I was not much aware about it. I admit it’s my own mistake.”*

Another participant adds, *“He was positive before we get married, but he did not disclose his status to anyone. When his health condition is worsened, only then I came to know of my status too.”*

Another participant said, *“He hide his status earlier, but since I know he was an Intravenous Drug User (IDU) before, I got suspected and went myself for the test.”*

Another participant said, *“I came to suspect of my status when he started to get sick and so I went for check – up myself.”*

Another participant said, *“Soon after giving birth to my second child, I came to know about his status. I, myself was too strange to learn about my status.”*

The last participants said, *“My husband used to go out for his work to a very far off place. Sometimes his works require staying out for 2-3 days. He was not an IDU, but he got infected from a prostitute.”*

2. Day today life (How do you spend your time and what is your perfect way to spend your life?)

Since widowhood brings out sudden and unhappy changes in their life, they don't have much leisure time to spend unnecessary.

One participant said, *“I enjoyed spending my time in groups. When we come together we share our feelings, our joys and sorrows and sometimes crack jokes.”*

Another participant said, *“I spend my time with my children's. They understand my feeling and make me happy. They share funny story with me to ease my pain.”*

3. Supporting systems (Who were the people who look after you and your family?)

All the participants expressed that they were happy with the works of the NGO who were helping them out though not in huge financial support or other material help. They said they received educational support and training; like tailoring, knitting and other skills development for Income Generating Activities. With this support they are satisfied and content. If there is someone or somebody who would help and see to their requirement from head to toe they will be much happy but who will and can do that for them. However, they remained content with the little support the NGO provide for them.

4. Needs you required (Like for children academic purpose or for your family)

The participants feel, since financial and economic help can be the only help reaching out to them, the projects which are doing a good work

should continue doing it. Their utmost requirement is education, so that they help in spread awareness and stop the further spread of the disease. One participant said, *"I may die soon but the children who survived and not affected by the virus need strong support for the future."*

5. Opinion regarding treatment (Discriminate by anyone anywhere where you seek treatment)

One participant said, *"We, widows do need lots of treatment and counseling not only about AIDS but because we are concern of our outward appearance too."*

Another participant said, *"I feel free in the health centre because everyone understands my problems. They are good to me."*

Another participant said, *"Sometimes I fear the worker who helps me because they may not ensure my confidentiality even though they help me lots."*

Regarding treatment in health centre, one participant said, *"If we closely look at our individual life story, it is very heart breaking. At one time I am helpless even on medicine expenses of my child. Once my child felt sick in the middle of the night, there was no vehicle around to take her to the hospital, but thinking at least some medicine could relieve her for the night, I ran to a local pharmacy. On reaching the pharmacy, I knocked the pharmacy owner's door but he refuse to open. So, with nothing more to do I ran back home and seated near my child wishing she got some relieved and waiting patiently for the sun to rise soon. It is only when the sun rises that I took her to the hospital."*

Another participant said, *"When my mother knows about my status, she cried and said, that I may die soon."*

6. Face any problems (Like anyone disturbing in your personal matters)

As the participants were working for their own livelihood, they take up different profession. Some works in building construction site and some work as domestic helper.

One participant said, *“One day, while I was standing and waiting for a bus, a stranger passed by and commented me about my beauty. This is not a problem but the poor fellow does not know that I am living with the virus.”*

Another participant said, *“Till today, I have not faced any problem as such beside financial constraint. I roam about in groups with friends sometimes, but nobody have ever disturb me in my personal business.”*

Another participant said, *“I want to take – up something to earn money. So, I use to sell vegetables which sometimes I incurred loss but earn profit most of the time. My in – laws said they will help and support me to run a shop but I doubt there promises. I feels they won’t do for me because my husband died of drugs and they would feels I would spend the money unnecessarily.”*

7. Taking care of children (Suggestion for your children’s care and development)

Many of the participants face the difficulties in caring and rearing of their own children, mainly due to financial constraint. Generally, for a woman to keep asking from the parents for all the monetary help is something to be ashamed of. If the parents are rich enough to look after, there is no problem, but for poor family things are different. Sometimes even among the siblings they don’t like if their sister is economically dependent upon them.

One participant expressed, *“I feel shy of going back to my parents as I got married to a drug user against their wishes. After his dead, though his*

family did not look after my children and ill – treated me, I decided to take up the challenges. I need to be strong and live to the fullest for my children.”

Many participants, out of frustration and economic compulsion, work hard for their children only. One participant said, *“My only dreams is to crave out a good and meaningful life for my school going 14 years old daughter, fortunately not affected by the virus.”*

Another participant said, *“My eldest son works in building construction site and learn something for the family. Though his earning is merger he makes me happy and proud. He understands my needs and problem. I find my children cooperatives. I wish I would live lot longer to be with my children.”*

8. Association in groups (How do you feel being together)

One participant said, *“We helped each other in times of difficulties. We promote a sense of belongingness among ourselves. We coordinate with each other in times of illness.”*

Since each member comes from different locality, the group they maintain changes from time to time. One participant said, *“While I was in a group, our groups produce washing powder. We at that time earn a lot. We tried to continue doing it but its does not last long, as every one of us is busy with one or the other works.”*

Another participant said, *“We don’t hesitate doing anything. We talk freely and shared our problems together in groups. As we belong to a same status we understand more about our problems.”*

Group: 3

Agency: Network for Positive People (NPP)

No. of Participants: 5

Duration: 1 hour

1. General information (Background and transmission)

One participant said, *"I do not know that my husband is injecting drugs but the locality people talk about him. I got confused and directly asked him but he never told me the truth. At last when we had a fight, only then he disclosed it. But it was too late."*

Another participant adds, *"My husband serve in the Police department of Manipur. He was posted at Moreh (bordering town to Myanmar). He was not an IDU but he get infected through Commercial Sex Worker (CSW)."*

Another participant said, *"As my husband always get mixed up with herion and bad women, he passed on the virus to me too. I felt that AIDS is more vulnerable to those women who are of loose character."*

Another participant said, *"I wanted to say openly that I got infected from my husband. I have not done anything wrong nor have I live in immoral ways. It's him who brought the virus and made me alive today in this condition."*

2. Day today life (How do you spend your time and what is your perfect way to spend your life?)

One participant said, *"Earlier, I work with my physical. But now as my health conditions deteriorate, I cannot continue doing heavy work."*

Another participant said, *"Since I am the only bread winner in the family, I need to be strong. The only way to spend my life is to be in group. Being in group helps me reduce my stress."*

Another participant said, *"I don't know how to spend my life because whenever I look around there are loopholes. I wanted to fulfill my children*

wishes, and also wanted to satisfy their needs. I need to work and earn more. So there is not much time for me to spend my time leisurely.

3. Supporting systems (Who were the people who look after you and your family?)

One participant said, *"I got support from the NGO where I am working. I got not only my monthly salary but also many other compensation. I got psychological and mental support too. I would like to say, they supported half of my needs."*

Another participant said, *"As I am weak physically and also my health condition is deteriorating, I am not able to do heavy work or for long hours. But since, I got a small child to look after; I got the support from my parents. Their understanding to my problem is the happiest things to me."*

Another participant said, *"My parents understand me better. They took me to NGOs for medicines. They supported me in many different ways. It is because of their help that today, I am taking ART."*

Another participant said, *"I really thank my parent who is always on my side. If my parent did not allow me to enter, I would not be in this condition today. I know a friend who died because she got no support from anyone; her in – laws or her parents either. So, recalling all the things I consider myself to be lucky enough to have survived till today."*

Another participant said, *"I don't want to say associating with NGOs has no benefits. It true, we are not getting any monetary gain but the association has enriched our knowledge and mental peace."*

4. Needs you required (Like for children academic purpose or for your family)

One participant said, *"I learned almost all the supporting projects of NGOs are cutting down. With all these support though small, we get relief and we are content but even if this cuts down then what is the reason for living."*

Another participant said, *“As for me financial support is needed, but apart from that I wanted people to understand me and other PLWHA. Sometimes people take us very wrongly. Their views are strange. They gossip about me, my going in and going out, where I go and what I do. So I want my neighbor and the community people to understand us better.”*

Another participant said, *“As I am separated from my in-laws, I wanted to erase their wrong perception about me. If their son died, why they want to keep me in hell, I feel I am a member in their family too. I want them to feel the same for me and my children.”*

Another participant said, *“My urge is to fulfill my child’s education. Luckily she is not affected by the virus so I wanted her to go for further studies. I need support from Government of India and NGO to support her even during her admission.”*

Another participant said, *“I want both NGOs and Government Organization to help us by providing medicines prescribed by the Doctors. NGOs have helped us to some extent by giving medicines but for HIV/AIDS we have not got any helped.”*

5. Opinion regarding treatment (Discriminate by anyone anywhere where you seek treatment)

One participant said, *“I think now people were much aware of the virus. Whosoever, I met i.e., my friends who understand me, sometimes reminded me about my medicines. They ask me about my health conditions too.”*

Another participant said, *“I feel sad when I come to take ART in the health centre. Sometimes they neglect me, makes me to sit and wait for long hours without any information. Since I am living with the virus, the stigma makes me feel shy and scare to wait for a long hours.”*

Another participant said, *“When my husband fall sick, he was hospitalized and is kept in a separate room. Everyone asked me then ‘why is he kept alone and separated’. I failed to give answer. I feel ashamed of myself and*

sometimes I don't want to raise question to the doctors. That very moment I felt we were disregarded and ignored.

Another participant said, "Until now I don't find such discrimination done toward me. It seems people around are more good to me now."

6. Face any problems (Like anyone disturbing in your personal matters)

One participant said, "As I am a weaver and am earning for my own livelihood, there is no such disturbances from anyone. Or maybe because am not going out much and mingle with people.

Another participant said, "When some people who come to ask me, the community people refer to me as, 'oh! that IDUs wife and who also now with AIDS.' Such name they refer makes me really painful and sad. Sometimes, the locality people even pass mocking remarks to me."

Another participant said, "My in - laws ill - treated me. Whenever I walk out from the house, they keep on insulting me and I really don't understand what they feels and thinking about me. Sometimes, they yelled at me saying, 'you live like a prostitute, roaming here and there. Are you selling your body?' This really hurts me. Instead can't they have a concern about my life and my health? May be my in - laws are suspicious of my personal character and conduct."

Another participant said, "As I am staying with my parent, still now I do not find such comment. Instead, they seem to be more concern. My mother always accompanies me everywhere I go, may it be to get medicines."

Another participant said, "I don't feel like wearing good looking dress, because people viewed in different ways. My mind is selfish, I am always thinking negatively. The stigma that I have is the greatest mistakes. Sometimes, I feel why there is ART, why should they make us live longer, I should have die soon. To everywhere I look there is a problem and now I realized my helplessness. I just hate ART for also making me live long.

7. Taking care of children (Suggestion for your children's care and development)

One participant said, *"As social stigmatization of AIDS is evident, though I live with AIDS, I am trying hard to live lot longer by taking care of myself. I know people do not like me because my husband was an IDU. But what I feel bad is when my children got the same type of treatment."*

Another participant said, *"I overheard people saying to my children, 'as your parents are positive you will also get AIDS. Your father is a drug addict.' I, therefore feel very bad because not only me but even my children has to face the same stigma and live on."*

Another participant said, *"Since my husband is an IDU, he has not earned anything for the family. And if I also move out doing nothing and no earn, who will then feed my children?"*

This kind of response was coming out from the participant as another participant also said, *"There is no one in my family who is earning, so I go and work in building construction site. With the little earning I am supporting my children, so that they may live happily. They are my only hope."*

Another participant said, *"I have to deal things emotionally. I am not happy with my husband who passed away leaving nothing for me and my children. But what is the use of thinking now. I am trying hard so that my children are not in the same trap again, where people have to speak ill of them. I am teaching them that they should live strong with good character."*

8. Association in groups (How do you feel being together)

One participant expressed, *"We come to know each other from the training programme conducted by the NGOs. Thereafter, we keep contact and there is a rapport building too. I feel so happy to see us together again."*

One Participant said, *“There should be recognition of our work that we widows actually do. Also there should be a support for raising their productivity. I want people to know and understand us much more.”*

Another Participant said, *“We usually end up being homeless and no one to care about. But what to do, we enjoyed being together, sharing every little things. When we try sharing our problems with other who is not positive, we find difficult but the same is not a problems among us. We in other words understand each other better.”*

Another participant suggested. *“Group is very powerful, I would suggest. I wanted to share this to other participants too. Why don’t we do some income generating activities? Since we all have our own skills, we can start making agarbatis, candles, washing powder, soap etc.”*

Discussions:

This section presents the findings of the FGDs on background and its transmission, their day-to-day life, it’s supporting systems, their requirement for the children, opinion regarding the treatment they are receiving, any disturbances they faced, suggestion for their child care and development and being together with the other friends.

The existing interventions in Manipur have focused on IDUs with inadequate focus on services on women who are affected or inflicted with HIV/AIDS. The majority of the HIV/AIDS infection population in Manipur were /are IDUs and most people looked at that ‘High risk group’, forgetting that the injecting drug Users also have affected partners. In the discussion it was expressed that they were transmitted from their husband. It was found that their spouses were IDUs. In the initial stage they were not aware or concerned of being at the risk of HIV infection. They expressed that the diseases transmitted from men to women.

All the discussion were from the lower income group. They learnt to manage their everyday life and dealt with the physical self. It was also

found that widows were helpless, as they themselves were the main bread winner. They were bound to experience heavier responsibilities and they expressed the strain on households' resources and income.

Most of the discussants found that they were not able to meet the needs of their families, since the majority of them were poor. Regarding the supporting systems, it was found that the family was the main source of care and support .NGOs were providing materials needs in some areas and in few areas they do not get any material help. The utmost needs are those of basic materials.

From the discussion researcher come across that widow were deprived of all the privileges and suffered all the time. They faced problems within the family, neighborhood and community. The disease they live in brought the stigma upon themselves.

The role of widows in the economy and their status in society becomes crucial for the growth of children and the development. Many participants here expressed their concern about their children. They wanted their children to get a good education and live happily in the future.

Widows were the most difficult situation in life but still they faced the challenge boldly. They earned for themselves and for their children's need. They wanted their children not to be like their father who died of drugs and AIDS. They only wanted their children to grow strong and live like any other in the society.

Traditionally, women helped each other in times of difficulty. Good coordination was found among the group. They themselves facilitate peer support .The association with friends provide much moral support and reduce uncertainties. Few participants do form group earlier, but due to certain circumstances they did not work together again. They said they need support to begin again or form a group. They are going out for their own work and in their own interest.