

Aftermath of HIV Infection: Women's Struggles – Expert Perspectives

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Abstract:

Background: Women and girls accounted for about 48% of all new HIV infections in 2019. Women are still seen as the vectors or reason for the HIV infection and are blamed for their family's sickness. Subsequently they suffer stigma, rejection and expulsion from family and community. The crisis deepens not only because of legal and economic differences but also because of limited access to health, education and social security services.

Methods: This paper has been informed by ten completed interviews with the experts in the field of HIV and AIDS. The interviews, which were unstructured, took the form of guided conversations. They were conducted at a location and time nominated by the experts and lasted between two to three hours. The topics covered in the interviews included: woman empowerment, stigma discrimination, rights of woman, gender equality, awareness and government policies. The interviews were tape recorded and transcribed. Experts were selected in the study by taking into consideration their experience in HIV/AIDS practice for 10 or more years and those who have actively worked for women's rights. Methodology adopted was snowballing where networking relationships of these experts helped identify another expert providing services in HIV and AIDS domain.

Findings: Study findings suggest that HIV/AIDS awareness should lead to gender equality, empowerment and no stigma and discrimination. If HIV positive woman need to lead a dignified life in developing country like India, i) She needs to empower herself-economically, educationally and legally, ii) Women need to fight for gender equality. She needs to improve her knowledge about her rights and the disease itself, iii) Women need to utilize available policies and acts which can help them to fight with all the stigma and discrimination and give them what is their right; and IV) Families of infected women need to provide support to her which can make her moral high and also systems such as legal services need to be sensitized and be supportive to women who need legal services; also, opportunities must be created by government directly or through civil society organisations to make these women financially independent.

Key Words: HIV/AIDS, women empowerment, gender equality, expert's perspectives, stigma & discrimination.

1. Introduction

“The greatest single international failure in the response to HIV/AIDS is the failure to intervene, dramatically, on behalf of women.”(Stephen Lewis, *UN Envoy on HIV/AIDS in Africa*, 3rd International AIDS Society Conference, Rio de Janeiro, 2005, p. 3)

The impact of HIV/AIDS reaches far beyond the health sector. It has severe economic as well as social effects and they are much more severe in women than men. Globally, every week, around 5500 young women aged 15–24 years become infected with HIV¹. Women and girls accounted for about 48% of all new HIV infections in 2019². Women are still seen as the vectors or reason for the HIV infection and are blamed for their family's sickness. Subsequently they suffer stigma, rejection and expulsion from family and community. The crisis deepens not only because of legal and economic differences but also because of limited access to health, education and social security services.

In India, the low status of women, poverty, early marriage, trafficking, sex work, migration, lack of education, and gender discrimination are some of the factors responsible for increasing the vulnerability of women and girls to the HIV infection. Though there is law and policy but still implementation of that law, policy is an issue.

Equal status, empowerment, gender, stigma discrimination are the important aspects for improving quality of life of positive women. A study conducted in Ethiopia on quality of life of HIV positive women, who are on ART, suggest that high proportion of HIV positive women on ART had poor health-related quality of life which was affected by wealth index, social support and duration on antiretroviral therapy³ Social support is most significant factor for improved quality of life among women living with HIV, in fact the study conducted in Ethiopia on the quality of life of HIV positive women who are on ART found that, social support positively affect five of the six domains of quality of life⁴.

Indian society characterized by varied cultural, social and behavioural norms these are contributing factor which is affecting HIV positive women and it need to be analysed to form appropriate policies to deal with this grave issue. Literacy and education are important tools for gender empowerment⁵ because access to education, enables women to find employment and enjoy better economic status. Through economic independence the achieve autonomy which makes them less vulnerable to domestic violence and abuse.

Experts who have worked for HIV positive people for more than one decade are very well aware about their social, economic, legal and human right issues. While working on the HIV positive women's challenges to get the required in depth information and practical solutions for it views of experts in this field is very necessary. They are the people who have working very closely with them, fighting for their rights, helping them to lead normal life. The intellectual capacities of these experts can help to prepare policies, amend laws and build up support system and strategies to provide dignified life to HIV positive women because they have worked with system extensively so they are the right people who can point out the exact things which need to improve.

The present research article discuss about the experiences of these experts and their views while working with HIV positive women. The reality which is shared by these experts helps to understand the challenges positive women are facing and the need of intervention. The researcher, on the basis of

expert's opinions, has found that empowerment, awareness about rights and disease itself, utilization of HIV/AIDS act (2017) and family support are the four aspects on which HIV positive women's quality of life is dependent and government needs to work extensively on these aspects.

Objective of Study

To understand through experts in HIV/AIDS socio-economic and legal aspects that can improve quality of life of HIV positive women in India.

2. Research Methodology:

This paper has been informed by ten completed interviews with the experts in the field of HIV and AIDS. The interviews, which were unstructured, took the form of guided conversations. They were conducted at a location and time nominated by the experts and lasted between two to three hours. The topics covered in the interviews included: woman empowerment, stigma discrimination, rights of woman, gender equality, awareness and government policies. The interviews were tape recorded and transcribed. All the participants were from Pune city though their work spread across India and some of them have worked internationally too. Experts were selected in the study by taking into consideration their experience in HIV/AIDS practice for 10 or more years and those who have actively worked for women's rights. Methodology adopted was snowballing where networking relationships of these experts helped identify another expert providing services in HIV and AIDS domain. (*Please see annexure for experts' information*)

3. Result:

3.1. Empowerment

A. Gender Equality

A male dominated society like India plays a very important role in the case of women living with HIV/AIDS. In India, the notion is that husband in married relationship is equal to that of God, so their mistakes are pardoned by society. The husband's health is given foremost priority and wives health is given secondary priority. Counsellors from expert's cohort shared that women ignore their health by saying that "let my husband first get well then I will come for medicines" because they are taught from childhood to give priority to the needs of male member first, a role of care giver is always with female member from the house. Equal status in the society is still distant for Indian women. One of the study participant shared that "*women may get support but not equal to men, she has to sacrifice a lot*". The study participant who is activist and a lawyer too, was of opinion that (Indian) "*society is insensitive towards women*".

A counsellor shared a story, "A man lost his job due to HIV, his children were removed from the school so the wife had to take up domestic work but other men began to exploit the woman", which shows why women prefer to stay in the shadow, this very good example of male dominated society. One of the legal experts also shared that "*They can take divorce on the account of cruelty, but (women) fear that they won't be accepted by the society.*"

Another aspect of gender inequality is power to negotiate for her health. Women cannot negotiate for condom use so that she can prevent herself from getting this deadlier disease. All the counsellors from expert's panel said that men do not use condoms and if they counsel women to negotiate it with their husbands, there are instances that husbands came and fought with counsellors for teaching it to their wives. One of the expert shared that women who are commercial sex workers are more of loss because customers demand sex without condom and they are the one who are having multiple partners. The same expert also shared that during survey they came across with women who are married and for money having sex with few limited partners. They have to suffer more because they cannot disclose to their partners they are married and vice versa and have to accept no condom clause too. In both the cases if woman refuse she has to suffer physical violence too in some instances.

All the interviewed experts agreed that, HIV positive 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. One of the counsellor shared that *"she is not independent and that's why she cannot fight for her rights"*. She needs to be empowered to take her own decisions for- her physical and mental health, economic stability and equality.

Respondents also said that there were fewer cases where the wife is HIV positive while the husband is not (discordant couple) but their husbands are taking good care of them, even accompany them for tests. However, this scenario is very rare, in most of the instances, the spouses suspect their wives of being sexually promiscuous when they learn that the wife is HIV positive, even when the infection has occurred due to contaminated needles/blood. Such spouses abandon their wives and marry another woman. On the other hand, in a situation when the husband is HIV positive and the wife is not, the wife tends to remain with her husband and takes care of him. In such instances, the wives have to be persuaded a lot to do get their blood tested.

B. Education and Economic Independence

For the empowerment of women, education and good financial condition are very important aspects. The study participants, who are working in counselling field for more than eight years, shared that women who visit them are from lower middle class or from very poor families and ignorant about the disease because of no or less education. They do not understand that this disease has power to destroy their life and there is no cure for it. To substantiate this finding, one of the counsellors shared that in the rural areas girls are married off at early age and become pregnant. During ANC if the girl is tested positive, the girls insisted to explain the report either to her mother or mother-in-law they use to say *"mala kahi kalat nahi... majya sasur la kinhva majya aai la saanga"* (I don't understand anything please explain report to my mother or mother-in-law).

However, one study expert who is social rights activist mentioned that, very little attention is given towards women empowerment, NGOs and activists are working on it but efforts are not enough. The study participants who are lawyers, doctors, counsellors and representatives of social welfare organizations spoke about the kind of help they provided to women who were HIV positive. This included educating them on issues related to HIV/AIDS, counselling them on their health and legal rights, providing confidence building and providing them inputs to make them self-reliant.

All the respondents agreed that education does make difference while responding to HIV/AIDS. According to them, educated women are confident and fight for their rights. One of the counsellors shared her patient's statement which really depict empowered woman, *"My in-laws didn't give me my share of property but I will fight in the court and will ask them don't give me the property but do you at least take responsibility that your son/brother gave me this disease?"*

Counsellors among expert cohort shared that illiterate women are worse off because they have limited options to get economically stable and dependency of many years on husband makes it difficult to deal with challenges. According to experts to empowerment these women confidence building activities, improving facilities as well as the support system are important aspects to help these women. Some of the experts said that support groups can play important role within family for creating this support system.

Almost all the experts suggested skill based training for these women which can leads to self-employment. This includes tailoring, homemade food, agarbatti/candle making, decorative things, bag making etc. They can take up occupations which do not need certifications. With financial self-sufficiency, the ability to fight for their rights will be easier. Lawyer and human right activist from expert cohort said that *"We have to empower them for doing productive work. We need to give them strength for economic freedom... our system misses that."*

3.2 Awareness

A. Awareness of Laws and Rights

The fact shared by experts is *"When it comes to HIV, people think about medical help, nobody thinks about human rights"*. One of the lawyer among the respondents said that HIV has multi-dimensional aspects. Tackling HIV related issues is a continuous process. For example, the aspect of safe sex must be covered. Women friendly measures are needed in this regard. Contraceptives must be made easily available. Another aspect is laws and policies that support women; they need to be made aware of those laws and their rights. All the experts shared that the government should provide health insurance and treatment must be provided without any discrimination because health is as a basic right for these women. The expert reminds that the Act of HIV/AIDS mentions that doctors cannot refuse treatment to HIV positive person.

Almost all the experts raised a valid point that the illiterate women 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 lawyer, doctors, and counsellors reported that many of the women barely know about their rights, which is why they suffer discrimination and stigma. The system should be such that accessing rights is made easy.

All the experts are of opinion that the general public, especially people who are not infected, should be made aware of the legal rights of HIV-positive people. People need to know about the legal issues and lawyers need to be sensitized. NGO directors, lawyers, and activists mentioned the need for sensitization of lawyers and of the judicial system, is very necessary. One of the human right activists shared that 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 the this lawyer is taking cases of HIV-positive people.

Hence lawyer's 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 NGO or the organization.

A lawyer working for social-legal issues since the last 14 years for marginalized groups opined that although human rights are for everybody since birth, due to discrimination, some people are unable to access these rights. Women constitute one class in our society which cannot access its rights. She has seen cases where "*...there are cases where the women are not allowed custody of her children just because of her HIV status*". In most cases, women tend to be suppressed, although there are exceptions to this. According to one of the expert who is lawyer, "*They did not feel like knowing about their rights when the family started harassing them. They should have had a dialogue with someone regarding their rights. People come to us when violations happen, (.....they should come much before that)*"

All the experts also emphasized the issue of women's rights. They observed that HIV-positive women need to be educated about human rights but also need additional help/support in order to access these rights. Looking at women's vulnerability and unequal status of women in society, they need all kinds of support, especially family and economic support. Experts shared that HIV positive women are often not aware of their rights because they are made to think that being HIV-positive means that the sufferings they have undergo is something that they deserve. They are made to think in this way due to traditional values and the stigma attached to HIV-positive status in our society. Being diagnosed with a debilitating condition like HIV, impacts the woman psychologically too. Thus, many women begin to believe that they have not long to live and there is no point in standing up for their rights. They don't fight because they find it worthless.

Another counsellor cited the story of one of her clients. Her client, though well aware of her rights was extremely reluctant to repeatedly visit the court or make frequent visits to the police station for registering complaints. Her client was of the opinion that repeatedly taking time off from work to take follow up with the police and spending money to legally fight the case, does not pay off due to long drawn out justice and poor outcomes of legal cases. She told the counsellor that she would rather use the time spending quality time with her daughter and her parents. The client was a relatively well educated woman and had studied up to the second year of degree-college. Despite this, she was reluctant to pursue justice.

The counsellor expressed the view that many women choose this path of not fighting for their rights even when educated, as they find it cumbersome, "*Men often come to court but women fail to reach to the court*". This reflects on the functioning of the legal system (judiciary and police enforcement). Almost all the experts agree that legal system needs to improve. One of activist mentioned that "*...the system is against everything, for getting a work done, one need to visit the system 10 times, need money for commutation*".

B. Awareness about Disease

One of the experts expressed the view that women live in fear because in our society, a woman who lives alone or a woman with children, who lives without a male support is looked upon with suspicion. Society tends to stigmatize such women. This is why rather than opting to live separately HIV

positive women often chooses to live with their families/in-laws even if it becomes problematic or she has to face harassment. This is why despite knowing of their rights, women are reluctant to fight for them.

All the experts opined that there is still lot of awareness about the disease is required. Women, particularly rural women are still not aware about HIV/AIDS and its consequences according experts, *“In metros women at least approach us but in villages there is still lot of stigma”*. The stigma and discrimination is spreading because of lack of awareness. One of the counsellor from expert’s panel even said that “more than HIV positive people it is HIV negative people who need to be made aware about this disease and rights of these people”, for that she gave example of one of client her brother is not able to get girl for marriage just because his sister is HIV positive. This disease attacks on the character of woman and not just on her body. Because of lack of knowledge a HIV positive woman’s family made her to live in a hut outside the house and whole village abandoned her. She died because of lack of medicines and more of the stigma and discrimination.

All the counsellors from expert’s panel shared that after counselling, women understand the importance of HIV testing. College-going students approach counsellors and seek to be tested for HIV. Unwed women and widowed women also come forward for testing. This is a major change from the time when women, of their own accord, never came forward for testing. Now, women come for testing and often also bring their children for testing though percentage is less but encouraging. This is due to the awareness-raising efforts of government and various institutions.

According to NGO director from experts cohort, *“There are two types of stigma seen in HIV positive people, self -stigma and outside stigma. Self -stigma is more than the other”*, which leads to emotional distress. Apart from raising awareness, counselling is a source of psychological support for these women. In many cases, more than physical complaints, these women tend to have requirements of additional emotional support, expert feels that she should be treated as human, *“If she is HIV positive her feeling won’t die... right?”*. In instances where women are physically abused at home, counselling inputs include providing empowerment, courage and motivation. Among women who are HIV positive, widows also need additional help as they carry the responsibility of earning to take care of their family.

3.3 HIV/AIDS Act

HIV/AIDS Prevention Act (2017), is an act of the Parliament of India that provides for controlling and preventing of HIV/AIDS and securing the rights of individuals diagnosed with HIV/AIDS. The HIV/AIDS Prevention Act originated from a draft bill submitted by Lawyers Collective, a non-governmental organization.

Almost all the experts feel that the medical intervention and the enabling environment must go hand in hand. Legal experts from the cohort feels that HIV/AIDS bill (2017) can help to create this enabling environment. Lawyer and human right activist is very positive about implementation of HIV/AIDS bill. According him it can make huge difference in women’s life because *“it promises to create a system for legal issues”*. It will provide access for HIV positive people, to their legal rights. He further shared that PLHIVs are considered as a ‘under carpet population’, who doesn’t want to disclose their identity. In India people scared to get stigmatized and it prohibit them to come out in open and fight

for their rights. He thinks that now it is absolute need that PLHIVs have to come together and fight for their rights, it can be coming out on streets as 'Morcha' (gathering), and fight for fellow positive persons. He feels that it is not only organizations but positive people and especially women, should also demand reinforcement of the HIV/AIDS Bill.

One of the experts feels that it is Indian government's failure for not addressing the challenges faced by HIV positive women appropriately. The expert has questioned that "... *why aren't government taking the responsibility of these people? Overall GDP only 2% is spent on Health because health is not a priority for government. Then how much budget we can expect for HIV and women? How much do you think they will get?*" So there should be special measures for HIV infected and affected women, is what experts expect from government.

3.4 Family Support

Gender roles in most societies dictate that women are the care givers; hence have to bear the huge burden of AIDS care within families and communities. But does she get that care and support, particularly from family members, when she gets sick? One of the counsellors from expert's cohort said, "*Most of the time family do not give support and if wife is positive it is most difficult*".

All the respondents shared, based on the large amount of cases they came across of harassment, that women do not get support from their families. They shared that they have seen women were mentally harassed or even thrown out of the house by in-laws when they realize that she is infected with the disease, despite knowing that women may have got the virus from their own son. In-laws give support to daughter-in-law so that she can take care of their son who is sick, but as soon as the son dies, the daughter-in-law is thrown out of the house along with her children. The counsellor stressed further that, "*the real need of human rights is for widows in India, after husband's death their life is hell*".

Almost all the experts shared that families also need proper counselling regarding HIV/AIDS patient care and support. One of the experts shared that it is correct that she should fight for her rights but she alone cannot fight for rights, she needs support and family can be her biggest strength and support.

Respondents also believe that the fact that there is no cure, "*an HIV-positive person cannot become HIV negative*", and that leads to trauma. The main cause of concern for HIV positive women is their health and additionally if/when they lose their spouse, the additional burden of becoming responsible for their 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. Doctor from expert cohort felt that psychological support/moral support from the family is important. In his view, need of such psychological support increases after counselling. He stated that both human rights and health rights are important, so awareness-raising on these issues must be carried out.

An expert from cohort said that pressure from the family is responsible for women not coming forward to fight for their rights though they know the rights. A counsellor cited a case from Kolhapur where the woman's husband owns a grocery store and a house. Both properties are in the name of the husband. When the woman was informed that she could claim her property rights, she refused saying it could lead to her being abused by her in laws who may stop giving her food. However, among the respondents, some counsellor also received good feedback from some women who are HIV positive and

their husbands or in-laws or even the daughter-in-law took proper care of them and they were also supported by their family due to which they did not had to fight for their rights.

4. Discussion

Findings in this study is consistent with previous studies and showcases that much of the divide between what girls and women knew as "HIV prevention behavior" and what they actually have the power to do is rooted in gender inequality.⁶ All the social barriers roots down to one reason and that is gender inequality. Woman's/girl's health, education, economic independence, empowerment everything is depend on how equally she is treated in the family, community and society. While discussing with experts from HIV/AIDS field the most prominent factor which come out of it is gender inequality. There are many studies which highlight this point and urge respective countries to work upon it. But still there is lot be done in India. In India the prevention strategies are failing because "... does not speak to the reality of women's and girls' circumstances in part of the world"⁷. The prevention strategies have missed to pay sufficient attention towards critical aspects and those are, gender power and poverty. That is why after the death of the husband or disertation by husband and family, women's life becomes hell. One of the experts from the study rightly said, "Society is insensitive (towards woman)"

As per NFHS-4 data, nearly 22% women and 31.5% men have comprehensive knowledge about HIV/AIDS. If we can see overall, the knowledge level is less about the disease but in women it is dangerously low. The knowledge of disease is the important prevention tool and that makes girls and women vulnerable. Counsellors from cohort of experts have similar observation; most of the women are from lower economic background and with less education hence, have little knowledge of the disease and severity of being HIV positive. Giving less priority to education of girl child also leads to the point of gender inequality which is certainly a social aspect which country like India needs to work on priority basis.

Experts have raised concerns of widow HIV positive women. They think they are the worst affected by the disease. In India women with marital status of widow and divorced or separated have lower social status and if woman with such marital status is HIV positive then it increase her sufferings. As informed by the experts women are always blamed for husband having sexual relationship outside marriage, they are even blamed for the infection. In reality the infection rate is increasing, more rapidly among women, particularly among those women whose only high risk behaviour was being married.⁸

These expert's opinions suggest that these women constitute a vulnerable population who need additional services to optimize their health and who might benefit from peer support interventions and stigma-reduction programs for family and community members.⁹ One of the counsellor from experts cohort shared one of her patient's experience that she cannot eat enough food though everything is available at home, just because it is decided how much a woman can eat. Because of such mentality or cultural norms HIV positive woman is unable to maintain her health.

When women feel they are being judged or doubted by others, they are likely to protect themselves by avoiding medical and other support services, which they may actually need¹⁰. The social isolation of women living with HIV makes them especially dependent on medical practitioners. Yet

health care support is extremely problematic for many HIV positive women¹¹. There is abundant literature on the problems faced by women in negotiating condom use suggesting that women want to have access to female condoms¹². Though condom use is the only preventive method produced since the start of HIV pandemic, women in developing and under developing countries has virtually no access to the female condom¹³.

The social status and empowerment of women are two important aspects for combating the disease like HIV/AIDS in India. According to experts, from present study, women's risk of getting HIV infection increases because they lack economic rights. In the developing world women produce two-thirds of the food but she herself own less than 15% of land worldwide¹⁴. The lack of education, financial independence, exposure to mass media, and autonomy often leave women in many parts of the country unaware of the dangers of HIV/AIDS¹⁵. Previous literature from NFHS-3 data reveals mixed findings of poverty as significantly associated with HIV infection among women to a relatively inconsistent relationship between household wealth and individual HIV status.¹⁶

Experts assert that HIV positive women need to be empowered by making them well aware about their rights. A study conducted in Sub-Saharan Africa on women acting as heads or primary caregivers of HIV-affected households, found that when women's property and inheritance rights are supported they are better able to mitigate the negative economic and social consequences of AIDS¹⁷

All the respondents stressed on the point that to empower HIV positive women she needs to be economically independent because it will make her confident and improve her quality of life. Microfinance has one such good way to make these women independent. World Vision has conducted community banking programmes in which they successfully combined HIV/AIDS education with facility of microfinance to groups of 20–30 women. After evaluating the programme it is found that the women showed greater economic resilience, high level of HIV awareness and prevention behaviour, improved educational achievements in their children, and better nutrition within their families¹⁸

WHO in its "Consolidated guidelines on Sexual and Reproductive health and rights of woman living with HIV/AIDS"¹⁹ clearly state that there should be right based approach to deal with Sexual and Reproductive Health (SRH) issues of HIV positive women and human rights of HIV positive women needs to protected at all cost. Experts from the present study also state the urgency of it. The human rights activist and lawyer state that HIV positive people fail to understand their own rights and to fight for it. Women especially avoid taking legal or judicial help to fight against any unlawful thing because she do not have support of own (HIV positive) community. Only awareness about her rights and resources to get it is not enough, the enabling environment needs to be created. According to experts the process of legal system needs to be made more flexible to HIV positive people. Legal counselling is necessary. NGOs can play important role in providing mental, moral and legal support to these women. As suggested rightly by experts, legal counselling, family counselling, support groups of HIV positive women can help them to create their surrounding supportive and positive.

HIV/AIDS Act 2017 is important step taken by Indian government for giving dignified life to HIV positive people. This act will help HIV positive women to protect against the stigma and discrimination at community as well as at health care setting²⁰. The legal accountability will be on implementers now. That's why the lawyers, activist and director of NGOs feels that this act, if utilized by positive women, can help them to improve their life and they can lead dignified life in the society. One of

the experts rightly commented that for improvement in quality of life of HIV positive women all three 'A's'- awareness, acceptability and accessibility, have to complement each other and HIV/AIDS act can be safest tool for it.

The scenario which experts have shown through their experience is not very encouraging. The women who are living with HIV/AIDS still need lot of support, counselling, guidance and hand holding to fight with barriers which are not allowing her to live a happy and healthy life. Women will get empowered when they stop thinking that this disease is their 'Karma'; she has to come out of her own barriers to fight with outside barriers.

5. Suggestions by Experts to Improve the HIV Positive Woman's Quality of Life:

- NGOs can play vital role in providing legal guidance and resources to HIV positive women. They can also play major role in empowering these women to use their rights.
- NGOs engaged in HIV-related work should create support groups for HIV positive women. The medium of the support group is very effective in providing moral support and also for disseminating information.
- The government should create a special cell or department to tackle HIV related issues. Implementation of HIV/AIDS Act is crucial. According to experts 'legal system or process should be made easier'.
- HIV positive people need inputs in terms of training and skill building education so that they can be self-sustained.
- Female condoms need to be made available easily to women and awareness of the same needs to be done.

6. Conclusion:

More than disease prevention awareness needs to be at deeper level and need to take into consideration various aspects which affect normal life of HIV positive women. Now, after more than 30 years of HIV/AIDS existence, awareness should lead to gender equality, empowerment and no stigma and discrimination and then only HIV positive women can improve their quality of life. If HIV positive woman need to lead a dignified life in developing country like India, i) She needs to empower herself-economically, educationally and legally, ii) Women need to fight for gender equality she needs to improve her knowledge about her rights and the disease itself, iii) Women need to utilize available policies and acts which can help them to fight with all the stigma and discrimination and give them what is their right; and IV) Families of infected women need to provide support to her which can make her moral high and also systems such as legal services need to be sensitized and be supportive to women who need legal services; also, opportunities must be created by government directly or through civil society organisations to make these women financially independent.

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Annexure

Sr. No.	Name of the Expert	Profile	Experience
1.	Mrs. Ujjawala Kadam	President of NGO Soudamini-Network of Positive Women and Children Trust.	Since 1992 She is dedicatedly working and fighting for the rights of women living with HIV/AIDS. She has worked national and international level for the betterment of women living with HIV/AIDS.
2.	Mr. Manoj Pardeshi	General Secretary of National Coalition of PLHIV in India- NCPI+ and Regional Representative of Global Coalition of TB Activist.	Since last two decades he has dedicated his work for the People living with HIV/AIDS. He is working at national and international level on the Human right issues of people living with HIV/AIDS. He had helped Lawyers Collective organization for drafting the 'HIV/AIDS Bill'.
3.	Dr. Prakash Onawale	Medical officer and Trustee of NGO Deepgriha Society.	He is working since 37 years with the people living with HIV. He regularly has interaction with PLHIV as he attends clinic run for them. He was working for these people since 'Wake

			Up Pune initiative'. He is well aware with the issues of women living with HIV/AIDS.
4.	Adv. Asim Sarode	Human Rights Legal Activist, Freelance writer and lawyer.	He started his work by providing free legal aid to prisoners in Yerwada Central Prison. He provides legal to sex workers who are victimized under Immoral Traffic Act. He is founder of Sahayog Trust-Human rights and Law Defenders which is a legal wing run by students and volunteers. This mainly deals with cases that fall under vast umbrella of Human Rights.
5.	Adv. Rama Sarode	Lawyer and trainer	She is extensively working for women empowerment and rights. She is external member of POSH committees with corporate, trainer of Sexual Harassment of Women at Workplace, Child sexual abuse, domestic violence, human rights, and advocacy.
6.	Mrs. Nandita Ambike	Human Rights Activist and Executive Director of Foundation For Child Protection.	She is master trainer of Leadership Development and conduct trainings on women empowerment. She has fought for the human right issues of with sex workers, transgender and women living with HIV/AIDS.
7.	Mrs. Varsha Shirke	Counsellor at ANC clinic of Sassoon hospital.	Extensively and closely work with the issues of the women living with HIV since last 10 years.
8.	Mrs. Pradnya Mane	Counsellor at ART centre, Sassoon hospital.	Extensively and closely work with People living with HIV/AIDS since last 10 years. She come across several cases of HIV and need to interact with them on daily basis for support and care.
9.	Mrs. Prasanna Alone	Psychologist and Counsellor in clinical trials.	She has worked extensively in the clinical trials of NARI. Handled HIV counselling and worked very closely with people living with HIV. She is

			expert in psychological counselling and handled several cases of HIV positive people.
10.	Mrs. Suhasini Surve	Counsellor in B.J Medical Trial Unit.	She is working in HIV/AIDS field since last 13 years. She has worked in NARI's clinical trials and now working with B.J Medical college. She is closely working with women living HIV/AIDS and counselling them for several issues. Hence understands the issues related to HIV/AIDS.