

CHAPTER-V

SAGA OF HIV POSITIVE WOMEN: AN OVERVIEW

HIV/AIDS has become a global phenomenon which didn't spare any region or community. Primarily it was regarded as a health issue but now it is acknowledged that it is also affecting the psychological, social and economic aspects of PLWHA. It has affected primarily the people who are in their productive age and it led to increase in number of premature deaths which directly affects the socio-economic structure of the families. The disease has bridged the gap from high risk population to general population. The women who are homemakers have been seen more vulnerable to HIV than high risk population. They feel themselves safe in marriage whereas most of WLHA contract HIV from their husbands in monogamous relations with them. It is not easy for the WLHA to live a normal life while infected with HIV/AIDS. Stigma and discrimination attached with AIDS has affects women more than men. They face many challenges once getting infected with the disease i.e. expelled from their homes, fired from jobs, denied health care services, disowned by family and community which compel them to live a poor, isolated and neglected life.

The present study focused on the challenges faced by women living with HIV/AIDS. WLHA belonging to different sections of society and visiting ART center Ludhiana were included in the study. The focus was to understand their problems faced by HIV positive women, the type of support they get from their family members and reactions they get from others after their disclosure of HIV status.

The main objectives of the present study were:-

- To explore the profile of women living with HIV/AIDS in Ludhiana district;
- To highlight the knowledge and level of awareness of WLHA with regard to HIV/AIDS and its prevention;
- To examine the vulnerability of HIV/AIDS and understand the causes of HIV/AIDS among women in Ludhiana district;
- To identify different types of challenges, faced by women living with HIV/AIDS in family, community, healthcare and workplace;
- To identify the coping mechanisms used by women living with HIV/AIDS deal effectively with challenges related to their illness, stigma and discrimination.

For the present study sample was collected from ART centre Civil Hospital in Ludhiana. There are 11 ART Centres in Punjab and these are located in different districts of Punjab. Ludhiana district has third largest number of registered HIV positive patients in Punjab. Women have been neglected in HIV/AIDS research and prevention efforts both in India and abroad. Due to lack of attention to women's health issues, combined with biological differences in the ways HIV affects men and women, social and economic inequities have led not only to a dramatic rise in the number of women living with HIV. Many women are unaware that they are most vulnerable to the disease even when they themselves have not engaged in risky behaviour. HIV-positive women experience greater levels of stigma and discrimination and have less support.

Therefore for the present study HIV positive women in the age group of 15-60 years were selected. Qualitative research method was applied for the data collection and research design was partially exploratory and partially descriptive in nature. Total 67 respondents were interviewed. Thus in the present study qualitative approach has been used as a method of research in order to provide a better in depth understanding of women and girls living with HIV/AIDS in our society.

SUMMARY OF THE RESULTS

Results presented in the five chapters are summarized below.

Chapter-1

In the ‘**first Chapter**’ details about the HIV and its causes, way of transmission etc. was provided. The chapter highlighted the data on WLHA in India and abroad. Why HIV positive women constitute the topic of research has been elaborated. This chapter documented the problem of HIV positive women in India and abroad, while doing so, the extensive review of the literature on WLHA was done. The studies ranged from the topics like profile, their awareness on HIV, challenges they faced and reaction of others which affects their increased vulnerability to HIV. Review also focused on support system of WLHA and how they coped up with the problem. In the present study the theory of stigma and theory of ecology of poverty have been used. Further, methodology adopted to carry out the research, objectives and research questions, locale of the study, sample, tools and techniques of data collection have been discussed. There were total 67 respondents in the present study.

Chapter- 2

The first objective of the present study was to understand the profile of the respondents. Thus ‘**Second Chapter**’ dealt with the socio economic profile of the respondents. The chapter has been divided into three main sections i.e. profile of respondents, profile of the family of the orientation and profile of the family of procreation.

Results show that 29 were in the middle age group i.e. 35-45 years. There were 18 respondents whose age was between 25-35 years. There were nine respondents in the age group of 15-25 years. There were seven respondents in the age group of 45-55 years and four respondents who were above the age of 55 years.

With regard to marital status it was found that only five respondents were unmarried, remaining 62 had once married. Collected data shows that most of these respondents had no or very little information about HIV/AIDS, when they got married it was only after the illness or death of their husbands they came to know about HIV/AIDS. There were 34 widows of men who had died of AIDS and four widows whose husband had died of illness but they did not know their HIV status. There was one respondent who became widow at the age of 19 years; there were 17 respondents who got widowed when they were in the age group of 20-30 years. There were 16 respondents who became widows in age group of 30-40 years and remaining four respondents became widows in age group of 40-50 years. There were 14 married respondents living with their husbands. These women were socially and economically dependent on their husband. Even they knew that their husbands infected them, they could not leave them because of pressure of societal norms and their dependency on their husband. There were seven respondents who remarried. It includes one prisoner who was married at the age of 16 years to 40 years old man. Her husband died after a prolonged illness. She had a daughter from her first marriage. After his death she was married to her husband’s younger brother. There were two respondents who were divorced. The cause of divorce was their HIV status. There was one respondent whose husband deserted her after knowing her HIV status although he himself was also tested positive.

Results indicate that there were three respondents who got married when they were less than 15 years old, one respondent was 13 years old (case-13) and one was only 14 years old (case-32) at the time of marriage. There were 32 respondents who

got married between age group of 15-20 years. Most of the respondents were married at legal age i.e. 18 years. There were 25 respondents who were married at age group of 20-25 years. There were five respondents who were married late i.e. in the age group of 25-30 years.

Results show that out of 67 cases, there were 43 respondents who belonged to Sikh religion. The present study is based in Ludhiana district of Punjab which is a Sikh dominated state. The second highest number was of Hindu respondents i.e. 22. There was one respondent who was a Christian and one was from a Muslim community who were detected HIV positive. With regard to caste background, out of 67 respondents, there were 39 respondents who belonged to General category and remaining 28 belonged to reserved category.

16 respondents were illiterate and seven respondents were educated up to primary level. There were 17 respondents who had education up to middle level only. Some of them didn't pass the 8th standard due to lack of encouragement from parents. There were 13 respondents who were matriculate and 11 respondents had education up to plus 2 level. There were only three respondents who were graduates. 35 respondents were not doing any type of paid job, 12 of them were married and totally dependent on their husbands. There were nine respondents who were widows, five of them were living with their parents and two were living with their in laws, two of these were living with their sons (both in rural area) after the death of their husbands. These 35 respondents also include four students and one respondent who were in prison. There were 15 respondents who were in service and six of these respondents were working in health care centers on contract basis. There were two respondents who were graduates and working as school teachers. One respondent was a staff nurse in a Government hospital. There was one respondent who was working as a housekeeper in a mall. Two respondents were workers in factories and one respondent worked as a machine operator. Nine respondents were housemaids. Five respondents were self-employed, four of them had their own boutique and one was running a beauty parlour from her residence. Three respondents were included in others category, one was an orchestra dancer and two were female sex workers.

Findings with regard to income of the respondents show that there were 36 respondents in the low income group. A large number of respondents in the present study were poor, either they had no source of livelihood or were earning very minimal

amount. Out of 67, 26 respondents admitted that they had no income, it included 12 married housewives who were dependent on their husbands, nine widows - five of them were dependent on their parents, two were dependent on their in laws, and two were dependent on their sons. This category also included four students and one prisoner. Nine housewives had agriculture income. Five factory workers, one Asha workers, one Anganwari worker, four paramedical staff, two school teachers, three self-employed, one Orchestra dancer and two female sex workers were earning up to Rs 15,000/- per month. There were three respondents, a widow of an army jawan who was getting pension along with her salary and another widow of an army jawan was getting pension along with income from agricultural land. Another respondent was earning more than Rs. 15000/- per month from her parlour. In high salary group, there were includes only two respondents, one of them was a staff nurse and another had a large agricultural land.

Present findings show no difference in place of residence and vulnerability to HIV. There were 34 respondents who belonged to rural areas and 33 respondents were from urban area. Results show that 43 respondents did not own any residential accommodation. 26 respondents out of 43 were living with their in laws and 18 of them were widows. Eight respondents were living with their parents and six of them were widows and two were divorced. Seven respondents were living in rented accommodations and three of them were widows. There were 24 respondents who had their own house. There was one respondent who was unmarried she was living with her aunt after the death of her parents. There was one respondent who was living in a jail in Ludhiana. Before going to jail she was living with her in laws.

Present findings show that 27 respondents were living in very small houses in very congested areas. There were 22 respondents who were living in small houses and there was not much difference with regard to background 12 respondents was from rural background and 10 were from urban background. 16 respondents were living in medium sized houses of three rooms. There were only two respondents who had large houses. Results show that 37 respondents were living in joint family and 29 respondents were living in nuclear family.

With regard to social class, 50 respondents belonged to lower class, 15 belonged to working class and two respondents belonged to middle class and there was no respondent from upper class category.

Results show that out of 67 respondents, 25 respondents admitted that head of their families were illiterate and 12 heads of the families who were educated up to primary level. There were 12 respondents who admitted that head of their family had education upto middle level. There were nine heads of the family of respondents who were matriculate. There were six respondents who admitted that their fathers were graduates. There were three respondents whose fathers had studied up to high school. Fathers of 28 respondents were labourer, there were 13 respondents whose families had agriculture land and their fathers were farmers, fathers of 11 respondents were shopkeepers and small businessmen. There were 12 head of the families who were in service. Fathers of three respondents were included in other category i.e. one was working with orchestra, other was immigration agent and one was a taxi driver. Findings indicate that fathers of the respondents were engaged in lower and middle level of occupations.

There were 20 respondents who reported large family and 19 respondents mentioned small sized family. There were 28 respondents who belonged to medium sized family. There were seven respondents whose husbands were illiterate. There were five respondents whose husbands were educated up to primary level. There were 23 spouses of the respondents who had education upto middle level and 22 spouses of the respondents had studied up to matriculation and the three spouses of the respondents had education upto senior secondary level. There were only two respondents whose spouses were graduates. Husbands of 13 respondents were unskilled laborers and husbands of 11 respondents were skilled workers, husbands of 14 respondents were drivers, husbands of 15 respondents were in service (seven of them were doing Government job i.e. six were serving Indian army and one was in Indian railway) and eight husbands were engaged in private job (out of these six husbands were working in factories, one was a housekeeper in a mall in Ludhiana and one was a salesman). Husbands of 5 respondents were farmers and had their own agricultural land. There were four husbands who were doing other kind of works i.e. two of them were paathis in Gurudwara, one was a sewadar in a Mandir and one husband was working with an orchestra band. There was one husband who was unemployed; earlier he was a labourer but later stopped working.

Economic status of husbands of the respondents shows that there was one husband who was not working anywhere and he had no income. Husbands of 53 respondents were earning less than Rs. 15,000/- per month as they were engaged in

menial kinds of occupations. Husbands of eight respondents were in middle income group who were earning up to Rs 30,000 per month. There were no respondents whose spouses were earning more than Rs. 30,000/- per month. Such findings indicate that majority of respondent's belonged to lower and middle class background when it comes to income.

With regard to age gap with husbands, nine respondents had age difference of 1-3 years and only two respondents who had no age difference. There were 19 respondents who had age difference of 5-7 years, 12 respondents had age difference of 3-5 years and 12 respondents had age difference of 7-10 years. There were eight respondents whose age difference was of more than 10 years.

There were 51 respondents who had 1 to 3 children, there were ten respondents who had 3 to 6 children and there was one respondent who had no child. Present study showed that most of the respondents were living with the responsibility of 1 to 3 children and many of them were widows raising solely their children with limited income and resources. Results indicate that respondents had children of different age groups, There were 46 children who were young and in the age group of 0-10 years, 48 were in age group was between 10-20 years. There were 24 children who belonged to the age group of 20-30 years and there were eight children whose age was between 30- 40 years. Since the age of the respondents ranged from 15 to 55 plus.

Findings show that 30 respondents who had male children only, 12 respondents had female children only and 19 respondents had children of both the sexes. There was one respondent who had no child. Findings show that there were 114 children out of 126 who were tested HIV negative whereas 12 children were tested HIV positive.

Chapter-3

‘Third Chapter’ focused on the respondent’s awareness and knowledge about HIV, knowledge about treatment and how lack of awareness makes them vulnerable to get infected with HIV. The third Chapter covers the two objectives of the study i.e. to highlight the knowledge and level of awareness of WLHA with regard to HIV/AIDS and its prevention and to examine the vulnerability of HIV/AIDS and understand the causes of HIV/AIDS among women in Ludhiana district

Present findings show that there were 23 respondents who reported that they had no knowledge about HIV before getting tested for HIV. These respondents were illiterate and belonged to poor class. A large number of the respondents out of these 23 respondents were in the age group of 30 to 40 years and 15 were widows. Their husbands' waywardness resulted in HIV status for them. These innocent women suffered because their husbands did not disclose their HIV status to them and continued to indulge in unsafe sex with them. There were 44 respondents who admitted awareness about HIV but when they were probed about the disease, they also did not provide clear understanding of HIV/AIDS.

Results show that very few respondents had complete awareness about HIV/AIDS. There were 43 respondents who reported that HIV is considered to be a dirty disease because it is transmitted through heterosexual mode and it includes three graduate respondents also. There were 29 respondents who reported HIV carries a stigma with it that included two respondents who belonged to middle class, 15 respondents from working class and remaining 12 respondents were from lower class background. There were 31 respondents who argued that a specific type of people i.e. those who engage in high risk behaviour get HIV infection that included 20 widow respondents, eight married respondents, two remarried respondents and one deserted respondents who contracted infection from their partners. There were 27 respondents who reported that HIV is a dreadful disease that included 25 widows who had seen their husbands died of AIDS and two unmarried daughters, both parents of one was died of AIDS and one was living with her HIV positive widow mother, whereas her father also died of AIDS. There were 17 respondents who believed that it is a punishment by God to wrong doers that included three respondents with middle level education in the age group of 35-45 years and 14 respondents who were not educated and were in the age group of 25-45 years. There were 13 respondents who reported that there is no cure of the disease. These included four unmarried respondents who had education up to 10+2, six widows (one graduate, one matriculate and one was only middle pass), two married respondents one of them was graduate and the other was matriculate and one divorced respondent who was also graduate.

Findings reveal that respondents were not clear about the actual mode of HIV transmission and they gave wrong responses about its transmission. It is quite ironical that these women are HIV positive and getting treatment from ART Centre. There

were 35 respondents who mentioned that unprotected sex causes HIV transmission, 19 respondents were of the opinion that only female sex workers could be infected with HIV as they make physical relations with multiple persons out of whom 15 respondents have been visiting ART for last 0-3 years, 19 have been visiting ART for last 3-6 years, 18 have been visiting ART for 6-9 years, 10 from 9-12 years and remaining six were taking treatment from 12 years and above. These respondents were of the notion that married women are safe whereas 13 respondents were widow whose husbands died of AIDS and six respondents were married and were HIV positive themselves. There were 39 respondents who argued that people with immoral behaviour get infected with HIV as they indulge in sex with multiple partners. All these 39 respondents had contracted HIV from their husbands. There were 30 respondents who admitted that HIV could be transmitted through infected syringes used by HIV positive persons and husbands of three respondents were IDUs. There were 25 respondents who stated that HIV could be transmitted from infected mother to her children and there were four respondents who got HIV from their mothers and children of eight respondents were HIV positive. There were 15 respondents who mentioned that blood transfusion can cause HIV if blood contains HIV virus. Since two respondents reported that they contracted HIV through blood transfusion. There were seven respondents who reported tattoos and piercing with infected needle causes HIV transmission. There were 14 respondents who admitted that HIV could spread by hugging or touching HIV positive person. 15 respondents were of opinion that HIV spreads by sharing food with HIV infected person or eating food cooked by HIV positive person, most of these respondents were illiterate. There were nine respondents who mentioned that mosquito bite can transmit HIV virus to a healthy person. There were 13 respondents who stated that HIV could be transmitted through kissing an infected person. Findings show that 31 respondents had obtained knowledge about HIV/AIDS from electronic media and 20 respondents gained knowledge through print media. There were 15 respondents who reported that their husbands who were HIV positive provided them information. There were six respondents who gained information about HIV from their peer group that included five unmarried respondents in the age group of 15-25 years. There were five respondents who admitted that they came to know about HIV/AIDS from their teachers.

Results show that 13 respondents were in the age group of 15-25 years, 29 respondents were in the age group of 25-35 years, 16 respondents were in the age group of 35-45 years and five respondents who were in the age group of 45 years and above when they were tested HIV. There were four respondents who were born HIV positive as their mothers were HIV positive.

Result shows that 34 respondents were tested for HIV after their husbands were detected HIV positive. 16 respondents were tested for HIV when they continuously remained sick for long duration. Many of these respondents were down with persistent fever for three to four weeks, some of these were also suffering with upset stomach and frequent weight loss. It also includes one unmarried respondent who had skin problem and was sexually active. At initial stage of their illness these women took medicine from local doctors and when there was no improvement in their condition they approached Government hospitals. During screening these women were found to be HIV positive. Ten respondents were detected HIV positive during antenatal checkup. There were three respondents who were tested positive when their mothers were diagnosed HIV positive. There were two respondents who were FSWs. They were healthy with no sign of illness but they were voluntarily tested for HIV by an NGO during awareness camp and one respondent who was a prisoner was tested by Jail authorities. There was one respondent who was tested for HIV when her three months daughter admitted to the hospital was tested HIV positive.

There were 51 respondents who were infected through heterosexual mode and that too having sex with the single partner, their husbands. It includes 38 widows, eight married respondents, three remarried respondents, one deserted respondent and one unmarried respondent. There were five respondents out of 38 widows who reported that their husbands didn't disclose their HIV status to them and two reported that their husbands were themselves not aware of their HIV status. 21 respondents out of these 51 had age difference of 5 to 7 years with their husbands and were quite young at the time of their marriage. Out of these 51 respondents 19 respondents were illiterate; the 12 respondents had education upto middle class. Wives of high risk husbands i.e. truck drivers reported that their husbands had immoral behaviour before marriage also but their parents did not bother or inquire about that. After getting married they came to know the real side of the picture but they were not able to negotiate for safe sex as they had no knowledge about HIV/AIDS. There were eight

respondents reported their helplessness as they did not know the source of information. They had some myths and perceptions in this regard (three of these respondents were illiterate, two had education up to middle level, one respondent was matriculate and there were two respondents who had education up to senior secondary level). There were four respondents who were infected from their mothers during their birth as their mothers were HIV positive. Two respondents got infected by infected syringes used by medical care workers. Two respondents got infected through blood transfusion.

There were 50 respondents who opined that HIV/AIDS related information should be provided to children in schools. Although these respondents were in favour of providing sex education and HIV information in schools but they were not communicating with their children in this regard. They argued that teachers can play this role more effectively. Ironically out of 67 respondents, only 15 respondents had disclosed their HIV status to their children whereas remaining 46 respondents had no courage to talk to their children in this regard. There were five unmarried respondents and one respondent had no child.

There were 13 respondents who reported that there is no cure of the disease. These included four unmarried respondents who had education up to 10+2, six widows (one graduate, one matriculate and one was only middle), two married respondents one of them was graduate and the other was matriculate and one divorced respondent who was also graduate. Results show that there were 20 respondents who were pessimistic about the treatment. They reported that there is no permanent cure for HIV that included 12 widows who lost their husbands to AIDS, four unmarried respondents and four married respondents. There were 14 respondents who were optimistic about the treatment taken by them from ART Centres. They reported that there is a medicine for HIV and they will not die untreated and they were taking medicine regularly for 12 and more years that included married respondents whose husbands were also positive. There were 13 respondents who were seeking treatment but were not sure about the future because of financial liabilities and lack of support system. They were taking medicine only because it is given free of cost. There were 12 respondents who reported that they were seeking spiritual treatment from Gurus and Deras to get rid of the disease along with ART. There were 15 respondents admitted that they have approached local vaidas who claimed to cure HIV/AIDS. They came to

know about them through advertisements appearing in vernacular dailies.18 respondents claimed that they sought alternate treatment i.e. AYUSH.

Findings show that there were 33 respondents who came to know about ART centre from Government hospital and 15 respondents were referred from Private hospital to the ART Centre. There were 14 respondents who came to know about ART from their husbands. There were five respondents who came to know about ART centre from their relatives when their husbands died of AIDS.

Results indicate that there were 47 respondents reported no side effects of medicine. There were 4 respondents who reported fatigue as a consequence of ART initially for few days but later it improved and they continued with their daily routine. There were nine respondents reported insomnia. Five respondents reported loss of appetite and five respondents had severe nausea when they started their ART medicine. Six respondents had diarrhea for a few days but were fine later on. There were seven respondents who felt headache at initial stages but later on they didn't face any problems. Most of the respondents reported that when they were given medicine for the first time they were intimated about the side effects by medical staff. Four respondents who were widows reported their husbands also faced side effects of ART initially.

Present findings show that there were 19 respondents who were taking treatment for the period of 3-6 years. There were 18 respondents who were taking ART for 6-9 years. 15 respondents were on ART for last 3 years. Nine respondents were taking medicine from ART for last 9-12 years. Seven respondents were on medicine for more than 12 years. Many of these 67 respondents had good CD4 count during their first visit to ART after detection of HIV when they were tested positive and only later their ART was started.

Results show that there were 19 respondents who had a fear of being stigmatized in ART Centre as stigma is attached with the disease that included five unmarried respondents and two respondents belonged to middle class background who had not disclosed their HIV status to their family members thus didn't want to be noticed. There were 18 respondents who felt comfortable at ART Centre during their first visit as they were treated very nicely and empathetically by ART staff. 35 respondents were tense about the treatment at ART Centre. It included 19 widows

who had lost their husbands. They were quite apprehensive whether they would be cured. There were 13 respondents reported that they were hopeful that medicine would help them to live a prolonged healthy life. There were 25 respondents who were relieved that as they were given free medicine at ART centre as their economic condition was not good to buy such expensive medicines. Further when they saw large number of patients they were relieved. All 67 respondents admitted that they were asked by ART staff to take medicine regularly without miss. 39 respondents admitted that they were given information on modes of HIV transmission. 47 respondents were provided information on precautions to be taken by respondents. 39 respondents stated that they were counselled properly as they were informed about medicine, transmission, precautions etc. when they first time visited ART Centre.

Results show that most of the respondents visited the ART Centre once in a month and to collect their medicine. Some of them were reluctant to visit ART every month so they collected 2 months medicine. It also included economically poor respondents who were not able to spend on fares. Two respondents were visiting ART Centre twice or thrice in a month as they had some other health issues also.

Present finding shows the clinical stage of respondents. There were 61 respondents who were at stage I, there were three respondents who had reached to the second stage, there were three two respondents who were at fourth Stage and remaining one respondent was at third Stage. The diet, duration of illness and taking medicine in time affects the clinical stage of a person. The clinical stage also depends on when the patient started with ART and how seriously they were following the instructions like risk reduction behaviour especially about condom use, substance use and about dietary habits. Most of the women in present belonged to poor sections and nine respondents were engaged in menial kinds of job for their and their children's survival. It is very difficult to monitor their adherence to medications.

Present findings show that there were 29 respondents who most of the time commuted to ART Centre by bus, sometimes alone and sometimes with family members. These respondents were coming to ART from far off rural areas. The bus was a cheapest and easily accessible mode of transportation for them. There were 20 respondents who often travelled by auto rickshaw to reach to ART Centre and these respondents were living in urban areas. 18 respondents were using their own vehicles.

Findings show that there were 25 respondents who come on their own to ART Centre for taking medicine. Nine respondents were accompanied to the ART Centre by their HIV positive husbands. 12 respondents were accompanied by their in laws and four respondents were accompanied to the ART by their siblings with whom they had shared their HIV status. Parents of seven respondents were accompanied by their parents to the hospital as these respondents were living with their parents. One unmarried respondent was coming to ART Centre with her maternal aunt. Respondent in prison was accompanied to ART Centre by deputed jail authority.

Results show that there were 41 respondents reported satisfaction with the services and treatment provided in ART Centres. These respondents had developed good relations with medical staff as respondents were taking treatment for last 6 to 12 years and more. Another reason for satisfaction as reported by respondents was availability of free medicines and testing facilities as most of these respondents were widows with poor economic background. There were 15 respondents who were not satisfied with the treatment out of these seven were taking treatment for last 3 years and eight respondents for 3 to 6 years, nine were widows and had lost their husbands due to AIDS. 11 respondents were partially satisfied with the treatment. They admitted stigma and discrimination.

With regard to precautions taken by respondents during ART, results show that only 16 respondents admitted of using condoms during sex that included married women. 15 respondents admitted that they do not share food with their children and other family members. They often serve them in separate plates that included nine widows and six married women. 14 respondents reported that they refrain from kissing and embracing their children. There were ten respondents who always remain conscious about cuts and other injuries during cooking food. Seven respondents admitted that they wash their clothes separately.

Chapter- 4

The ‘**Fourth Chapter**’ focuses on fourth and fifth objectives of the present study i.e. to identify different types of challenges, faced by women living with HIV/AIDS in family, community, healthcare and workplace; and to identify the coping mechanisms used by women living with HIV/AIDS deal effectively with challenges related to their illness, stigma and discrimination.

Respondents gave their perception about different challenges faced by HIV positive women. There were 42 respondents who felt that stigma and discrimination is the biggest challenge for WLHA as it prevents them from disclosing their HIV status to others and seeking their support. There were 41 respondents who admitted that lack of awareness about HIV as important challenge. For 37 respondents lack of support is the big challenge for women living with HIV. Eight respondents whose children were tested HIV positive blamed their lack of awareness for infecting children from the disease. For 31 respondents health issues is major challenge faced by WLHA. For 28 respondents the disclosure of HIV status to others is the major challenge. For 21 respondents vulnerability of children for WLHA is a big challenge. There were 31 respondents who felt lack of awareness and health issues both were major challenges for WLHA. For 37 respondents both stigma-discrimination and lack of support were important challenges that WLHA face. For 21 respondent's stigma and discrimination, economic challenges and increased vulnerability of children were the challenges for WLHA. Such findings indicate that stigma and discrimination as well as lack of support were the major challenges faced by women suffering from HIV/AIDS.

There were 41 respondents who admitted that **lack of awareness** about HIV is the biggest challenge faced by HIV positive persons. It also included 23 respondents who were not aware of HIV/AIDS and its mode of transmission. These 23 respondents were illiterate, it included 15 widows, five married respondents, one remarried respondent, one unmarried respondent and one divorced respondent. There were 18 respondents who admitted that they had knowledge about HIV but on further probing they gave wrong responses. It included ten widow, six married respondents and two remarried respondents. Respondents reported that they would have safeguarded themselves if they had knowledge about HIV. Respondents who had contracted HIV through infected syringes and blood admitted that it was their lack of awareness about modes of transmission that they became HIV infected. It included two respondents who were infected through blood transfusion i.e. one married respondent and one divorced respondent whose husbands were tested HIV negative; two were infected through HIV infected syringe during treatment. According to them proper awareness about mode of transmission could have saved them.

Results show that there were 11 respondents who felt that HIV infection affects the **physical health** of a person and lessens her capability of doing any work. It included seven widows, three married respondents and one deserted respondent. These respondents reported that they themselves feel physical deterioration of health as they were not able work efficiently after getting HIV as they used to do earlier. They feel tired and weak due to their illness. In spite of poor health these women have to do all household chores and take care of other family members. In addition to physical health, some respondents reported deterioration in mental health.

Out of 32 respondents who reported **economic challenge** as one of the biggest challenge, 27 respondents were economically dependent on their husbands, their parents, in laws and relatives and seven of them had HIV positive children. There were two married FSWs, three housemaids one divorced and two widows who were working. Such findings clearly indicate economic dependency faced by WLHA forces them to indulge in high risk behaviour. Lack of skill to be actively engage in productive work, their HIV status and those of their children makes them vulnerable to poverty and abuse. The respondents who were living with their in laws after the death of their husbands and could not go to their natal family because they had no support from them. They compromised with the situation and finally decided to live with their in laws to get financial help for children and for themselves. Although most of them were blamed for killing their husbands and their integrity was questioned but they kept mum because of their economic dependency on their in laws. Family members try to maintain distance from these women and hardly come forward to help them. The death of husbands who were the sole earner in the family makes these women economically weak. These single mothers face financial difficulties in meeting even the day to day expenses of running a home.

Stigma and discrimination faced by WLHA emerged as one of the biggest challenges. There were 41 respondents who faced discrimination and stigma by their own families. Their life changed after they were found to be HIV positive, the behaviour of their family members changed towards them. It included 27 widows who were stigmatized and discriminated for their illness by their in laws, seven married and two remarried respondents were discriminated by their husbands, two unmarried respondents were ill-treated by their father, one divorced and two widow respondents were discriminated by their parents and siblings. The lack of necessary HIV-related

knowledge and skills in communicating about sensitive topics (e.g., sexual behaviours and HIV transmission) can be also a barrier in acceptance of HIV positive woman in our society. There were 24 respondents who faced physically discrimination from their family members. Most of these were physically discriminated by their in laws. It included seven respondents who were thrown out of husband's house by in laws, two unmarried respondents whose father illtreated them, five widows who were not allowed to enter the kitchen, four widows who were given separate utensils by in laws, three married respondents who were physically abused by their husbands, three married respondents were asked to live in a separate house with their husbands. Violence is a particularly harsh form of discrimination faced by women. Women and girls report increased violence for requesting condom use, accessing voluntary testing and counselling, refusing sex within or outside marriage, or for testing HIV positive.

There were 41 respondents who were psychologically discriminated by their family members. It included 26 respondents who were living with their in laws i.e. 18 widows and eight married respondents. They were blamed as being woman of loose character by their in laws. It also included seven respondents i.e. five widows and two divorced respondents who were living in parental family. They were sometimes psychologically discriminated by their sisters in law. It included four widows, three married and one remarried respondent who faced psychological discrimination from their in laws. Moreover, women were often blamed by their in-laws for infecting their husbands by not controlling their husbands' urges to have sex with other women.

There were 39 respondents who faced economic discrimination from their family members. Most of these respondents were not working and were widows, they were not given money for their basic needs. Seven women were asked to leave the house of their in-laws after their husbands died and denied their inheritance. There were two respondents who faced sexual discrimination by the close relatives in husband's family. There were 34 respondents who faced social discrimination; they were socially ostracized by their family and relatives. These respondents were not invited in family functions by their relatives fearing they would also get stigmatized if they interacted with them. Sexual intercourse being the main route of transmission fuels the beliefs of 'unacceptable' and 'immoral' sexual behaviour, and God's punishment in the form of an untreatable illness, which results in intense blame for

the victim. It also included two respondents whose children had blamed them for their illness.

31 respondents faced discrimination in health care system. These respondents were mistreated, they were attended late, they were questioned on morality, their characters were doubted and their HIV status was disclosed to others without their consent. It included seven pregnant respondents, five widows (husbands were alive at that time) and two married respondents who were ill-treated by health care providers during antenatal checkup and delivery, eleven respondents were ill when they visited health care centre and after detection of their HIV status the behaviour of health care providers changed and these respondents were ignored for the treatment, remaining 11 respondents i.e. six widows, four married and one remarried respondent faced public humiliation and prejudices in health care settings. There were 23 respondents who were discriminated by paramedical staffs in hospitals. There were five respondents who were discriminated by doctors in hospitals. There were three respondents who were discriminated by class-IV staff in hospitals. They talked to respondents rudely due to their HIV status, refused to work for them and also passed loose comments. There were 14 respondents who faced physical and psychological discrimination by health care providers. Speculations were made about their character. Further without their consent their status was disclosed to others.

14 respondents who had disclosed their HIV status at work place faced discrimination from their colleagues, employers and clients. It included four self-employed respondents, one of them was running a beauty parlour at home and three respondents were doing stitching work. These respondents were sometimes discriminated by their clients and they spread rumours about these respondents in the community, four were working in health department and they too faced discrimination in the hospital, two were housemaids and they were many times denied work when their HIV status was known, two respondents were factory workers who were discriminated by their colleagues, one was a housekeeper who was a widow and her husband was also working in the same mall before his death. Her HIV status was known to all at workplace and faced discrimination there. It also included one anganwadi worker who was discriminated by her colleagues who passed comments on her illness and she was forced to leave the job. There were nine respondents who faced physical discriminated by their employers, colleagues and clients.

There were 11 respondents who faced psychological discrimination at their work place in form of character assassination. They were excluded from office functions and programmes, their colleagues avoid them and do not like to share food with them also. There were two respondents who were housemaids were economically discriminated. They were fired from their work when their HIV status was known to their employers.

Results show that there were 25 respondents who were discriminated by neighbours and community members. It included 16 widows whose HIV status was known in the neighbourhood and community after their husbands died of AIDS, seven married respondents whose HIV status was known to the people around as her family members discussed their illness with these neighbours and two unmarried respondents who were sisters, their HIV status was disclosed in neighbourhood by their father and they had contracted infection from their HIV positive mother. These respondents were experiencing the discriminatory attitude of community members after their getting tested HIV positive. They maintain distance with these respondents and least interested to keep contact with them. There were 15 respondents who were physically discriminated by their community as people do not maintain any contact with them. They neither invite them to their place nor visit their houses. They do not share anything from them and do not allow their children to play with their children. There were 17 respondents who were psychologically discriminated by their community members. These respondents faced psychological discrimination when people do gossips about their illness, spread rumors about their character and blame them for killing their husbands. There were ten respondents who were socially discriminated by isolating them by their community. There were two respondents reported that hardly anyone from their neighbourhood came to cremation of their husbands

There were some respondents who faced discrimination at more than one place. There were 31 respondents who were discriminated in family and health sector both. There were 25 respondents who were discriminated at two places i.e. family and Health Sector, there were 11 respondents who were discriminated in family and work place and 20 respondents faced discrimination in family and community. There were seven respondents who were discriminated in family, Health Sector, Work Place. There were eight respondents who were discriminated in all four places i.e. Family, Health Sector, Work Place, community. There were 12 respondents who were discriminated Health sector and Work place.

Disclosure of HIV status to others is one of the biggest challenge was reported by 28 respondents. There were 17 respondents who shared their HIV status with their husbands as they themselves were tested first. It included ten ANC respondents who were tested first and seven respondents who fall ill and during investigations in hospital found positive, two married respondents who were FSWs tested positive during an HIV awareness camp and shared their illness with their husbands, six widows who were tested for HIV after their husband's death (four shared their status with their parents and siblings and two shared it with their children who accompanied them to the hospital. There were four respondents who did not share their HIV status with anyone. 41 respondents admitted that they faced discrimination by family members because their HIV status was known to them. Out of these 41 respondents, 39 respondents faced stigma and blame for bringing the infection in the family. They were blamed for infecting their husbands with that dreadful disease. There were 37 respondents who faced character assassination; they were made guilty of bringing shame to the family even though in most of the cases husbands were tested positive prior to their HIV tests. There were 36 respondents who faced hatred for being infected with HIV/AIDS. There were only 13 respondents who received sympathy from others and that too from their parents. Five unmarried respondents had support of their parents. Eight respondents were widows and they were staying with their in laws after the death of their husbands, their parents were emotionally supported them.

37 respondents advocated that **lack of support** is the biggest challenge for women living with HIV/AIDS. Women are often seen as a burden both by parents and in laws. HIV positive women don't receive support from their parents, spouses and in laws. There were 13 married respondents who were not supported by their husbands after disclosure of their status, they were humiliated and degraded by their husbands. Husbands of four remarried respondents were not ready to get them tested for HIV and continued to insist that they were negative. Husband of one respondent deserted her although he himself was HIV positive. In many cases where respondents were infected through heterosexual contact with their husbands and their husbands were died of AIDS, there in laws blame their daughter in laws and do not support them emotionally, socially and financially. They never ready to take the responsibility of HIV positive daughter-in-law. They blamed their daughters-in-law in spite of the fact that HIV status of their sons was known to them. There were seven respondents who

did not get support from their parental family as their parents had died and their brothers were reluctant to support due to stigma attached to them. These respondents were denied any kind of help and support from their parental family. There were some respondents who were getting social, economic and emotional support from their family members- parental and in laws.

There were 21 respondents who believed **increased vulnerability of children** was the biggest challenge for WLHA. There were 10 respondents who were mothers of HIV positive children. In addition to taking care of their own health they had to provide proper care to their HIV children. According to traditional role ideology women are often seen as the main care providers in the family. In spite of their own illness they have to prioritize the healthcare of other family members. HIV positive women are devalued due to their illness and their importance in the family lessens. WLHA lives the life of infected and affected both. Once woman is tested positive her mind remains busy thinking about the health and future of the children. This stress increase more if the woman is a widow and economically instable. Thus HIV positive mothers who are not gainfully employed in addition to health care have to face burden of the most basic needs such as food, housing, medication and education for children. Insecurity about future of their children keeps them under mental stress.

Two respondents also faced separation from their children when they were thrown out of their husband's house after detection of their HIV status after the death of their husbands. Some respondents stopped sending their children to school because of economic difficulties due to HIV.

Fifth objective is to identify the coping mechanisms used by these women living to deal effectively with these challenges. Keeping this in mind information on reactions of the respondents after knowing their HIV status was obtained. Results show that 25 respondents reported that they didn't feel anything after receiving their HIV test report as they had never heard about HIV/AIDS before in their lives. There were 19 respondents became scared of death when they came to know since it was a non-curable disease these included 13 mothers who lost their husbands due to AIDS and worried about the future of their children. There were 14 respondents who became annoyed as their husbands had infected them with non-curable disease that included three respondents whose husbands were IDUs and five respondents whose husbands were frequently visiting sex workers. 16 respondents were shattered to

know about their HIV status that included 12 widows and four married women with small children. There were six respondents who couldn't believe that they were infected with HIV as they had never indulged in any risk taking activity. There were 17 respondents who blamed others for infecting them that included four unmarried respondents who blamed their parents and four respondents blamed their in-laws who concealed their sons HIV status and married them, remaining nine respondents blamed their husbands for infecting them. There were five respondents who were shocked to see their HIV positive test reports.

Results show that there were 37 respondents who didn't disclose their HIV status to others to avoid stigma and discrimination. It included 15 widows, ten married respondent, six remarried respondents and four unmarried respondents, one deserted respondent and one divorced respondent. They tried to share their HIV status with only near ones but tried to hide their disease from others. There were 35 respondents who kept themselves busy in household chores so that they don't get time to think about their disease all time. It included 23 widows, ten married and two unmarried respondents. There were 25 respondents who try to keep themselves busy in meditation and prayers to get strength and peace. It included 14 widows, eight married, two divorced and one deserted respondent. There were 23 respondents who adopted the avoidance method to minimize stigmatized comments from family and community which included 12 widows and six married respondents who were living with their in laws and five widow respondents who were living with their parents. There were 12 respondents who used denial and rejection coping mechanism to live normal life.

After summarizing the results an effort has been made to answer the research questions undertaken for the study.

RESEARCH QUESTIONS

The present study aimed to answer the research questions such as:

1. Do socio-demographic variables influence the status of women with regard to HIV/AIDS?

It was found that the socio demographic variables influence the status of women with regard to HIV/AIDS. Their present age, marital status, age at marriage, age difference with husband, their education, family background, education of head of

the family, education of husband, caste and class, family composition and house ownership all affects directly affects women's vulnerability to HIV/AIDS. It was found that these entire variables were interrelated. Women of uneducated parents were more likely to be illiterate or less educated. Their lack of education and poverty prevented them to have knowledge about sex related issues and they were not economically dependent. Further many of them were married at early age with much older persons. Their wider age gap with their husbands and their economic dependency on them lessened their bargaining power in marriage. Further the type of family and ownership of house and locality affected their vulnerability to HIV. Qualification and occupation of husbands also played an important role in making respondents HIV positive. Less educated or illiterate husbands who worked in high risk occupations had more probability to indulge in high risk behaviour and transmit their infection to their wives at home.

2. Do level of awareness about HIV/AIDS play significant role in lives of HIV positive women?

Lack of awareness about HIV, its mode of transmissions and prevention played a very significant role in lives of HIV positive women. Many women carry many misconceptions about HIV/AIDS and its mode of transmissions and a majority were either illiterate or had low level of education. Most of the respondents were feeling themselves safe in marital sex whereas a large number of women had contracted HIV from their husbands whom they had trusted. They were tested for HIV infection after their husbands were tested positive or died of AIDS. They themselves hardly bothered about their health whenever they got ill. Most of them were tested for HIV when their husbands were tested positive or they were ill or they were pregnant or their mothers were found to be positive. Women had low level of awareness about HIV. There were 15 respondents who did not share food with their children and other family members. They often serve them in separate plates that included nine widows and six married women. There were 14 respondents who reported that they refrain from kissing and embracing their children. There were ten respondents who always remain conscious about cuts and other injuries during cooking food. There were seven respondents who wash their clothes separately to avoid their infection from spreading to others. Such responses clearly indicate respondents lack complete knowledge on modes of transmission of HIV/AIDS. It is illiteracy, ignorance and inadequate counseling at ART centre which is responsible for this erroneous information.

3. Do profile and causes determine the psychosocial experiences of HIV positive women?

There were 51 respondents who admitted that they were infected through heterosexual contact with their husbands. In most of the cases husbands were engaged in high risk behaviour outside matrimony and contracted HIV which they transmit to their wives. Low level of education, economic dependency, age difference with their husbands and cultural norms prevent these women to question the behaviour of their spouses. Further they are not able to negotiate for safe sex as they had no knowledge about HIV/AIDS. The husbands are not faithful to their wives and they force themselves on their wives when they are drunk or intoxicated. According to some respondents they have to face violence also when they resist their husbands. During such situation awareness about preventive measures goes waste.

It is a common perception in society that is women's disease. As consequence stigma and discrimination is attached to the victim. Women are more often blamed for getting infected with the disease. They are blamed to bring the infection in the family and labeled characterless. No one bothers that their husbands were first tested for HIV or died of AIDS. Most women are often blamed by their mothers-in-law for infecting their sons by not keeping the check on their waywardness. Stigma and discrimination surrounding HIV and AIDS has heavy impact psychosocial life of these women. They were socially ostracized by their family and relatives. These respondents are not invited in family functions by their relatives fearing they would also get stigmatized if they interact with them.

4. What are the challenges faced by women living with HIV/AIDS?

WLHA face many challenges in their day to day life. Stigma and discrimination and economic disparities emerged as the major challenges faced by HIV positive women. Lack of awareness about HIV emerged as the challenge for WLHA as it makes them vulnerable to HIV and they transmit this infection to their children and sometimes to their partners. WLHA face physical and psychological health issues after getting infected with HIV. Another important challenge is economic, poverty and economic instability in parental family does not allow women to become independent and after getting infection and widowhood they become poorer. They face stigma and discrimination in family, health care systems,

work place and community. It is seen as a dirty disease so respondents refrain from disclosing their HIV status to others thus there is fewer adherences of prevention measures. It has been found that after disclosure a very few women get the support from their families and relatives. Another important challenge is vulnerability of children of WLHA who face economic, psychological and social inequalities. Of all the mentioned challenges, economic challenge and stigma associated with illness which makes the very existence of WLHA difficult emerged as the most important.

5. How do women living with HIV/AIDS cope with illness, stigma, and discrimination?

Women whether married or single, divorced or widowed, sex workers or migrants are most susceptible to the negative impacts of HIV and AIDS due to both biological and cultural reasons. Research has proven that women are biologically more prone to HIV infections than men. Further, cultural factors place them in lower position and they are not able to safe guard themselves against infection whether she is a sex worker or housewife. WLHA along with illness carry the stigma of HIV/AIDS as these women are considered to be carrier of infection. There is a common perception in society that WLHA deserve their HIV positive status because they have done something ‘wrong’. Stigma and discrimination does not only make it difficult for these women to cope with their illness on a personal level, but it also interferes with attempts to fight the AIDS epidemic as a whole. WLHA face stigma and discrimination in the family, in health care system, and work place. Parents and in-laws are not ready to keep them, left with no alternative they live a life of misery and agony. HIV positive women keep themselves busy in household chores or meditation so that they don’t get time to think about their disease and problems associated with it. For majority of women it is their survival which is important rather than the stigma attached to PLWHA.

After summarizing the results an effort has been made to highlight the main findings of the study.

MAIN FINDINGS

- Results of the present study show that a large number of respondents i.e. 51 were infected through heterosexual mode of transmission. These respondents

were in monogamous relation with their husbands and had never indulged in any other high risk activity. Results support the findings different researchers that argue that the bulk of HIV occur due to unprotected heterosexual intercourse (Cock et al. 1994; Lee et al. 2009; Leister, 2007; Miller and Lester, 2003; Morrison, 2006; Santhya and Jejeebhoy, 2007; Raj et al. 2013; UNAIDS, 2009; Vlassoff et al. 2013).

- Results of the present study show that majority of married women become victim of HIV because of high risk behaviour of their husbands. Some respondents were aware about the high risk behaviour of their husbands but were helpless to mend their ways. They had no control over their husbands and if they questioned their husband's waywardness, they were beaten by their husbands and threatened to divorce them or to throw them out of their houses. Many husbands beat their wives for denial of sex and many respondents also experienced forced sex from their husbands. Results are in congruence with findings of Kistner, 2003; Morrison, 2006; Santhya and Jejeebhoy, 2007.
- The age group of WLHA show that a large number of respondents i.e. 38 were in the age group i.e. 35-45 years. There were 18 respondents in the age group of 25-35 years. These respondents were married at early age and most of them were married to older men. Results don't support Bruyn et al. 1995; Newman et al. 2000; Karim et al. 2010 who reported that young women contract HIV.
- Results indicate that certain people are more vulnerable to HIV such as IDUs, FSWs, migrants, truck drivers. Results support UNODC, 2004; Choi et al. (2006); Srirak et al. (2005); Shin et al. 1992, Enkhbold, 2017; Blitzer, 2003 and Maher, 1997.
- Another major finding in the present study is that gender inequality related to HIV/AIDS contributed to a higher rate of the disease, thus placing women at high vulnerability to HIV. Findings show that WLHA are the innocent victims of HIV/AIDS. Lack of education, economic dependency and patriarchal gender norms make women vulnerable. Research findings support Booth, 2004; Dugassa, 2009; Gilbert and Walker, 2002; Wechsberg, et al. 2010.

- Results of the present study show that majority of HIV women lacked awareness about HIV/AIDS. Findings revealed that main cause of HIV among these respondents were their lack of knowledge and awareness about HIV. They were not provided good education, married at early age and their socialization to remain unaware about sex issues were the main causes behind their getting infected with the dreadful disease. If they were educated and had acquired some knowledge about HIV at least they could have saved themselves. It is important to mention that sample was collected from ART center and all the respondents were visiting ART centre for treatment. Ironically they had misconceptions about transmission of AIDS and were not careful in following preventive measures. Results support Krishna et al. 2004; Meundi et al., 2008 and Mohammad et al. 2008; Rahangdale, 2010; Singh et al. 2016.
- Findings indicate that WLHA don't want to disclose their HIV status to others as they fear stigma and discrimination. WLHA engaged in paid work are afraid of losing their works do not disclose their status to others and that includes sex workers also. HIV status of woman is disclosed to others as most of them tested after their husbands' death. It has been found that not only wives of HIV negative husbands but also of HIV positive husbands face violence and inhuman treatment from their family and community. Respondents in the study felt uncomfortable to disclose their HIV status because they feared shame, humiliation and discrimination. Findings coincide with Kimberly et al. 1995; Marks et al. 1992 and Serovich et al. 1998.
- Another major finding of the present study is that economic challenge faced by WLHA.

Many widows with HIV are thrown out from their in laws houses, not given their share in property and no one bothers their physical, psychological and economic needs. Many of these respondents faced economic instability before and after getting infected with HIV. Almost all respondents were not professionally qualified so either they were housewives or working in unorganized sectors according to their education. A large number of respondents were dependent on their husbands, in laws and parents. Those who were labourers, self-employed, factory workers or other working class were also not earning much that they could manage the day to day expenses of children and family easily. Findings showed that economic dependency compels

WLHA to live a disgraceful and stigmatized life where they often look at others for support and money. Results coincide with findings of Dunkle et al. 2004; Hunter 2007; Rodrigo and Rajapakse, 2010 and negate the results of Hanson & Hanson, 2008; Johnson and Way, 2006; Mishra et al. 2007.

- Present findings show that HIV related stigma is more attached with women than men. Respondents in the present study were victims but treated as culprits. Respondent faced stigma and discrimination because it is associated with morality. Women are stigmatized in family, health care centres, work place and community. Results are in congruence with Banteyerga, 2005; Bharat et al. 2001; Buzy and Gayle, 1996; Li et al. 2008; Liamputpong et al. 2009; Pallikadavath et al. 2005; Parker and Aggleton, 2003; Short and Vissandjée, 2017)
- Results show that women face maximum discrimination at the hands of family members and staff at health care centers. Women face discrimination in families because lots of misconceptions in society about HIV, people just know that it is a dirty disease and only immoral people get that. In health care centers although the doctor and other medical staff are sensitized about the infection but they are afraid to get infected as they come in direct contact with patients. Results support Bharat and Aggleton, 1999; Campbell, 1999; Tarakeshwar et al. 2006; Thomas et al. 2005; UNAIDS, 2000 ;Van Hollen, 2011.

DISCUSSION

Research all over the world suggests that the HIV epidemic affects men and women differently. The differences are seen in terms of vulnerability HIV infection as well as in terms of impact. Roles, responsibilities, and allocation of resources are very gender specific. It can be argued that WLHA are the innocent victims of HIV. Women in India like other patriarchal societies have secondary status. Unequal gender relations and women's socio-economic dependency make them vulnerable to HIV. Initially only high risk population was thought to be at risk of HIV but data around the world shows that it has spread to the general population, especially among women. The number of HIV cases among women especially housewives who remain in monogamous relations is also increasing. Apart from biological factors socio-

cultural factors place women at a greater risk of contracting HIV than men. In our society, women are discouraged to discuss issues such as extramarital partners, use of barrier methods/protection, timing and safety of sexual contact and their own sexual pleasure. The belief that it is utmost important duty of a woman to satisfy physical needs of a man takes away her rights of saying no to their husbands.

Gender-based norms also increase men's risk of HIV infection. From a young age, boys are socialized to associate prolific sexual activity with masculinity and they are encouraged to be sexually active and knowledgeable regarding sexual issues. Women on other hand are expected to be unaware about their reproductive health, sex and other sex related issues. Researchers have shown that mothers in Indian families hesitantly tell their daughters about the menstruation which is a biological process. Sex is a taboo word in most of Indian households. Parents are not ready to invest in their daughters' education thus schools as a source of information about sexuality also remains missing in the lives of most of the women. Uneducated girls, or illiterate women, are less likely to have the information and education on HIV/AIDS or reproductive health especially in our society where it is believed that sex related education promotes promiscuity and spoil girls. Girls are married off at younger age to older men thus enter into asymmetrical marital relations. Most of these men are sexually experienced and have indulged in high risk activities before marriage. Women who are ignorant about HIV, economically dependent on husbands, with no knowledge about their reproductive rights are never in condition to discuss the sex related matter with their husbands and ask them for safe sex. Men have sex with commercial sex workers without using any preventive methods and at home also they have unsafe sex with their wives. HIV infection is transmitted from FSW to men and further they transmit it to their wives who are not in position to question high risk behaviour of their husbands. Since most infected women are of child bearing age, they face the likelihood of infecting their children. Findings also suggest that their poor economic situation aggravates the severity of the problem.

When women are infected with HIV/AIDS they face number of challenges. Since the most common mode of transmission is sexual mode WLHA are often blamed for bringing infection in the family. Families and community ostracize them as promiscuous and bad women. Most of HIV positive women in present study were facing double jeopardy of being a widow and poor. Further lack of education, lack of

economic stability and cultural barriers make their lives miserable. These women have to face stigma and discrimination though they may not be directly responsible in getting infected. Due to their marginal social position they have deal with often unsupportive relatives and community members. Women infected with HIV face stigma, humiliation and discrimination from family, health care centre, work place and community. WLHA face many different types of discrimination. They are thrown out of their houses, they are not given share in the property, they are not given custody of their children etc. HIV positive women who face all these things are neglected by all. The labeling discourages them to take their treatment and force them to live a poor isolated life. They are not supported by their own families for whom they served since birth or after marriage. They are neglected and devalued and treated as unwanted creature in society. Health providers also discriminate women with HIV/AIDS by refusing to touch them, withholding treatment, disclosing their HIV status to others thus deny confidentiality and hospital facilities. Such inhumane behaviour of family members and health providers discourage WLHA from seeking treatment and adhering to it. Results indicated that due to fear of future discrimination WLHA don't disclose their HIV status and continue to suffer saliently. Women who could not disclose their condition were extremely isolated, lacked family and community support, feared the future and felt hopeless.

Poverty dominated the lives of the interviewees in this study, either as a consequence of their family's pre-existing low economic status or destitution as a result of the disease. For the present study theory of stigma and theory of ecology of poverty and HIV/AIDS were used as 50 respondents belonged to lower section of the society. Results show that married, monogamous, heterosexual women are highly vulnerable. Due to poor economic conditions most of the respondents could not attain higher education and were married off young to lowly qualified men of higher age. Since the knowledge about HIV, its mode of transmission and means to avoid infection is non-existing in society, men continue to indulge in high risk behaviour thus making their wives vulnerable. Lack of awareness about HIV and economic dependency of women on their husbands do not allow them to bargain for safer sex and many of them get HIV infection. After getting infected and becoming widows of AIDS persons many of them remain economically dependent on their in laws, parents and relatives where most of these women face stigma and discrimination along with

poverty. In addition, poverty pushes some women into risky behaviour or dangerous situations. With no other options in sight, they may resort to sex work to feed their families. The position for widows resulting from HIV/AIDS is particularly grave, without a breadwinner and protector, women are again made vulnerable. Poverty and economic dependence are not the only reasons it is difficult for many women to insist on using protection. In some cases, they are not comfortable speaking about sexual issues. In other cases, women may submit to unsafe sexual practices in order to preserve a relationship especially those involve in sex trade thus continue to spread infection.

Research indicates that gendered roles of masculinity and femininity ultimately manifest as gender power imbalance, and it is this imbalance that lies at the heart of gender-based inequities and disparities. Gender inequality and social marginalization place women at a relative disadvantage in a sexual relationship and limit their negotiating power and ability to protect themselves against HIV infection. Women face discrimination since before their birth. HIV/AIDS imposes yet another layer of stigma and discrimination upon their shoulders.

Patriarchal constraints restrict women's access to basic livelihood necessities and resources make them vulnerable to poverty thus exploitation. It is important to find ways to empower women by increasing their access to education and employment opportunities and by implementing policies and programs that eliminate gender inequality.

Recommendations

In view of the above discussion, the following recommendations about the challenges facing WLHA can be made.

- There is a need to evolve woman-centered health services that consciously adopts the perspectives of women, their families and communities. This means that health services see women as active participants in, as well as beneficiaries of, trusted health systems that respond to women's needs, rights and preferences in humane and holistic ways.
- Counselling on HIV/AIDS should be emphasized not only to the infected but also to the families or people handling the HIV/AIDS victims. Family

counselling especially will go a long way to alleviate the psychological and social problems such as negative reaction of family members, discrimination in society among other problems.

- There is urgent need to increase educational opportunities for women and girls. Educating girls is an effective way of empowering them to become more informed and equipped to succeed in life.
- The low-income women should be encouraged to engage in income generating activities to enable them raise enough money to keep themselves and their families.
- Since HIV/AIDS is rapidly spreading among the married partners, measures should be taken to stop the spread because it leads to more people getting HIV/AIDS.
- People in general should be sensitized about HIV/AIDS. Many misconceptions about HIV/AIDS are prevalent and people living with HIV/AIDS are being discriminated against or isolated.

LIMITATIONS OF THE STUDY

The goal of this study was to highlight the main challenges faced by HIV positive women visiting ART center, Ludhiana. While the results shed important light on some aspects, the study has some important limitations that need to be acknowledged.

1. The target group in this study was HIV positive women visiting ART therefore it is evident that conclusions can only apply to similar groups of women.
2. For the present study sample was collected from ART center Ludhiana, and only those respondents who volunteered for interview were consulted. Most of the respondents belonged to lower class and women belonging to upper section didn't participate in the study. In absence of higher class respondents general view related to challenges faced by WLHA could not formed.
3. For the present study unit of analysis were WLHA, their husbands and other family members were not included. In order to draw a holistic picture, perception of family members should have been taken.
4. For the present study review was limited to articles published in English only in different national and International Journals decade. It is possible that

important studies published in other languages and outside the search limits were missed.

5. As already mentioned above, the primary respondents in this study were WLHA visiting ART center. This study explored the ways in which women experienced living with the illness and the coping strategies that they employed. However, study didn't explore the coping strategies used by other household members, especially the primary care givers of WLHA.

SUGGESTIONS FOR THE FUTURE RESEARCH

The researcher recommends further research to be done on the following aspects of HIV/AIDS;

1. A survey can be done on the prevalence and factors contributing to the rapid spread of HIV/AIDS among women.
2. A comparative study consisting of equal number of males and females living with HIV/AIDS can be done.
3. A comparative study of different ART centers in the state of Punjab can be beneficial to provide overview of Governmental initiatives in this regard.
4. The participants in the current study were all women who were taking treatment from ART center. There can be some people with HIV/AIDS symptoms living in society but choose not to seek treatment and help, what social characteristics they have and why they choose not to do so can be interesting topic of research.

CONCLUSION

The main aim of this study was to highlight the challenges faced by WLHA. HIV is a global issue which is speedily spreading from high risk population to general population and from urban to rural areas. The number of WLHA is increasing all over the world. Due to gender inequalities and stigma and discrimination position of HIV positive woman is pitiable. Gender inequalities exacerbate the vulnerability and the risk to HIV/AIDS increasing the lack of access to information and services. Stigma and discrimination against WLHA leads to fear of rejection, silence and denial. Since women and girls of various ages are vulnerable to the infection, they are in need of support to overcome the economic and social effects of the epidemic.

WLHA are victim of both inequality and poverty. The reason that many women are poor in the first place is highly related to gender inequality. To this effect, even if policies give women more access to resources, if they lack the social and cultural support framework to enact changes in their lives, increased access may not have much effect on their health risks. Present study indicates that women's health issues and their reproductive rights are often neglected. In parental family not much money is spent on their education and they are not provided any type of sex education. Women's economic dependency on parents and later on husbands results in denial of reproductive rights. Due to gender inequalities and stigma and discrimination, WLHA are treated as untouchables and they face various type of discrimination. If the awareness and sensitization programmes are organized at grass root level on HIV/AIDS then such stigma and discrimination can be lessened which is a biggest barrier for WLHA to get medicine and support from their families and live their life with dignity.