

## **CHAPTER VIII**

### **DISCUSSION, CONCLUSION AND RECOMMENDATION**

## **Chapter 8**

### **Discussion, Conclusion and Recommendations**

#### **8.1 Discussion**

The study discussed the issues of utilization of health services among the widows living with HIV/AIDS in Manipur. It was indeed a difficult task for most of the widows to seek the health services due to its financial problems, time constraints, distance, stigma and discrimination. Hence the chapter attempts to gather the findings and link it with the other literature in an attempt to derive an understanding of the utilization pattern of health services by the widows living with HIV/AIDS.

##### **8.1.1 Mode of transmission:**

Heterosexual transmission from IDU to their spouse was the mode of HIV transmission for all the widows in this study. The result was found similar with the study done by (Lamkang, et al., 2009) on assessing the quality of life and needs of HIV/AIDS patients in Manipur. In a study by Pande, S. et al., 2000, on transmission of HIV from injecting drug user to their wives it was found that majority of the wives of IDUs tested in Manipur were HIV positive. The Manipur AIDS control Society (2005) documented this outcome of many HIV positive widows in Manipur since the first case of HIV positive was reported in Manipur three decades ago among the IDUs.

##### **8.1.2 Living Arrangement:**

Many of the respondents were left with the responsibility of children to look after with in-laws barely concerned in looking after the children and daughter-in-law. And therefore with no one to depend they either came back and stayed at their maternal house or stayed in a rented house. Another arrangement was having a separate kitchen in their in-laws house. This finding was corroborate by another study conducted in rural India where the HIV widows were mostly supported by their parental family members (Gujjarappa et al., 2004).

##### **8.1.3 Status of the Widows:**

Majority of the widows belong to low socio economic class. The result was supported with other studies conducted in Western and African countries (Sayles,JN., et al., 2007; Titilope, A.A., et al., 2011). The respondents in the study were either unemployed therefore did not have any household income or low, daily-wage jobs as most of them sustained by means of

self employment. Many of those were employed in NGOs working for the people living with HIV/AIDS. The result substantiates the finding of (Hollen, C.V, 2010, Lamkang, et al., 2009) in India. Therefore with little income, majority of the HIV-positive individuals are of lower socio-economic status and have difficulties accessing much-needed health care (Vyavaharkar, M.V., et al., 2008) and this is particularly true for widows in our study.

#### **8.1.4 Disclosure of their HIV status:**

The current study found the husbands of these widows not confiding their positive status to their wives. This finding was supported by studies done in other parts of India (Mulye, R., et al., 2005, Lamkang, et al., 2009). Some of the widows came to know about their status when their husband reached the advanced disease stage or during pregnancy or childbirth or when they themselves felt sick or at the time of surgery. The finding validate the study conducted by the (UNAIDS 2000).

In India, spouses of all HIV-positive men are advised to undergo HIV testing whether seeking medical services or not. Here in this kind of situation many came to know about their status. In this kind of testing, no consent is provided and there is no pre- or post-test counselling. In many health centres, pre and post-test counselling were not even performed according to guidelines issued by NACO. The results support the studies by (MacNaughton, G.2004); Exchange, 2008 ) on women's health-care services in the Context of HIV/AIDS.

Majority of the HIV patients did not want to reveal their status to anyone other than close family members (Mulye, R., et al., 2005). Likewise the study revealed that vast majority disclosed their result to at least one person, specifically to their family members. As confessing their own status often leads to ridicule and judgement among the larger extended family WLHAs only tell their immediate family members about their status. And sometimes they do not reveal their status to their own parents. A similar finding was shown in a study conducted in Puerto Rico, Ethiopia, as well as in Manipur respectively (Ruiz-Torres, Y. at al., 2007; Deribe, K., et al 2008; Lamkang, et al., 2009).

Women whose partners die of AIDS often face social rejection related to the disease (Human Rights Watch, 2002, 2003; ICRW, 2005). The respondents in the study were also ostracized by the society once they come to know about their positive status. And thus due to this fear of being segregated by the society some of the respondents were apprehensive in disclosing their status to family and friends. Similar to our study a study conducted within Mumbai and Bangalore also found that due to the fear of stigma and discrimination, people living with HIV/AIDS were discouraged from being open about their sero-status (UNAIDS, 2000). This was true as reaction of the family members when disclosed their status were mostly shocked,

dejected and abandoned by their in-laws (Ogunjuyigbe, P.O. et al., 2009) which is also the finding of this present study.

The most common reason for non disclosure of many HIV infected individuals was fear of rejection and the stigma associated with AIDS. In a focus group discussion the respondents in the present study shared about the experience of lack of support systems, stress, suicidal thoughts, and concerns for their children. The focus group participants described other manifestations of discrimination that includes being isolated and forced to use separate kitchen utensils, and keeping to their own room. Similar findings have also been found in other studies (Roura, M., et al., 2009; Cloete, A. et al., 2010; UNAIDS, 2001).

The situation in her in-laws' household was indeed physically and emotionally abusive. They did not feel welcome in their in-laws' homes, because of their HIV status. They lacked individual economic autonomy when they lived with their in-laws. And though they came back and stayed in their parents' house they lived alone as they do not want being a burden to their parents or siblings and bring shame to the house. The similar result is found in the study conducted amongst the HIV positive AIDS widows in Vietnam (Oosterhoff, P. et al., 2010).

Among those widows who disclosed their status expressed that they have no regret for disclosing their status to the family. The same result can be found in study conducted on psychosocial impact of disclosure of HIV sero-status and also in a study that identified the needs by poor women with HIV (Titilope, A.A. et al., 2011; Bunting, S. M. et al., 1999). It may be because the widows felt that by disclosing their status they may get the economic support for them as well as for their children. As found in other study of Mayfield Arnold, E. et al., 2001) the participants reported that the main reason for continuing to be open about their HIV status was the support they received in the HIV organizations.

#### **8.1.5 Patients with ART treatment:**

Most of the widows were on ART at the time of study. Respondents reported having stopped medications was revealed from the present study. The reason being side effects which induce them in discontinuing the ART drugs (Sarna, A. et al., 2008). These side-effects were swollen face, and nausea. This side effect was common as study conducted by (Hardon, A. P. et al., 2007) also states that the most frequently mentioned side effects by ARV users were body rash, swollen legs, nausea, headache, increased heart rate, diarrhoea and vomiting. A few of the respondents even took ART without the consultation of the doctor. Similar finding can be found in a study conducted among patients on treatment in Ho Chi Minh City (Trinh T. Tony et al 2011). Thirty percent had prior ART exposure not under the supervision of a Ministry of

Health monitored site. Prior unmonitored ART exposure was shown to be a major risk aspect for treatment failure in the study. Patients in developing countries with a history of unmonitored ART usage are at risk of improper administration of medications as well as exposure to substandard or counterfeit drugs. If not look upon properly these patients will be at risk not only for harmful side effects but also for the development of HIV drug resistance.

#### **8.1.6 Utilization of health services and Support groups:**

Many of the widows lack in getting social support. Thereby for single mothers it becomes vulnerable since they lacked the support. HIV positive African women in London have also reported about missing support from kinship network (Doyal, L., & Anderson, J., 2005).

However it terms of getting support some respondents received from their maternal families. This support and care were shown to them by their maternal families. This finding is no different with the study conducted among the people living with HIV/AIDS in Ho Chi Minh City, Vietnam (Thi, M. D. A. et al., 2008) where HIV infected widows received support from their maternal families. Very few of the respondents in the present study were also fortunate to be taken care by their friends which can be also be seen in studies conducted on HIV/AIDS and care families. (Burgoyne & Saunders, 2000; Johnston, D.,1995).

Unlike the study that has been conducted in Outpatient Clinic in Birmingham, Alabama (Krawczyk, C.S.et al., 2006), there was no indication in the present study that specific sources and forms of social support had differential influences on the utilization of health services and better perceived over health and that it improved the immune function (Namir, S. et al., 1989). Researchers incorporating specific providers of social support (e.g., family, friends, partner) have reported that family members are not viewed as particularly helpful to HIV-positive persons (Hough, E.S.et al., 2005). But persons absent of social relationships or social support have been shown to be more likely to visit the health-care systems (Kouzis, A. C., & Eaton, W. W. (1998) which supports the present study.

The result of the present study also found indirect association with the utilization of services and support system. The same result is found in a study to identify the factors that lead people to visit a doctor in Brazil (Sassi, R.M.et al., 2003). Individual's social and psychological characteristics can affect health services utilization, but neither social support nor family dysfunction was associated to the outcome.

Due to the lack of support either from the maternal or their in-laws all the widows has looked for some kind of support in HIV/AIDS organizations. The meetings in the support groups created a feeling of togetherness. The previous feeling of fear that the HIV diagnosis could

involuntarily be acknowledged by friends or associates changed to a feeling of togetherness where the participants perceived that all the persons at the organization had HIV in common.

Having HIV network was the noble endeavour that was adopted by all the HIV positive widows in this study. The widows exercised their personal agency by joining their HIV networks. This network were useful both socially and economically. They sought psychological and economic support from these networks. These network were also important in providing financial resources to enable widows to support the purchase of necessities such as food and other essential needs. The focus group discussion reveal the network as a source of influence for the widows to survive and take care of their children even if she moved from her nuptial home to her natal home. Flora.K, et al., 2010 also found the benefits of social networking in which it states that network strengthen the cohesion of women and they are the best platform for women to solve widowhood and AIDS related problems.

#### **8.1.7 Utilization of health services and socio demographic characteristic:**

Utilization of health care services is of paramount importance. It affects the well-being of the widows living with HIV/AIDS as well as her family. In a study by (Aslan,D.,et al., 2006) it was revealed that the level of knowledge regarding health and the cultural background of the participants may direct the utilization behaviour. The result of this study however turn out to be contradictory with other studies (Arcury, A. T.,et al., 2005) where predisposing factors is found significant with the health service utilization,

A study conducted in Netherland (Droomers &Westert, 2004) show that the lower socioeconomic groups utilize more health services because of their frequent illnesses. The study examines the effect of socioeconomic differences in co morbidity on the association between socioeconomic status and multiple use of health service.

However the present study found no significance with the socio demographic characteristic with the health seeking behaviour. The result was supported with a study conducted in Bangladesh on health seeking behaviour in which no significance was found between the age group and health seeking behaviour of the respondents (Ahmed, S.M. et al., 2005). The same can be seen in study of Primary Care Treatment Needs and Experiences among the HIV/AIDS individuals in Florida (Fontana, L. & Beckerman, A. 2007). Similar trend was found in a quantitative study conducted in Kahe ward of Kilimanjaro region, northern Tanzania in which no significant differences between the proportions of respondents that

pertained to the different demographic variables with regard to utilization of the different health services (Kisanga, F.S. et al., 2004).

A case study conducted in Thailand (Jian,H & Chai,P. 2008) reported ethnicity not being as an important factor for utilization of health care services. The study also does not support the finding of the other study in which the level of education play an important role in seeking HIV/AIDS health services (Fontana, L. & Beckerman, A. 2007). The study results are inconclusive with respect to the influence of other predisposing and enabling factors. In the same way multivariate logistic regression estimates do not show any significant impact of these factors on the use of health care services in this study. The result is comparable with the finding of the study in Ethiopia on maternal health seeking behaviour (Ethiopian Society of Population Studies, 2005).

The enabling resources may also have an insignificant effect on the use of health service utilization. This result had been confirmed with other study conducted on accessing of health services in urban areas, in Ghana (Fosu, G.B. 1989). It was found in the study that none of the enabling variables had any significant effect on the use of health services at either the household or the respondent level. But those who know the location of the nearest health centres are more likely to use the services than those who are not aware of the health centres.

Availability of a health services and transportation facilities in the village, played important roles in improving health service utilization. Respondents who lived in the village with a health centre and public bus routes linking with the outside were significantly more likely to utilize health care services than respondents who lived in the villages without these facilities (Hu. J, and Podhisita C, 2008).

Our results show that women living in urban areas are more likely to deliver in a health facility rather than at home without assistance. Urban areas typically have better access and availability of health facilities (Jayaraman, A. et al., 2008). The study supports the result with the study of (Janjua, N.Z. et al., 2006) that there is lack of facilities in rural areas that made the doctors tend to stay in urban areas. This lack of facilities made the widows to go to the urban health centres to receive the health amenities.

#### **8.1.8 Differential utilization of Public and Private Health Services:**

Every individual have different choices in utilizing the health services when felt sick and have their own reason of using those particular services, be it government or private health centre, traditional or self treatment. And hence it is imperative to know the dynamics and interactions

that make a person decide why, when and where to seek services and which health service facility to attend.

In terms of treatment, allopathic has been the most commonly reported choice of healthcare sought by women in the present study sample. The study is same with the study of (Durr-E-Nayab, 2005) where in Pakistan many of the women reporting symptoms of reproductive tract infections preferred allopathic over other kind of treatment. The respondents of the present expressed strong faith in medical science, agreeing that a doctor is more knowledgeable on health matters than the traditional healers. Professing confidence in the knowledge and expertise of medical doctors, most of the respondents usually consulted a doctor at the first sign of illness.

The preference for health services varies according to purpose and situation. When the respondents have opportunistic infection and short-term illnesses, they visit health service centres due to their familiarity with the doctors. However, if they are suffering from a major illness and need hospitalization, they seek treatment from an experienced specialist in big health centres. On the whole, a large number of respondents prefer to seek treatment offered by the NGO centres as they are familiar with the doctors and feel comfortable to share their concerns.

However, some respondents resorted to self- medication rather than consulting a health professional. The same result is found in health-seeking behaviour of urban poor communities in Philippines (Malanyaon, & Conception, 1995). The majority of the patients who reported being ill chose doctors or drug sellers as their first line of care. Reasons behind the choice of the first health service provider were good quality care, proximity to home and good behaviour of service provider. The finding supports the study on the health seeking behaviour in Chakaria, Bangladesh (FHS, 2008).

Modern Government health services were used by many participants in this present study. This higher utilization of government health service indicates the importance of the government health sector in delivering health services for the PLWHA. A lower proportion of people utilizing services offered by the private sector may be due to the incapability of private sector hospitals and dispensaries to meet consumer needs in terms of the treatment related to PLWHA. The increased in utilization with government sector may be due to perceived better eminence of care provided by them in comparison to private sector. The result was contradictory to other studies in which private health services were mostly used (Fonck, K., et al., 2001; Janjua, N.Z. et al., 2006).



Like other studies (Kisanga, F.S. et al., 2004; Aslan, D. et al., 2006) respondents in this study sought mostly from modern health care especially government health facilities. In terms of HIV testing all the respondents in the study had their HIV testing in the government hospitals.

This finding was supported by study conducted by UNAIDS 2009 among the four states in India. Among respondents who were tested for HIV, however, close to or over 50 percent received the test from a private for-profit or private non-profit provider in all states except Manipur. The public sector turned out to be the leading source of HIV testing in Manipur (70 percent of men and 75 percent of women), and the private for-profit sector thus provided a much smaller overall proportion of testing. This may be because the facilities that the patient received in the government health sector in Manipur maybe better in terms of HIV/AIDS testing.

The same has been reported in a study by Demographic Health Survey from 12 countries reported that majority of people received HIV testing in public facilities (Wang et al for USAIDS 2010, Mazzilli, C. and Davis , 2009). Patients reported that they went to government health facilities because of qualified skilled staff, and affordable services (Kiguli, J.et al., 2009). It was said that convenience or nearness of the facility location. In a study by (Aslan D et al 2006) women reported visiting state hospitals most frequently followed by visiting private health services and primary health care institutions.

A study on health seeking behaviour and access to treatment conducted in Johannesburg reported the use of public health facilities compared to the private health facilities which agree with the finding of the present study. A small proportion of the respondents sought treatment, care, and advice from traditional healers and private health-care facilities (Population Council, 2009).

We also found that traditional medicine had only a marginal role in the health seeking behaviour of the widows living with HIV/AIDS in Manipur. The predominance of preventable diseases may partly explain the low use of traditional healers, because many people now are generally aware of the efficacy of modern medicine in treating acute illnesses (Fosu, G.B. 1989).

Self medication which was relatively common among the respondents has been associated with pain of all kinds. The treatment were done in patent medicine stores chemists and traditional treatment homes as it is far cheaper or perhaps as they often felt sick they now what all medicines they have to take. The use of pharmacies points to some element of self-medication (Durr-E-Nayab 2005, Akinawo E.O. & Oguntimehin F. 1997).

Similarly with a study by (Diop, F., et al., 1998) the prevalence of self-medication does not vary much by demographic characteristics of the individual or the socioeconomic characteristics. Although self treatment is an important alternative and supplement to formal health care, it is important to look into the matter that health care decision taken by sick individuals are safe and appropriate (Ahmed, et al., 2005).

But it cannot be denied that private health centre was also used for different purposes by many. The use of private health sector for HIV testing and STI care among the wealthy patients were found also in studies (Ramchandani, S. R. et al., 2007). A study in Zambia found majority of patients visiting government urban health centres for STDs had already received some treatment, mostly from private clinics (Faxelid et al. 1998). The possible cause maybe its stigmatizing nature of the disease people living with HIV/AIDS must have perceived that the private sector provides more convenient, accessible and confidential care to them comparatively to government health sector (Walker, D. et al., 2001).

They visited the private sector mainly for its assumed high quality of care, and they visited the informal sector because they were advised or taken by somebody who had good experience with a certain provider. On the other hand those receiving medical services at public clinics perceive them as having longer waiting times and more limited access than a private care centres. Other reason was the negative attitudes of health workers towards patients (Kiguli, J. et al., 2009).

The study result substantiate the finding of other study (Gangoli, 2002) in which it was found that the reason of choosing the private health centres was that state run hospitals though cheaper with better treatment, the doctors in the government hospitals are often impolite and unsupportive. Private doctors take time off to explain the illness to the women and talk to them politely. The patients also went more often to chemist, traditional healers, private hospitals and mission hospital (Fonck, K. et al., 2001).

It was reported that in most of the countries, utilization of the private sector increased with wealth, although a substantial proportion of women from the poorest households sought care from the private sector (Wang, W. et al., 2010). The result is contradictory with the present finding of the study in which majority seek services in government than in private health centres.

Thus the perception of limited access and long waits and travel times may compromise the patients' use of medical services (Voeten, H.A. et al. 2004).

### **8.1.9 Reasons for delay/ not seeking treatment:**

The pattern of health seeking behaviour in this study was conditioned by the present economic conditions, distances to the health facilities and perception of the health services providers. The decision to seek health services depended on the type of illness suffered. Majority of the respondents in the study delayed in seeking health services. Frequently reported symptoms such as fever ,headache, body pain might have been underestimated mainly because of not taking the symptoms seriously, distance, lack of time, and financial difficulties to name a few.

Other factors affecting the quality of services delivered by health facilities includes poor attitude of the health workers. Quality was viewed as an important influence on utilization of services. Respondents mentioned that everybody would have liked to seek health services from facilities where there was proper medical treatment, with drugs, and adequate health staff. The results of the study show that user perceptions and definitions of the quality of health services depend on a number of factors related to technical competence, accessibility to services, interpersonal relations and presence of adequate drugs, supplies, staff and facility amenities. Patient satisfaction is one of the factors that influence whether a person seeks medical advice, complies with treatments and maintains a relationship with the provider or health facility. The same finding can be seen in (Kiguli.J. et al., 2009) in community's perspectives and perceptions on quality of health care delivery in two Uganda districts.

Barriers to care include difficulty in scheduling appointments around family commitments and clinic hours, and disrespectful treatment by office staff and providers themselves. The study group mentioned being treated badly by some of their providers and office staff, which made them reluctant to return. Similar finding is found in the study that explores health care needs and perceived barriers in obtaining health care among the women and children in United States (Johnson, MO. 2001).

Many widows in the study delayed in seeking the treatment as they considered their illness to be not sufficient enough to seek the health services. The finding supports the study in Rawalpindi (Durr-E-Nayab, 2005) in which many women do not feel the need to seek help because they consider that, it is a normal thing to occur to them. The seriousness and severity with which a symptom was perceived was reflected in the decision to seek health services. Some of the widows decision to seek help depends upon the severity of the disease. Whether a symptom is perceived as a cause of concern or not by the widows is significantly associated with the decision to seek help, with those getting more worried about the symptom more likely to seek treatment, for all the symptoms.

Lack of time another reason for not seeking help implies lack of importance given by women to the symptoms of any kind. Time could be found if a thing is deemed important enough to give attention upon. The reason must be due to their frequent ill health that leads the widows to ignore their health. In the present study, the widows were predominantly daily wage earners with meagre income. So the affected activity tended to be carrying out of household chore instead of going and seeking the health services. Lack of resources to access any health service and taking the symptom as something common, not needing attention, are the two main reasons for not seeking help. The choice of the health-provider consulted for a symptom is linked to the perceived cause of the symptom.

It was reported that the reason for not visiting any health institution at the time of their illness was because they felt that the disease did not require any treatment, symptoms had disappeared, and insufficient money to consult a health service provider. Similar result was also supported by other studies (Aslan, D, et al., 2006; Voeten, H.A. et al., 2004)

A focus group conducted on health seeking behaviours in Gambia reveal financial reason is the greatest barriers to seek care. Accessing the finances to pay for treatment was a major consideration. Another frequent problem was that of distance to health-centre services and lack of transport to access those facilities available (Miles, K. et al., 2001). With no social support they depend upon themselves or to their maternal family for money in terms of illness and hence lack of financial resources plays an important role in delaying the treatment.

In Botswana, programme managers reported that people often sought services only when they could no longer hide their symptoms. By then, they were desperately ill, well beyond the optimal stage for drug intervention (Skinner, D. 2002. A study on health seeking behaviour and perceptions regarding quality of health care services in Agra also confirm that people approach health services only when there is no improvement or if the problem aggravates (M Jain, et al 2006). Perceived need is frequently viewed as being necessary but not adequate for entry into care as also confirm in as confirm by finding of (Leaf, P. J. et al., 1988) as numerous numbers of factors become a concern for utilizing the health services.

Various reasons that researchers like Fonck K et al., 2001 describe were lack of knowledge about the importance of seeking prompt medical care and lack of available services which uphold the result of our study. Inconvenience of the location becomes a serious concern. The greatest barriers for positives involved transportation, cost, and fear of being seen at an STD clinic. Other difficulty included in this region were lack of program or information availability, organization unhelpful, lack of knowledge of referrals, and fears of stigma and discrimination which was supported by other study (California State University, 2006).

The unique characteristics including perceived need, geographic distance and lack of transportation isolate women from health services (Vyavaharkar, et al., 2008). A study conducted by (Aslan, D et al., 2006) on factors influencing utilization of health services by women in Turkey found the same result that frequently reported symptoms such as fatigue and headache might have been underestimated due to lack of awareness, and this might have caused a decrease in women seeking the health services. For instance due to the illness common cough or cold was considered normal by the respondents. Even tiredness which was a very common symptom and often believe to be normal characteristic of HIV illness became a serious illness to some respondents. The perception that treatment was not necessary or that the condition was not serious (Koenig, M.A. et al., 2007) lead many respondents of our study in delaying the treatment.

Respondents cited several barriers in locating and accessing resources including lack of transportation, stigma and discrimination. Some of the women identified lack of transportation as a major barrier to accessing much needed services. This qualitative study by (Vyavaharkar et al., 2008) explored perceptions and experiences of HIV-positive rural African American women. The discussion revealed inadequacies, poor quality, and gaps in the services. The major issues that emerged were: unsatisfactory medical services, lack of patient-provider communication and lack of coordination and collaboration between different providers, services and programs

On the other, identified factors which may hinder the health care facilities services establishment and implementation include the people's crisis-orientation toward health, misconceptions about rational health care, lack of confidence in health facilities and personnel, lack of technical skills and capability of the people, lack of regular source of income and poor living conditions (Malanyaon & Conception, 1995). Delays in seeking appropriate care, difficulties in physically accessing services, have been noted as the three crucial barriers that inhibit access to healthcare services. (USAID, 2009)

The focus group discussion done on the barrier to voluntary HIV counselling result in South Africa (Meiberg, A. E. et al., 2008) reveal clearly that HIV/AIDS is still an epidemic of ignorance, fear and denial. Respondents indicated that PLWHA are victims of huge discrimination and experience social isolation. Furthermore, participants reported that they do not want to be seen as friend or relative of somebody with AIDS, because they fear to become stigmatized themselves. Participants were afraid to become rejected by family members after disclosure of their sero-status.

Most of the respondents in the present study reported that they were satisfied with the services provided by the health service providers. Indeed, the responses ranged mostly between improved condition and full recovery. A few of them, however, reported that they were dissatisfied with the service provided by the health care providers. Dissatisfaction among the patients is also found in an exploratory study (Akinlawo E.O. & Oguntimehin F. 1997) conducted in southwest Nigeria. Dissatisfaction was mainly due to the unfriendly behaviour of the health service providers and also because their illness or symptoms was improving at all.

The finding uphold the study conducted by Nolan, R. L., et al., 1967 in which it was found that availability of appointments with the health service professional could be an element in utilization. The result advocates that expansion of appointment hours is an empiric method available to produce more effectual use of preventive services.

#### **8.1.10 Stigma and Discrimination in health centres:**

As found in other studies (UNAIDS 2000; Synergy 2005; H. Banteyega et al., 2004) the widows living with HIV/AIDS in our study come across with differential forms of stigma and discrimination that includes isolating HIV-positive patients, extra precaution, verbal abuse, gossiping, disclosing HIV status without consent, differential treatment, neglecting and denied of health services. There is denial in treatment as soon as they come to know about their HIV status.

Fear of contagion was the most common barrier which prevented doctors from treating HIV infected patients. These fears were expressed not only in respect of surgical procedures, but some doctors were afraid of even droplets from sneezing and shaking hands with the respondents. This must be because of lack of training, lack of adequate medical knowledge, and lack of experience in treating HIV infected patients as the main reason for not wanting to treat HIV-infected patients. The result confirmed the finding of (Naidoo P, 2006).

The widows had a fear of being identified by their known people while accessing care at the treatment centre. The finding upholds the studies conducted among the HIV patients in Kerala and in Los Angeles by (Thimothy, R. et al., 2006; Sayles, JN. et al., 2007)

Thus stigma and discrimination may also compel people to conceal medicines, which may result in inconsistent doses (DFID 2007). A study (Mahendra et al., 2006) in three hospitals in New Delhi reported the same common manifestations of stigma and discrimination by people living with HIV/AIDS and health service workers. Some of the respondents in the present study reported some type of segregation and isolation of patients because of their HIV status.

In one of the hospitals it was reported that HIV-positive patients were placed outside the ward away from other patients or given a corner bed that was placed at a noticeable distance from other beds in the ward.

However, in practice ward staff and non treating staff who did not need to know that a patient was HIV-positive for any clinical reason were also often informed of the patient's status. Usually, doctors informed their peers as well as nurses and ward staff in their department about the patient's HIV status so that they could take "adequate precautions" to protect themselves while treating or handling the patient. Similarly, the nurses and ward staff reported informing their peers in the hospital. Hospital staff took inadequate precautions with the general patient population and excessive precautions with patients they thought to be HIV-positive.

Issues relating to confidentiality in health settings, disclosure of HIV status without consent, and provision of information remain a challenge for people living with HIV in the UK. HIV-related stigma is one of the primary hurdles in addressing prevention and care issues and creates a stumbling block in ensuring access to essential services (PLWHIV, 2009 UK).

Respondents in a study in Vietnam (Thi, M. D. A. et al., 2008) reported that discrimination from nurses and orderlies was more common than from physicians. Lack of adequate knowledge about HIV and fear of contracting HIV may contribute to the way these health care workers treated PLHIV. However, respondents also reported abusive behaviour from physicians. Some participants felt that there was a recent reduction in discriminatory attitudes and behaviour in the health care sector. Experiences related to discrimination seemed to be occurring less frequently, and health care providers in HIV clinics in particular were noted to treat patients with more respect. Some respondents reported avoiding health care services due to past experiences of discrimination in health facilities. Many noted that they would only seek health care for extremely severe conditions. The fact that discrimination was encountered more often from nurses and orderlies than from physicians supports a conclusion that lack of training and poor knowledge underlie the poor treatment that many PLHIV experience in health care settings.

Substandard medical care and an atmosphere of stigmatization led some PLHIV to avoid health care facilities altogether. Confidentiality is also frequently breached by hospital staffs who disclose HIV test results to other staff not involved in the care and to family members or friends accompanying the patient. A strong guarantee of confidentiality of HIV/AIDS-related information thus became the central component of successful HIV/AIDS programs (MacNaughton, 2004). The finding of these studies was supported by our study as many felt

that the discrimination is prevalent among the health service providers especially for the nurses and the confidentiality being shared among the staff without their consent.

But on the other hand it cannot be denied that there was also certain section of widows who never experiences stigma in the health setting. A significant proportion of the respondents agreed that health services are also easily available. This could have been generated by the strong awareness campaigns conducted by the NGOs and the creation of a lawyer's collective forum for the rights of the PLWHA. The latter deals only with the problems or issues related to them and try to resolve these. The service providers are conscious that any untoward incidents that occur can be reported to the NGOs. The organization can take suitable action against the health service providers. This legal service provided for the PLWHA has empowered the HIV/AIDs victims to demand for their rights. Without the influence of the NGOs, the situation could have been different.

## **8.2 Conclusion**

HIV/AIDS becomes the major public health problem and women/widows are the most vulnerable group to get infected with the disease. AIDS has created a generation of relatively young and middle age widows. A number of factors such as economic status, occupation and education have a great influence on the utilization of health services and affect the access to health service facilities. There are very few studies conducted among the widows living with HIV/AIDS in India and none focuses on their utilization pattern of health services and health related aspects. The review of literature reveals the differential utilization and the reason for seeking the health services. The possible reasons for different patterns can be observed due to their availability and accessibility, population differences that could influence the health seeking behaviour, and possible barriers such as discrimination. Deliberate impediment or discrimination has been observed. It also describes the various reasons for not seeking the health services by individuals in spite of their illnesses. Patients' beliefs, values, and previous experiences with health care services, as well as demographic factors, influence the level and type of care they seek and receive. Reimbursement policies and procedures, coordination of sectors of the service delivery system, attitudes among providers towards patients, and referral and access patterns to specialized care, all affect receipt of health care by patients (L. Fontana & A.Beckerman et al;2007). The chapter summarizes the data to bring out the various aspects of utilization pattern and also the major obstacles faced by widows in utilizing the health facilities.

This section identifies some of the key findings that impact on the utilization of health services by the HIV infected widows and draws conclusions to deal with these issues.



### **8.2.1 Dealing with Stigma and Discrimination:**

The study revealed that once the family came to know about the status of these widows the manifestations of stigma and discrimination ranged from isolating behaviour to hostile words. Counselling for family members of these widows could help them to better understand HIV infection, besides training being given to them could improve their homecare skills while minimizing the risk of transmission. And due to stigma and discrimination there were still people who wish not to disclose their status to anyone. In some way they are affected by both enacted and internal stigma related to HIV/AIDS. This internalized stigma leads to withdrawal, depression, unwillingness to disclose the HIV status and also affects their health-seeking behavior. However, it was found out in the in-depth interview that some of the participants who were well informed and those who were members of the support groups reported that they were coping with the illness and were open about their HIV-status. It can be said that this catastrophe of HIV/AIDS is not only the problem of HIV/AIDS-infected people themselves, but also the problem of their families and their communities. Their families are responsible for bringing them to this stage of hardship. A system of social networks and social support can enhance an individual's ability to access new contacts and information and to identify and solve problems. If the support provided helps to reduce uncertainty and unpredictability or helps to produce desired outcomes, then a sense of personal control over specific situations and life domains will be enhanced. People's social network linkages may help them interpret events or problems in a more positive and constructive light (Thoits 1995 in Glanz K, et al., 2002). Several researchers have argued that the lack of support from friends, family and the community reduces disclosure and produces more rejection and discrimination which ultimately increase emotional distress experienced by those who are HIV positive (Bond et al., 2002; Niang et al., 2003).

### **8.2.2 Breaking Economic and Geographical Barriers:**

When HIV enters a home, financial responsibilities and burdens also increase. It is a fact that widows who have never worked outside their homes throughout their lives, have to enter the workforce for the first time and are in a disadvantaged position. Moreover, they had to take care of their health. Also since a large number were staying independently with their children, it was difficult for them to make both ends meet. Testimony from the widows' life histories and focus group discussions provide clear evidence of the hardship faced by these women. It is therefore important to implement programmes and policies to strengthen their economic condition, for instance, by providing information and training regarding income generation. Thus special programmes through a comprehensive package that includes shelter, economic

support through income generating activities, and health care facilities programmes should be set up.

The finding showed that the level of perception of the need for health services differ from individual to individual. There is a lack of awareness in some respondents and so they do not perceive the symptoms to be important for seeking treatment. And though they are aware, financial difficulties, lack of time and distance became barriers to access the services. Financial problems continue to prove a major constraint for both in the urban and rural areas.

These become a factor responsible for not utilizing the existing health facilities by widows in the study. The need of money for transportation becomes a concern for many of the widows. Transport issues play a much stronger role in rural areas than in more urban setting – people on low incomes who do not have access to their own transport are much more likely to find it difficult to access services. Shortage of infrastructure still persists in rural areas affecting all classes. Adequate resources need to be allocated for expanding the network of public health facilities in rural areas (Mukherjee, A.N & Karmakar, K. 2008). The infrastructure should be created keeping in mind the actual needs of the widows by setting up new health centres and also strengthening the existing ones. Proper equipment with health professionals should be available. It was observed that many health centres do not have permanent doctors. The doctors who were there visited only for few hours. Improvements in physical and infrastructure resources, financial resources, technical resources, and support services may all have a tremendous impact on improving patient care. Upgrading the skills and expanding the numbers of trained health providers and caregivers will also make a tremendous contribution to allow a given community to provide better care and improve the quality of life of infected individuals (Mazin, R.2001).

### **8.2.3 Improving Health Care Delivery and Increasing Utilization:**

In-depth interview ART patients' health-seeking behaviour identified factors affecting sustained attendance at treatment clinics. Almost all study participants suggested that the service should be brought closer to the clients. As ART has still not reached in some parts of the areas in Manipur, it will also be necessary to accelerate the decentralization of ART to improve access to treatment in the rural areas and particularly in the peripheral regions and zones, and to improve the treatment and care environment (Kloos, H.et al., 2007). Free HIV treatment must be made more widely accessible, and people must know about it.

Ideally, care for people with AIDS should start with voluntary counselling and HIV testing. And this care includes psychological, social, and economic support as well as broad- based

medical care incorporating nutritional advice, prevention and treatment of opportunistic infections, and palliative care (Furber ,AS et al., 2004).

But it was also found out in this study that no counselling had been given to those who were going to initiate the ART. It is necessary that the provision of pre- and post- counselling be carried out in an appropriate manner. This pre- and post-test counselling thus will prepare the groundwork for making use of the results in a proactive manner which includes correction of misconceptions, exploration of sources of potential social support, adherence to treatment protocols, and, most importantly, the introduction of a positive framework for coping with HIV(IJSW, 2005).

The utilization of health services depends on the availability of quality of health services and on the ability of people to utilize the health services effectively. Further there are also a few who are not aware of the services being provided for them. To make use of a health service, an individual must know where this service is located. Thus an appropriate health service infrastructure is the need of the hour. The knowledge factor is key to the availability concept, since lack of knowledge about the existence of a service will lead to the underutilization of the services.

The study shows that not all the health needs are perceived to be important to seek health services as it also depends upon the severity of the disease. The study also provides insights into why some people opt out of certain services, why people are late in attending services and why some levels of health facilities are bypassed by intended users. These behaviours should be taken into account in organizing the provision of health care, thereby responding to demand side considerations to maximize utilization and utility of health services to the people (Mazzilli, C. and Davis , no date).

Other important finding of the study is that self treatment has been used by many of the respondents for the purpose of minor ailments so there is a need to make them understand the use and misuse of self medication. In many of the places medicines of every type are usually available from drug vendors without medical prescription. And people use such medicines for self-treatment. As the drugstores were easily accessible it becomes handy for many to go and purchase the medicine for their illness. In order to make self treatment safe, measures are needed to increase health related knowledge and skills to facilitate decision making about whether self treatment is indicated and if so which therapeutic regimen is appropriate. (Ahmed, et al., 2005). It is essential that drug store be aware of health issues faced by the patients. Basic pharmaceutical training should be made available and regulatory measures should be introduced to control the use of potentially dangerous drugs.

Increased basic knowledge about patients' rationale for choosing a particular service could provide measures of the extent to which the existing complementary health care resources need adjustments to bring them closer to achieving the desired objectives (Rabiel. B, 1989). The overall utilization of health services turns out to be that of public health centres. The variability of the probability of choosing a government hospital, however, is relatively high. This is because most of the HIV treatments were conducted in government hospitals rather than in private health centres. However due to several reasons people went and utilized the services being provided by the private health sectors. The private health service providers may play a role in increasing access to essential HIV prevention, care, and treatment services through partnerships with governments and donors. Such partnerships may relieve current bottlenecks resulting from infrastructure and human resource constraints in the public sector and may help countries reach the ambitious goal of universal access to HIV services (Wang et al., 2010).

Importance of doctor- patient relationships in accessing care is found from the study. The probability of visits to health centres, however, is influenced mostly by known doctors. In this way they can share their problems without any hesitation. The others were distance, good doctors, specialized treatment and less stigmatization. What we need for HIV care is a change in our outlook and updating of our understanding of the healthcare delivery system. The isolated development of HIV care should be avoided and it should be integrated with the larger development of the healthcare system.

A conclusion is that the utilization of health services is rationed according to patients' health status and familiarity of the health professional. On the other hand, the utilization of pharmacies and drug stores is to a large extent influenced by easy accessibility and thus functions as an alternative to general practice.

The study also highlights the weaknesses regarding the planning, financing and evaluation in providing effective support for widows living with HIV/AIDS. It is necessary to take into consideration all these factors and deliver a comprehensive health service system that will enable the widows to use the facilities to the maximum. While taking the necessary steps for the improvement of the health services- government officials, social workers, counsellors and members of HIV positive persons' networks should be incorporated in a formal structure of the programme for its accountability between the medical providers and the patients.

The non - governmental organizations have become one of the essential resources for widows living with HIV/AIDS. Their capacity to reach the infected individuals in all possible ways has made them very popular among the people living with HIV/AIDS. Hence, necessary care

should be taken in terms of promotional (in terms of health services and awareness) and rehabilitative actions that should be undertaken by the government. There is a need to extend support and encouragement for the widows living with HIV/AIDS so that they can come out openly and educate the masses. Significant steps must be taken to make health care accessible to all. There is a need for government to allocate more funds for medicine and supplies so that the patients will be benefited a lot. More facilities should be created so that unnecessary delay and heavy rush can be avoided.

Making the health services available is not enough for the proper utilization of the services but a proper monitoring and evaluation should be created to ensure quality of services rendered. Thus, health system performance monitoring requires an understanding of the characteristics of individuals who use care, as well as the profiles of those with unmet needs (Watson et al 2004). Further coordinated efforts should be made, on the part of the government and other concerned bodies at all levels, to get better utilization of health care services. A collaborative approach involving public health professionals, academicians, NGOs and the government can contribute to the better utilization of the health services.

### **8.3 Recommendation**

It is utmost importance for clients to feel welcomed and valued when attending any kind of health service facilities. Therefore creating an atmosphere which is favourable by all is in maximum need. The researcher attempted how health services can be brought to the level in which it can be accessible by all the widows living with HIV/AIDS.

In order to reach out to all the PLWHA it is necessary to introduce health centres in every nook and corner of the country. A field investigation should be conducted to see the geographical convenience of the population. It should be established in an area where it could provide maximum coverage and accessibility.

Provision to look into the matter of the transport facilities for in case if the illness could not be treated in the particular health centre especially in the rural areas. Besides appointment of the village health workers is very important to carry out the emergency service.

Improvement of quality of health care service should not only focus on infrastructure but comprise provision of essential drugs and adequate numbers of motivated health workers as well.

Multiple needs must be addressed simultaneously and create efficiencies in delivering services. There is a need to increase opportunities that will identify unrealized needs and reach more people with more services.

Provision of appropriate information about HIV/AIDS should be taught to all the health professional as well as among the communities. Necessary to raise awareness at all levels through advocacy and social mobilization.

Health service providers should organized in an interactive forum by a trained facilitator. Program should be done by combining both the health service provider and People living with HIV/AIDS. People with HIV and AIDS have a central role in stigma reduction at any level of intervention and provide a strong basis on which to build successful programs. Bearing the brunt of stigma, those living with HIV have the life experience and knowledge needed to design and implement appropriate stigma-reduction responses

Ensuring a well functioning public health system at all levels- including functioning laboratories for detection, peripheral hospitals capable of treating patients with common OI, well functioning larger hospitals capable of treating all aspects of AIDS, and well functioning system for health education is an essential prerequisite.

Governments, with support from NGOs and lawyers, should equip health service providers with training in non- discrimination, informed consent, confidentiality, duty to treat, and specific needs so as to ensure that staff within health care settings provide care in a manner that is non-discriminatory and protective of their human rights.

Equipping health workers with the knowledge and skills necessary to protect themselves from occupational transmission of HIV is a key step in addressing fear-based stigma. Empowering of health workers by providing equipment necessary to practice universal precautions- gloves for invasive procedures, sharps containers, adequate water and soap or disinfectant for hand washing, and post-exposure prophylaxis in case of work-related/potential exposure to HIV.

Health workers should be given training in self-protection against, and prevention of HIV transmission occurring during handling of blood, body fluids, organs and tissues.

There should be a monitoring of health worker attitudes and behaviours to assess progress. It is important to set up anti-stigma policies and benchmarks that health facilities can use for assessing their efforts.

Need to develop legal and policy framework that protects the human rights of PLHA and those affected by the epidemic and that helps to mitigate the impact of HIV/AIDS.

The policy makers should invest in long term integrated services to promote the well being of the PLWHA by integrating services that address their social and emotional needs. Policy-makers and programme implementers should link treatment programmes with specific interventions to empower PLWHA to cope with the disclosure of HIV status to a trusted family member or friend as well as to maintain or re-integrate into family and community life while on therapy

Government should form and implement programmes which aim to reduce the HIV stigma and discrimination among health services providers.

Proper and strong monitoring and evaluation in all deliberate actions to eradicate stigma and discrimination is required.

Government must find ways to bring together ministries of NGOs, social welfare, social scientist and work with cooperation to eradicate the stigma and discrimination issue

Future HIV treatment and care programmes should take a broad, holistic approach and consider the financial impact of HIV on the financial well-being of infected individuals and their families. Interventions should be developed to mitigate the financial burden on families with one or more than one HIV-infected individual. Financial planning and financial counselling could also be a part of comprehensive healthcare services to HIV infected individuals and their households.

#### **8.4 Limitation of the study**

These findings may not be generalizable since the study was done in only one state. However the findings give a fair idea about the pattern of health seeking among the widows population. Other community members, such as health service providers and family members of PLHIV, were not included, so the sources of information were limited. Nevertheless, the findings reflect the voices of those who participated, and point to measures that can be taken to decrease stigma and discrimination against PLHIV.

On a more optimistic note, we are encouraged by recent signs of reduction of stigma and discrimination against PLHIV. Furthermore, according to study participants, as more health workers are trained and gain experience in caring for PLHIV, the level of discrimination in health service settings appears to be decreasing. Certain rights of PLHIV are now protected by Vietnamese law. However, stigma and discrimination remain a constant in the lives of widows living with HIV/AIDS, and continuing efforts are needed to ensure that the gains made are reinforced and not lost. Further studies involving larger number of widows from the

rural areas need to be conducted as these may highlight possible differences in attitudes between the rural and urban areas that could not be seen in this study.

### **8.5 Respondents' Suggestion**

In the in-depth interview the respondents were asked about the services they would need or would be interested in having. In this the women identified a list of services including transportation, counselling, specialized medical care programs, peer support programs, financial support, employment, nutrition, medicines, and childcare services especially education and nutrition. Participants identified education as key to addressing the majority of issues associated with HIV disease. The findings clearly document the need for assistance for patients obtaining needed health services, for many did not seek the health services because of the financial constraints. The point that is apparent here is that the financial barrier could only be solved by creating job to the widows living with HIV/AIDS. By saying this it can also be said that utilization pattern of health care is complex, that involves many barriers, and having financial security does not eliminate the problem but also required having a better understanding of the disease. Study participants shared that the availability of low-cost or free antiretroviral medications, along with improved attitudes of health care providers, would decrease discrimination against PLHIV. Another suggestion was to create a centre for HIV-infected or affected children and a centre for people in the last stages of AIDS.

## **Appendix One:**

### **Case Studies of widows living with HIV/AIDS**

Four case studies are presented in this Appendix. These cases were found a little unique by the researcher and therefore selected for the study. The cases explore their history on how they became HIV positive and the struggle they face for their existence to live as Widows Living with HIV/AIDS.

The researcher thought that it would be in line with the purpose of this study to explore the life events of the respondents as it would help in better understanding the trial and tribulation the respondents went through.

#### **Case 1:**

She was 29 years and had studied up to 12<sup>th</sup> standard. She had a four year old daughter and stayed in a rented house. She would earn Rs.700- 800 a month by selling handicrafts items. At the time when she got married she knew that her husband was an IDU (Intravenous drug



user). He had promised her that after marriage he would stop taking drugs. However to her dismay, one day she came to know from his friends that he was still continuing with his old habit. Because of his nature, problems started creeping into their family. After one and half years of their marriage, her husband felt very sick. She was only 25 years at that time. They admitted him in a hospital and after hearing his history the doctors advised them to go for an HIV test. As the result turned out to be positive, the doctors advised her to undergo the same test. She was very depressed when her result also turned out to be positive '*I was feeling very bad as I have a daughter to look after. If I happen to fall sick who is going to look after her?*'. A few weeks later her husband expired. Her in-laws started harassing her. They no longer wanted her to stay in their house. She had become a burden for them. They would often tell her to leave the house. She continued to suffer at the hands of her in-laws, as she did not have a place to go and neither did she want to become a burden for her parents. Her in-laws started isolating her by keeping all her belongings separately and segregating the woman and her child into one room.

One day she started bleeding and needed to be hospitalized. Since she had no one at her aid, she called upon her younger sister and together they went to a hospital. The hospital authority, after learning of her HIV positive status asked her to go and seek treatment in any other hospital under the pretext of not having room for her. It was well past mid-night; at that odd hour she was clueless as to where to go. She and her sister pleaded to the authority to take her in. However after much persuasion the authority finally agreed and gave her a small place near the toilet. She was given saline and kept there for few days. During her stay, no one from the staff treated her well and gave her proper treatment. When asked why she had told the truth, she said that she did so, in order to get proper treatment from the hospital. She further added that however later she had realized that she had committed a big mistake by telling this *bitter truth* (in her own words).

After some days she was discharged from the hospital. At home she had none to cater to her needs. Therefore she had to again call her sister for help. However, her in-laws' behaviour towards her remained unchanged. On the contrary, the situation worsened. They started making her life miserable. At one point, she started thinking seriously to leave her in-laws house forever. And she did so. With her daughter in one hand, and her luggage in another, she left the house and started staying separately in a rented house. She soon joined for a vocational training in NGOs working for the people living with HIV/AIDS. Here they were taught different courses. Trades, for instance, like making bags, tailoring were taught. She was still continuing the course at the organization. She shared that this training helped her in earning her daily bread and in paying her rent. When asked if it was sufficient to run the

household, she said that although it was not sufficient, she felt happy that she could manage to be independent. Her parents would also provide support time to time, whenever needed by her.

She particularly suggested that in order to enhance the health setting, the health professionals needed to be trained more in the field of HIV/AIDS. She felt that there were many who were unaware of this disease. Educating them, as she felt, would enhance the care for the PLWHA thus helping in reducing the stigma and discrimination at the hospital setting

### **Case 2:**

Leaving all her fears behind of being a HIV positive, she is one of those women who openly came out in public to create awareness on HIV/AIDS among the PLWHA as well as among general population at a time when there was a strong stigma and discrimination in the society. She is a tribal girl and was married to a Brahmin boy and is carrying this disease for the past 14 years. She is 41 and has three children. Her youngest daughter was also an HIV positive. She came to know about her status when her husband fell sick. Even after undergoing treatment for a long time, his health was still not improving. The doctor then advised him to go for HIV test. Her husband tested positive hence she was also advised to do the same testing. Upon testing she was also diagnosed as carrying the HIV virus. At this time of diagnosis she was already six months pregnant.

Doctors and nurses all of a sudden started behaving in a very strange way. Moreover they were no longer cooperative with her. They did not want to come near to her husband. Despite being in hospital, his condition worsened further and after few days he died.

After her husband's death, nobody from his family came to help her. They started avoiding her and told her to leave the house so that they could take over her husband's property. But she did not let them do that, and very courageously fought against them. She filed a case and won it. She now has a small piece of land for herself and for her children. In her own words, she said... *'As it is my children's share why should I leave it? So I fought against them. Now I have my own share, a small piece of land, which I will hand over to my children'*.

During all her struggle for her right, she was continuously tortured and threatened by her in-laws. She however kept up her spirit and gave a tough fight to them. She reveals that she was fortunate enough to have her elder brother, who supported her in every possible way. However, as she did not want to be a burden to her natal family, all the time she thought of taking up a job. During that time there were very few NGOs. So she joined COCP (continuum

care and support Program) which is the first NGO working in the field of HIV/AIDS and started earning a bit for her family.

She continued by saying that before she came to this stage, she had to face a lot of problems both from her in-laws as well as from the society. The stigma and discrimination during the nineties were very high. People were afraid to sit and talk with those who were positive and therefore many people did not disclose their status out of fear of being discriminated against. Even her neighbour did not want to interact with her. Her children, most of the time, stayed at home as they did not have friends at all. Even now also, she said, that she observed the health professionals being reluctant in touching the PLWHA. She expressed her disappointment for not being able to support her family. Her eldest son had to drop out of school because she could not support him any longer for his education, which has resulted in his starting to earn at a very young age. Her second daughter has also stopped her education for she was not able to support her. She said she was going to regret this for the rest of her life for not being able to support her children's education. Now, her youngest is the only one who is going to school as she had received support from a catholic educational institution. She stayed there in the hostel for her education. However, she had to be brought back, because she often used to fall sick. And because of her continuous sickness she has now been admitted to a nearby school, not far away from home. It is a fact that most of the time she was worried of her younger daughter as she was waiting to start her second line (ART). She said that her daughter was just three years when she was tested positive.

When asked if the authorities of her new school knew about her daughter's status she said till now they have not disclosed it as they fear that they might rusticate her daughter because of her HIV status.

When asked for suggestion, on what she would like to do to stop the stigma and discrimination in health setting, she said that although the attitude of people towards PLHA have changed a lot, it is still not wiped off fully from the society as well as from the health service setting. She shared an instance, wherein, she was once hospitalized, and the staff there feared to give her injection even after wearing gloves. They provided the care and services reluctantly. Even when her daughter was admitted a few years ago she received the same treatment from the health professionals. However she felt happy to see the change when her daughter was admitted again recently, where she got lot of co-operation from the staff. So she felt that the right kind of awareness about HIV/AIDS has brought this change in the attitude and behaviour of staff. On the other hand she still feels that there is still less awareness among the staff and therefore educating them is very important. At the same time trained counsellors are also very less. She also added that counselling should be done by a

trained counsellor only as most people do not get proper counselling after being diagnosed with HIV. The services of pre and post test counselling for those who go for voluntary blood testing are not adequate. She finds this as very essential for many as people might go in to a depression when they come to know about their status and knowing the right kind of medication and precaution may help future course of action. The health centre is a setting where people come for testing; they should be properly treated, counselled and guided.

### **Case 3:**

She is 38 and has two children. She came to know about her HIV status when her husband was hospitalized. She was not aware of her husband's IDU status when she got married to him. But in spite of getting infected from him, it is quite astonishing that she did not have any regret for getting the disease. In fact she considered it as a precious gift from her husband. She further narrated that while on his dying bed, he told her that he loved her so much and as he does not want her to get re-married, he gave her the infection. Even after her husband's death, she still takes pride in her being HIV positive.

After her husband's death, she had to suffer a lot at her in-laws place. They would beat her almost every day. She narrated an incident where her brother-in-law pulled her by her hair and dragged her outside the house. The in-laws threw away all her belongings outside of the house. They didn't want her to stay with them. Though her parents told her to come back, she did not want to go back as she felt she has the right to stay in her in-laws' house. As the problem occurred frequently in the family, she kept her two children in her natal home and requested them to look after her children whereas she stayed alone with the in-laws. Her son was in 4<sup>th</sup> standard whereas her daughter was in 2<sup>nd</sup> standard. She said *'It is my house and why should I leave it? They want to throw me out of the house as they want to grab my husband's property. I also have a son and he has the right to get his father's share'*.

She heard about the NGOs working for People living with HIV/AIDs and started associating herself in a few of them. She gained a lot of strength and after meeting many people, she felt she was not alone. She became determined to stay back and to fight against her in-laws. Finally, she decided to file a case against her in-laws. She consulted some NGOs and asked for their support. They agreed and consulted the lawyers' collective forum. The case was on for a year and finally she got justice. According to the court order she got a share in her husband's property. For this case she said she did not have to spend anything as everything was arranged by the NGO. She expressed her gratitude towards the NGO and its efforts. She was still working with the NGO. Her in-laws did not change at all though and therefore she did not want her children to be with her. She is afraid that if they are with her they might have

to face the same stigmatization and discrimination from the society. They might also not be able to find friends there which are not so in the village at her parents' place. The children were still with her parents where they go to school. She would visit them once every month.

When asked about her opinion with regard to the improvements in health facilities; she shared that she found the awareness among the health professionals very low. She further said that she had a terrible experience when her husband was hospitalized. The staffs in the hospital did not want to touch him at all. She felt very bad and so she brought him home and took care of him all by herself. This kind of treatment at the health setting from the health staff actually deteriorates the psychological condition of the patients and their families even further.

#### **Case 4:**

She is a Muslim and her age is 32. She had studied till her fifth grade and is a mother of two children. She came to know about her HIV positive status when she was undergoing few tests during her ante-natal care, which included the test for HIV. She was not aware of her husband's HIV positive status though she knew that he was an IDU. Her husband did not disclose anything to her. When she came back just after the delivery of her baby her husband asked for physical intimacy which she declined for she was very weak. She said *'I had just come back after my delivery and was feeling very weak and what he asked was not at all possible'*. She further continued that, her husband went and brought another woman and slept with her in the house. She was completely shocked with this behaviour of her husband.

Her trauma did not end there; her husband threw her out of the house for denying him a sexual favour. He also divorced her on the same ground. She further added that *"I told him at that moment that God will punish him for what he did to me and that happened exactly. He died within a year after this incident"*. She then came back to her parental house but did not want to stay much longer as all her brothers were married having their own families. She did not want to be a burden on them. After a year she started staying in a rented house and tried to earn her living by selling vegetables. Even though it is her elder daughter only who goes to school she found it hard to fulfil all the needs. Seeing all this, some of her friends who were already in the field of flesh trade suggested to her to be a part of their group. Although she did not wish to join them initially, she later changed her decision for the sake of her children.

When asked how much she could earn per day, she replied saying that she could earn Rs. 200-250 per customer, which was better than her earning from selling vegetables for Rs 100 per day. She continued engaging with customers till the day she fell ill. She went to the hospital for the check up where she was diagnosed as being HIV positive. She did not have the

courage to disclose this fact even to her family members. Unable to cope with this, she started visiting NGOs for counselling. They gave her condoms so that she could give them to her customers. They counselled her and made her understand about the condom usage, its advantages and the way to use it. They also informed her about the various STIs and related things. But later she found out that many customers were not willing to use it and as a result she started losing money. Some of them agreed while some did not want to use condoms at all. When asked if the customer ever came to know about her status, she said till then she had not disclosed to them but tried to tell them to use condoms as far as possible.

When asked if she encountered any kind of discrimination in the health setting, she said that she never visited any hospital after her test but whenever she felt sick she would go to the NGO's clinic. And the reason she gave for her preference was that it was nearby and at the same time she felt free in sharing her problems with the doctors at the NGOs.

As far as her present profession was concerned she said that she did not want to continue it anymore. But with no option left she said she will have to continue for some time more till she is able to save some money. She does not have any idea about what she would do if she has to stop this profession as the earning from her vegetable business is very meagre. Though NGOs provide support, sometimes it is/was not sufficient at all. The government also, she complained, does not do anything for them. She felt if the government could provide jobs, then it would be very much beneficial for them.