

‘COUNSELLING: A PREREQUISITE TO IMPROVE QUALITY OF LIFE OF HIV POSITIVE WOMEN’

Shirin Shikalgar¹, Lokesh Gujarappa², Satish Shirsath³

¹Symbiosis Community Outreach Programme and Extension,
Symbiosis International (Deemed University), Pune, India

² United Way, Bengaluru, India

³Savitribai Phule Pune University, Pune, India

¹shirin.s@siu.edu.in

Abstract

Background: Globally, proportion of HIV positive women is higher compared to men (WHO, 2019), so is the socio-economic burden women experience. An effective way to mitigate this burden is by creating opportunities for women. More than 40% of people living with HIV infection in India are women. Experiences of HIV are different in men and women.

Methods: A mixed method research design was employed. The study included quantitative survey of 147 HIV positive women in Maharashtra. Qualitative component included ten in depth interviews with the stakeholders providing legal, medical and psychological services. Qualitative data was analysed thematically, whereas, quantitative data was analysed using non-parametric test.

Findings: Findings of the study show that education improves knowledge and contributes to empowerment. This study confirms the assertion made through quantitative findings that systemic support structures and empowerment of women need to be integral part of counselling and counsellors certainly has bigger role to play in it.

Conclusion: For Healthy and dignified life HIV positive women need support of counsellors. Four areas of counselling have been emerged through this study- Legal and Right based counselling, family counselling, counselling on awareness of disease and psychological counselling. These four areas are vital to empower HIV positive women to lead a dignified life with care and support

Key words: HIV/AIDS, counselling, rights, women, empowerment

Introduction

The impact of HIV/AIDS has not been limited to the health sector it has reached far beyond that. It has not only economic but social implications too which affects severely to women than men. Women are seen as the vectors or reason for the spread of HIV infection. Women are blamed for bringing bad name to the family and consequently suffer stigma, rejection, and expulsion from family and community¹. WHO (2019) factsheet reveals that globally, 37.9 million people are living with HIV/AIDS of it 36.2 million are Adults (male 17.4 million and female 18.8 million).

According to NACO 2017 report, the total number of people living with HIV (PLHIV) in India is estimated at 21.40 lakhs. More than 40% of people living with HIV infection in India are women. Experiences of HIV are different in men and women which could create challenge for India who has ambitious target of ending HIV infection incidence by 2030. In India, the low social status of women, poverty, early marriage, trafficking, sex work, migration, lack of education & gender discrimination are some of the factors responsible for increasing the vulnerability of women & girls to HIV infection².

Though AIDS has same manifestations in men and women, there are studies, which suggest that may be there is need of different approaches for female patients as combination of social, physiological and psychological factors appear to define implications among women. A research finding suggests that ART adherence depends

on interconnected psychosocial mechanisms and if improvement in adherence is required, interventions need to address both mental health and interpersonal factors, especially for minority women³. Specific psychosocial issues serve as barriers to treatment and adherence in women. Hence, it becomes very essential and crucial that women get support and guidance through counselling in such situations.

Worldwide studies conducted on HIV/AIDS counselling suggest that HIV/AIDS counselling guide people to take informed decisions, cope in a better way with their conditions, live more healthy and positive life and ultimately, prevent HIV transmission. It is a dialogue between a client and a care provider who guides and helps client to cope with stress. HIV/AIDS counselling is necessary because being HIV positive is a lifelong phenomenon as there is no cure yet, the positive person has to face broad range of physical, social, psychological and economic needs and problems.

The present research study would like to emphasise that counsellors have to work with HIV positive women in a holistic way. They can play vital role in guiding these women to lead a dignified and healthy life. In Indian context, the experiences of HIV are different in men and women and it calls for different strategies to address these experiences. Right now counsellors are playing role of pre and post-test counsellor, but they have to go beyond that and help women to understand their rights, need to provide legal guidance, have to teach them coping mechanisms, have to help them to gain emotional and mental peace. They also have to help to deal with family issues as support of family can help the women to deal with all, social, financial and emotional issues.

Research Methodology:

2.1 Objective:

1. To understand counselling needs of women living with HIV
2. To provide recommendations for widening counselling scope while counselling HIV positive women

2.2 Research Design: A mixed method research design; methodology comprise of both qualitative and quantitative method. Quantitative part included a survey of women infected with HIV using a structured questionnaire. The women participants were selected through NGOs working with HIV positive women. Interviews were conducted after seeking consent and ethical approval. Experts from different field were contacted and interviews were recorded after their permission.

2.3. Inclusion criteria: HIV positive women above age of 18 years living in Pune City and Pimpri Chinchwad City limits

2.4 Selection of sample: A non-probability sample was undertaken to assess the perceptions and experiences of infected women. NGOs working in these twin cities were contacted and women who fulfilled the inclusion criteria were identified. A written informed consent of these women was sought, only those who were willing to participate in the study were approached for interviews.

2.5 Sample Size: Sample was selected from the list of HIV positive women, provided by the four major not for profit organisations working in these two cities. The sampling frame was the total number of HIV infected women registered with the Non-Governmental Organisations (NGO). Optimum sample size was calculated using Krejcie and Morgan prescribed sample size table. The optimum sample size calculated was 147.

Qualitative exploration included expert interviews of social workers, human rights activists, counsellors, NGO directors, lawyers, and doctors. Ten expert interviews were conducted.

2.6 Data collection Tools:

Structured questionnaire: Interviews of women living with HIV/AIDS. Semi-structured questionnaire: Structured interviews of experts working in this field.

Secondary data collection included review of national and international publications such as books, magazines, journals, research articles, reports published by NGOs, government as well as private publishers.

2.7 Data analysis:

Quantitative data collected through the structured questionnaire was entered in Microsoft excel software, imported into SPSS (Statistical Package for Social Sciences) and analysed in terms of finding the association between independent variables and dependent variables such as family support, legal rights, mental health and awareness of disease. Chi square test was used to find the association. Qualitative data was first transcribed and then translated into English then coded and code specific quotations were analysed and interpreted.

2.7 Ethical Consideration: Written consent was taken from all the participants. Experts gave oral consent, which is recorded while conducting interview.

Results:

Quantitative results

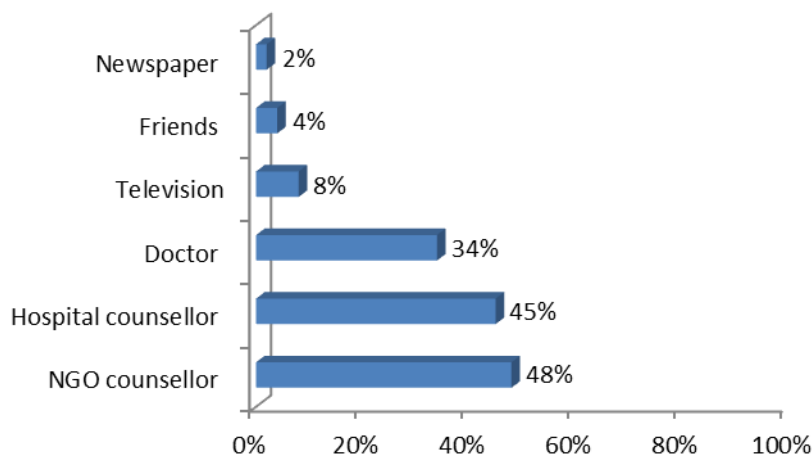
Information collected from 147 women was used for quantitative analysis. Most among these were from the middle age group (30 to 50 yr); married or widowed; educated; having a regular employment or are housewives; majority of them did not report the income, 65% of the respondents reporting two or more number of children (see Table1).

Table 1 Demographic characteristics of the study population

Variable	Frequency (N=147)	Percent
Age		
Less than 30 years	18	12%
31 – 39 years	66	45%
40 – 49 years	37	25%
More than 50	5	4%
Age not known	21	14%
Education		
Illiterate	29	20%
1st to 5th standard	24	16%
6th to 10th standard	71	49%
11th to 12th standard	16	11%
Graduate	6	4%
Marital Status		
Married	68	46%
Unmarried	6	4%
Widow	60	41%
Separated	8	6%
Divorced	5	3%

Variable	Frequency (N=147)	Percent
Income		
Less than Rs 3000	30	20%
Rs 3001 to Rs 5000	32	22%
Rs 5001 to Rs 10000	17	12%
More than Rs 10000	5	3%
Income not known	43	43%
Occupation		
Housewife	38	26%
Household work	24	16%
Domestic maid		
Daily wage earner	13	9%
Regular employment	44	30%
Student	5	3%
Unemployed	9	6%
Other	14	10%
Number of children		
No child	13	9%
One	33	22%
Two	53	37%
Three	23	16%
More than four	17	12%
Information not available	4	4%

Figure 1 Sources of Information on HIV and AIDS (n=137)



In the present study counsellors from both hospital (45%) and NGO (48%), emerged as the main source of information about HIV/AIDs for women participants. Second most frequently reported source of information was doctor (34%). Counsellors and doctors play vital role in imparting awareness of HIV/AIDS as well as about fundamental rights.

Other than awareness and health related counselling there are some other counselling needs of HIV positive women emerged in this study, these could be categorised into: legal and right based counselling, family counselling and psychological counselling.

3.2 Legal counselling: Among all the women, 29% actually opposed any discriminatory effort. Awareness about discrimination being a criminal offence is quite high among women (64%); among these women, 51% had experienced discrimination. Only 29% of the women who were aware of legality of the issue and faced discrimination actually opposed any such discrimination (See figure2).

Figure 1 Awareness and opposition to discriminatory practice

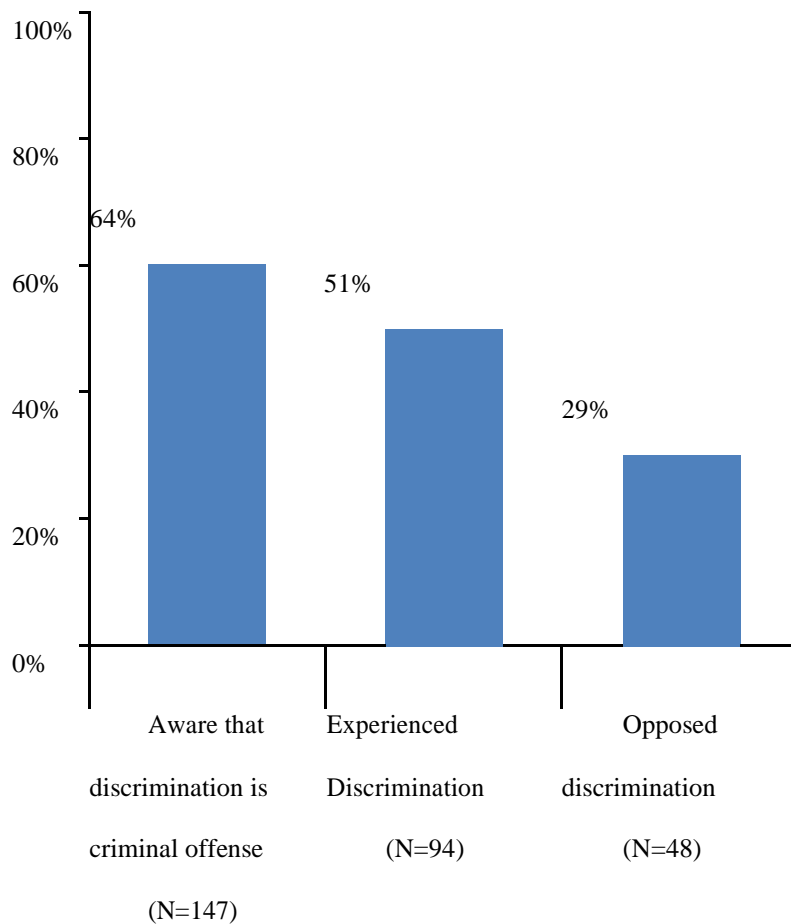


Table 2: Awareness about rights among women living with HIV/AIDS

Awareness about rights	Percent
Right in property (N=147)	79.6%
Right to confidentiality (N=147)	66.7%
Right to denial of physical relationships against wish (n=147)	66.7%
Individual rights (N=147)	50.0%
Right to work without denial (N=143)	49.0%

Right to treatment without denial (N=147)	46.3%
Human rights (N=146)	45.9%
Basic rights by law (N=147)	43.5%

3.3 Right based counselling: The study shows that less than 50% (45.6%) respondents were aware about the human rights, right to work without denial from employer, right to medical treatment without denial, right to necessities in the country. This indicates that a lot more needs to be done in this respect.

Figure 3 Awareness of human rights across educational categories (N=145)

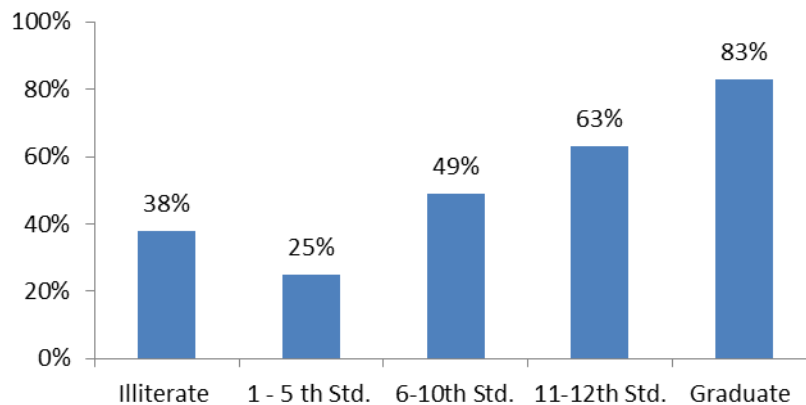


Table 3: Denied of Human Rights

Response	Frequency	Percent
Yes	35	24%
No	67	47%
Do not know	41	29%

Although over 46% of the women knew that they cannot be refused treatment, 54% of the women were not aware of it. (see Table 4). This suggests that there is scope for raising awareness of HIV-positive patients so as to empower them to access their rights.

Table 4: Aware that treatment cannot be denied by any health facility

Can't deny treatment	Frequency	Percentage
Yes	68	46.30%
No	79	53.70%
Total	147	100%

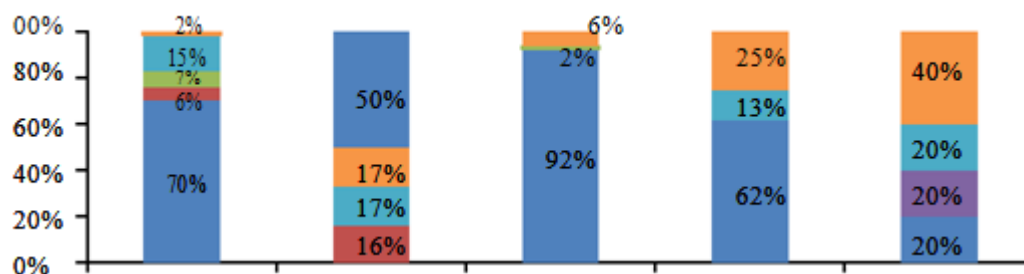
Table 5: Awareness about Human Rights

Education	Yes (n=66)	No (n=79)	Total (n=145)
Illiterate	11	18	29
Literate	55	61	116
<i>p value</i>	0.359		
Occupation	Yes (n=67)	No (n=77)	Total (n=144)
gainful employment	36	21	57
not in a gainful employment	31	56	87
<i>p value</i>	0.001		
Marital status	Yes (n=67)	No (n=79)	Total (n=146)
Married	33	34	67
Unmarried/widow/separated/divorced	34	45	79
<i>p value</i>	0.453		
Income	Yes (n=41)	No (n=43)	Total (n=84)
Less than Rs. 5000	27	35	62
More than Rs.5000	14	8	22
<i>p value</i>	0.105		

A chi square test of association as used to identify the background demographic variable that has closer association in determining the awareness about rights among the interviewed women.

Employment of the women emerged as the prominent variable determining awareness on the rights.

Infection through blood or the needle was cited as a source of infection by nearly 7% of the respondents (See figure 4). Contaminated blood implies negligence on the part of the health-care system and needs to be addressed along with other issues.



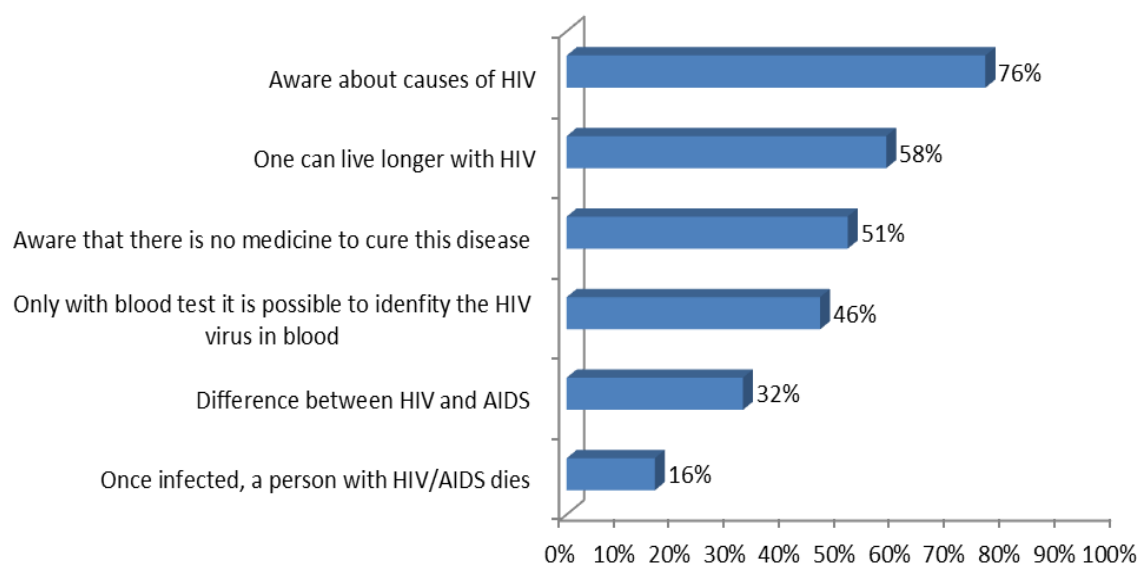
Married (N=68) Unmarried (N=6) Widow (N=60) Separated (N=8) Divorced (N=5)

■ Spouse, ■ Infected blood, ■ infected needle, ■ Friend, ■ No Knowledge, ■ Do not wish to tell ■ Mother

Figure 4: Source of Infection across marital status

But there is still space as more than 40% women are not aware that HIV cause death, as there is still no cure for this disease, there is need of consent before drawing blood for HIV testing. Most of the women informed that they got infection after marriage and husband is only sexual partner (see figure 4).

Figure 5 Awareness of HIV /AIDS



Although a majority of the women (66%) said they knew that they have the right to receive support from the family, the rest said they were not aware. This suggests that a more emphatic input is needed to make women aware of their rights.

With respect to the right to property, almost 80% of the women said they knew women have the right to property. It is worrisome to note that only a fifth of the women who were aware of the property rights have actually enforced their right. This could be because of the fact that lack of functional literacy among women and also lack of exposure to the outside world as many of these women were housewives. This shows that women need to be made aware about the resources available which can help them to enforce their rights. NGOs can play vital role in it.

The awareness about the right to physical intimacy only with consent was observed among 67% of the respondents. Nearly a third of the respondents were not being aware of this right is a matter that needs to be addressed and requires intervention in the form of wider dissemination about this right. For any medical intervention, while it is mandatory that a consent form be signed either by the patient or by the relative of the patient, it is seen that only 75% of the women had signed a consent form. A need for systemic changes and government interventions is indicated, so as to ensure that all existing norms are followed and women are made aware of their rights.

Table 6: Awareness about informed consent particulars (N=109)

Consent Issues	Percent
Not sharing information about illness with anyone	66%
Nobody will be informed about illness without my consent	51%
During the course of treatment, if need to be informed others, I will be taken into confidence	30%

Amongst Human Rights issues of HIV-positive persons, an important aspect is not being refused treatment. Fortunately, a large majority of the women respondents did not have to face this issue. However, a small proportion of women (13.6%) said they had been refused treatment.

Educational status determines the awareness about the right to receive support from the family. Looking at the role of income in awareness about the right to receive support from the family, it is seen that income does play an important role. All women who earned over Rs.5000 were aware. Higher income was connected with higher education and greater exposure and this perhaps contributes to improved awareness.

Though 91% women respondents were of opinion that if HIV positive women were given information about rights and legal aspects, their life will be better, healthy and happy but the fact is that only 50% women agreed being aware of their rights. Further, 82% women also affirmed that with such information women will be able to exercise their rights effectively in terms of protecting their and their children's interests and demand their rights. This information of study highlights that having knowledge of rights and enforcing those rights when needed has huge difference.

Family counselling:

Nearly fifty percent (48%) women reported taking self-care and none helped them. This represents sorry state of home care available to positive women in the study area.

Discrimination faced by women was mainly from the close relatives, as in most of the cases it is from the in laws (26), relatives (9) and neighbours (9). Women (5) also mentioned that there is discrimination from the medical fraternity in terms of avoidance behaviour or in term of lack of attention. Women and children suffer more with the consequences and stigma and discrimination within family.

In the present study women respondents mainly highlighted their own plight in terms of sufferings because of the HIV positive status; nearly 40% said that it is they themselves who have to bear the burden of being infected with HIV compared to other members in the family. About a tenth said that apart from them it is mainly the children, spouse and other family members who also have to bear the brunt of their HIV positive status.

In the present study, apart from the respondent herself, predominantly family members and the health personnel were aware of the HIV positive status of the respondents. Non-disclosure was quite evidently seen because of the stigma and fear of ostracism from the community. However, one of the positive sign was the disclosure with the family member (71%), doctors or counsellors (30%) and the immediate family members or close relative (21%) helps in seeking treatment. Forty seven percent women respondents said that they need financial support for treatment and they are getting it from the family, mostly from parents. Almost all the experts interviewed in the study shared that families also need proper counselling for care and support.

3.4 Counselling on awareness of disease

The present study explains on similar lines and able to capture the absolute fact regarding awareness status of HIV/AIDS disease among the women who are infected with the same disease. Details like "what you know about HIV?", close to 46% said that it can be diagnosed only through a blood test, it means more than 50% do not know proper way of diagnosis. Far fewer women said they knew the difference between HIV and AIDS (32%) and only 16% knew that the infection could cause death.

Ninety-one percent women respondents of this study said that they come to know about their HIV infection only after marriage. There were multiple sources of infection reported, nearly three fourth (74%) of the woman reported getting infected by the spouse and surprisingly 13% were completely unaware of the source of infection;

Psychological Counselling

In the present study nearly one in two women (45%; N=66) respondents reported experiencing discrimination because of their HIV positive status, predominantly by married women (52%) and widow (33%) and those who

are in service (38%). However, among women who were divorced, 60% reported experiencing discrimination and about 62% of women who were engaged in earning daily wages also had an experience of discrimination.

In the present study 70% among these women respondents were in the middle age group (30 to 50 years); 65% of the respondents reporting two or more number of children, 50% women have studied between 6th to 10th std. and only 5% have done graduation, 18% were illiterate.

Sixty eight percent of women in the study agreed that compared to women who were normal, HIV positive women face more problems in the society in terms of health issues (a third reported), stress (12%) and loneliness.

Discussion:

Legal and Right based counselling

Role of counselling in HIV/AIDS is perhaps more important than in any other disease. The research data shows women remember counsellors as the source of information prominently than any other source given the duration counsellors spend with the patient and they shared sensitive information as trust established.

The present study emerged with the specific areas but it shows that HIV positive women need to be made aware about their legal rights. It is clear that women are at risk of acquiring HIV when legal norms do not protect them and are not prepared by keeping their needs in mind. Women are most at risk when laws to protect them are weak. In sub-Saharan Africa, common law is associated with weaker female marital property laws. As a result, women have lower bargaining power within the family. They are more vulnerable to HIV as they have less power to negotiate safe sex practices as compared to their civil law counterparts⁴. In India, absence of adequate and appropriate legal rights give women secondary status, especially in relation to women's rights to divorce, to own and inherit property, to enter into contracts, to sue and testify in court, to consent to medical treatment and to open a bank account. For women living with HIV/AIDS means living with panic, stigmatization and discrimination including social rejection, denial and even violence within the family and the community.

The present study clearly points out that there is a need for awareness about rights among the women. Though the respondents know the existence of certain rights, they are not well equipped to use them and it is because of lack of knowledge. The knowledge about rights, when, where and how to use it, the resources to get it, are missing. One NGO Director and activist questioned that the illiterate women, who don't know how to read and write, do not understand legal issues or right-based content very easily; so one cannot expect that they will come forward and fight for themselves, they need guidance and support. Respondents including lawyers, doctors, and counsellors reported that many of the women barely know about their rights, which is why they suffer discrimination and stigma.

It is found that women were denied health related rights by health care givers. Experts interviewed in the study pointed out that women should be made aware about their rights and motivate them to ask for it. Study shows that though women are aware their legal rights, which are available for them, but reluctant to take action against any injustice occur to them or any legal steps against them. A reason which came out is, legal system is insensitive towards needs of women. The experts informed that lawyers do not take cases because they feel the client may die then who will pay his/her fees?

Confidentiality of HIV positive client is not kept in the court. They should be given fast track trials as health of these clients always has ups and downs. They also have financial constraints which can be affected with prolong trials. Sometimes they are single parents and only earning member in the family so they cannot afford to lose their wages or take frequent leaves from the work. Legal issues also create stress which adds more problems in their life. Sometimes these legal cases are against their family members itself which creates problems in relationship and cause more issues.

Right now there are very less organizations like Lawyers Collective who work towards legal and policy related issues of HIV positive people in India. Some of the NGOs guide PLHIVs through awareness or finding resources for them but India neither have low cost legal provisions for PLHIVs nor NGOs getting funding for this issue. The insensitivity about issue, psychologically and economically costing legal system doesn't give easy access to the justice.

This shows that women need to be made aware about the resources available which can help them to enforce their rights. NGOs can play vital role in it.

Amongst Human Rights issues of HIV-positive persons, an important aspect is not being refused treatment. Fortunately, a large majority of the women respondents did not have to face this issue. However, a small proportion of women (13.6%) said they had been refused treatment. Such instances must be looked into by the appropriate authorities and the person responsible for such refusal must be taken to task.

Experts interviewed in the study expressed that women should be independent to survive in this society. In order to help women gain independence, confidence building should be done through counselling, and more importantly, they should be made aware of their rights so that they can live with the disease in the society with self-respect. She needs to be empowered to take her own decisions for her physical and mental health, economic stability and equality.

Family counselling:

Support of family, community, and friends are very important aspect of care and support in the life of women living with HIV/AIDS. Family support included financial assistance, support in the disclosure process, daily routine activities, medical assistance or psychological support. Studies have shown that family support can reduce the stress. The moral support of family and friends can help women to empower herself.

A study on care givers conducted in southern part of India by Vishnu Chandran (2016) highlights the need to counsel the caregivers on how to deal with PLWHA in the family. Family care plays a major role in the general wellbeing of HIV positive women⁵. Women who are infected not only have to take care of themselves but she has to look after the whole household despite her illness.

It is necessary that counsellors should conduct counselling session with other family members who are aware about the positive status of a person. This can help to create support and care system for the WLHA.

Sensitization of the disease can be much easier if family is involved. Counsellor interviewed in the study shared her experience, she said that the fear of discrimination and 'questioning' by the society for an abnormal behaviour is so high that HIV positive women do not want the counsellor or the social worker to visit them in the village. The women in villages are so much scared that they fear non-cooperation even from the family members once they come to know about the illness. Women are ready to travel long distance and visit the counsellor in the city than the counsellor or the social worker visiting their homes.

HIV positive women also suggested sharing awareness message with all the women in the community and not only with them alone so as to avoid unpleasant questions from the other women. Stigma and discrimination attached to this disease compel HIV positive people to hide their identity. A study conducted in southern part of India suggest that "internalized stigma and a lack of social support were associated with a lower quality of life... it requires stigma-reduction programs for family and community members."⁶. Disclosure of the HIV status information corroborates with the fact that it is immediate family members who are the primary care givers for the people living with HIV/AIDS.

This is expected in a society where women tend to be devoted to the spouse but men tend to be promiscuous. The study conducted by Basant K. Pradhan and Ramamani Sunder for United Nations Development Programs

(UNDP, 2006) show that in India, especially in the family, there is a strong gender bias in HIV and AIDS related stigma and discrimination. Women & men are treated differently in the family. While men are likely to be accepted but women are always blamed even when they are infected by their husbands. This is very important that wives have all the right to know about her spouse status and save them from the deadliest disease of the world. Looking at the other side of coin, women also do not demand to know about her spouse's HIV status because she herself unaware about the disease and its consequences. It is very important that the counsellors need to encourage husbands, who are detected with HIV positive result, to inform their wives and conducting HIV test on them also.

Counselling on awareness of disease:

According to UNAIDS 2018 reports India's HIV epidemic is slowing down. Between 2010 and 2017 new infections declined by 27% and AIDS-related deaths falling by 56%⁷. Increasing awareness among the general population and key affected populations about HIV prevention is a central focus of NACO's programme NACP IV. However, as of 2017, only 22% of young women (aged 15-24) and 32% of young men knew how to prevent HIV⁸. This is reflected in the wider population, as only one-fifth of women and one-third of men (aged 15-49) had comprehensive knowledge of HIV and AIDS⁹.

In order to understand the effect of the background variables such as age, education, marital status, occupation and income of the respondents, these variables were cross tabulated with the outcome variables of HIV/AIDS awareness. Middle aged women (31-39 years), those who were studied up to 10th standard, married or widowed, having income up to Rs.5000 and are in regular employment reported increased awareness about HIV/AIDS.

Data analysis further revealed that women who are young, illiterate, unmarried, having poor income and unemployed / having irregular income are mainly vulnerable due to limited knowledge about HIV/AIDS. But if we take into account the another perception which says the ignorance of these women as well as unawareness towards getting the knowledge about the disease it suggests that after so many years of infection, they should have at least know that there is no cure for this disease and death can only give relief from it. Unless they have proper knowledge of the disease they cannot take care of their health and also other family members. It shows that may be counsellors need to give more efforts to convince for partner testing because counselling have power to help in change in behaviour, change in thinking.

Psychological Counselling:

Stigma and discrimination isolates women from community and society at large. Women who are infected and also caregivers in the family, drain all their resources, energy to take care of aligned person. But it isolates them from their usual social activities. It affects her health because she strains herself under the position of the caregiver. It requires unconditional support and confidence to fight against all the odds, against the societal norms.

When education is less, understanding or gravity of the disease and the options of employment are also less. Some women with HIV may not have people around to provide emotional support or other types of help. Health care workers and counsellor need to help emotionally vulnerable women to get family support. A study explains that the support provided by family makes multiple levels of positive impact on people living with HIV/AIDS, suggesting the importance of including families in HIV/AIDS intervention programs¹⁰.

Women who are abandoned by their own families, by own husband, by the whole society has to go with more emotional turmoil. Identifying psychological, emotional needs of women is crucial for counsellor as study has shown that emotional wellbeing affect the medication they are taking.

The findings of study conducted in Ontario Canada suggest that there is significant relationship between psychological distress and low CD4 count, socioeconomic factors which shape the demography of women living with HIV¹¹. The researcher explains that the success of antiretroviral therapy depends on the psychological

factors like depression because it can affect the treatment and because of that women are in need of greater supportive services.

The supportive services, which government and NGOs providing to HIV positive women, need innovations and wider coverage. A study was conducted in Karnataka, India, which assessed the acceptability of nurse-delivered mobile phone-based counselling to support adherence to antiretroviral treatment (ART) and self-care behaviours among HIV-positive women in India. Findings indicate that, when compared with text messaging, mobile phone-based counselling could be a more acceptable way to engage with women on ART, especially those with limited literacy¹².

The emotional needs of these women are much severe because of marital status. In India married woman has high status but if the woman is divorced or widow and HIV positive then she has to face worse stigma and discrimination. In spite of so many advances in the management and treatment, it appears the lives of many HIV positive women remain greatly affected by the infection with gender specific stigma and stereotypes¹³.

The Stigma and discrimination attack self-esteem of such women. Families, as well as the community, isolate them and this restricts them from living normal healthy life. A social stigma leads to self-stigma. She feels inferior because of severe shaming, sometimes by her own family. This is creating tremendous stress in their lives; counsellors are not giving much attention to these issues. Emotional support in such situations is utmost necessity and can show positive impact on the health of women.

Respondents from the study also believe the fact that there is no cure, “an HIV-positive person cannot become HIV negative”, leads to trauma. The main cause of concern for HIV positive women is their health and additionally if they lose their spouse the responsibility of the family gets placed on their shoulders. In some instances when the family isn’t supportive, they are often forced to move out and find accommodation elsewhere.

Respondents expressed the view that women should be independent to survive in this society. In order to help women gain independence, confidence building should be done through counselling, and more importantly, they should be made aware of their rights so that they can live with the disease in the society with self-respect. She needs to be empowered to take her own decisions for- her physical and mental health, economic stability and equality.

Recommendation:

1. Counsellors need to be connected to legal system so that they can guide and encourage women to use their rights.
2. Though women are aware of their rights but when time comes to act on it they are lacking that courage. Legal system needs to be sensitized for the same so that access to it will be easier for women
3. There is a need for sensitization of lawyers and of the judicial system. Lawyers hesitate to take cases of people living with HIV/AIDS because if the person dies, there will be financial loss, a stigma will attach that this lawyer is taking cases of HIV-positive people. Hence, lawyers’ attitude towards HIV-positive people of economically lower status makes it difficult to take advantage of legal system. Knowledge about HIV/AIDS and confidentiality are the important issues, which lawyers do not handle very carefully. Because of this, women respondents also find it comfortable to take help through NGOs.
4. Confidentiality, economic situation of the client, time constraints of the client, the physical condition of the client are the aspects which needs to be taken into consideration while dealing with HIV positive client especially women client.
5. Counsellors can play vital role in checking the women’s awareness about the disease, removing any misconception regarding it and updating correct and recent information. Women’s concerns and queries need to

be handled sensitively. However, counsellors are not going beyond routine Pre and Post-test counselling. The awareness of disease not only limited to Pre and Post-test it needs to reach out to women's health and emotional well-being.

6. Husbands need to be strongly encouraged to inform their partners about HIV status.

7. There are incidences where HIV positive women were denied health services. The appropriate authorities must look into such instances.

8. The education and employment of women are the factors that influence the decision of enforcement of rights. A larger study would be needed to substantiate the relationship between education and employment with the enforcement of rights by women.

Conclusion:

Women are inherently at disadvantage because of the gender inequality in the society. Limited education, income-generating avenues, patriarchal pressures in marital relationship hinder woman's empowerment possibilities. These factors were found to have a compounding effect in general on women's health and more specifically if they are infected with HIV.

Experts in the field reiterated that society at large needs to be sensitized so as to enforce existing norms against discrimination and to tackle the stigma aspect which remains a major issue in the Indian context. Working towards changing the mind-set was an important aspect as per the experts. Interviews with experts in the field of HIV, confirmed many of the findings from the survey of 147 HIV-positive women.

Findings of the study show that education improves knowledge and contributes to empowerment. This study confirms the assertion made through quantitative findings that systemic support structures and empowerment of women need to be integral part of counselling and counsellors certainly has bigger role to play in it.

Four areas of counselling are suggested in through this study-

- **Legal and Right based counselling:** accessibility to the legal system could be improved and linked with the counselling services for regular follow up. Counselling is a corner stone of HIV disclosure and treatment. Compared to awareness programs that are period specific, mostly one way and non-specific, counselling provides a way forward to educate the HIV positive person with knowledge about their basic rights, health rights, and rights specifically in the context of life after HIV. The study highlights the influence of education in determining positive living by HIV positive women and hence counselling can be considered as a means of information dissemination of rights. Rights can strongly be enforced when there is legal backing and hence the study calls for urgent action on the HIV/AIDS bill passed by parliament, which guarantees these rights to the infected person. A complete psycho-social, health and legal care framework can be a way forward to provide a dignified life to the HIV infected persons and families.

- **Family Counselling:** The moral support of family and friends can help women to empower herself.

Care and support of family is important aspect in the life of WLHA. Counsellors need to look at this aspect for creating a support system for the woman.

- **Counselling on awareness of disease:** There is an emergent need to correct and complete

information about HIV /AIDS and its health, social, economic implications on women's lives. Women can be reached through existing avenues such as support groups, NGOs, health centres etc.

- **Psychological counselling:** Stigma and discrimination, loneliness, burden of responsibilities, role of care giver create tremendous stress and can create mental health problems. Counsellors need to tap these issues in a patient and counsel and guide them for dealing with these stressful situations.

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