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Barriers to Avail Health Related Services by the Women Living with HIV/AIDS in Manipur

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Abstract:
This paper reports on the results of eight (8) semi-strctured focus group discussions and twenty (20) case studies carried out with 100 women living with HIV/AIDS in four districts viz., Imphal East, Imphal West, Churachandpur and Ukhrul of Manipur, one of the north-eastern states of India bordering Myanmar. In this paper, we analyse the stigma and discrimination faced by the women living with HIV/AIDS (WLHA) at the health care facilities where they seek treatment. Findings show that the health care sector is perhaps the most conspicuous context of HIV/AIDS related discrimination, stigmatization and denial. Most of the participants described their experiences vis-a-vis the denials of basic services in seeking treatment for general illness. These impediments included early discharge from hospital, delays in treatment, slow service, postponed surgery, conditional treatment and unwilling to do any job which involves blood. They also spoke to how medical staff refused to touch them and gave oral medicines rather than injections and denied medical treatment such as administering insulin, vitamin and drip injection. Another area in which stigma and discrimination affect women living with HIV/AIDS (WLHA) is reproductive health. It is also observed that HIV positive women often get caught between pressures from health workers not to have children and pressures from family members to have children. Most of the young respondents reported doctors/nurses were not willing to perform delivery on them. Many a time when they revealed their status the doctors/nurses hesitated to handle them. Some respondents responded that at the time of their delivery government hospital's staffs (doctors/nurses) immediately sent them to private hospitals saying that requisite facilities are not available with them. We hope the present report can improve care and support services to women living with HIV/AIDS. It can help to prevent HIV infection, improve access to HIV treatment, care and support, and lessen the impact of HIV/AIDS, particularly among the most vulnerable and marginalized section.

Keywords: *HIV/AIDS, Focus Group Discussions, Case Studies, Churachandpur, Ukhrul*

1. Introduction

The disease-AIDS which has no cure till today remains a challenge to mankind. Unlike most other conditions, however, there can be extreme stigma-related stress, such as fear and secrecy, which can compound existing burdens of illness and coping (Richmond and Ross, 1995).

Women and girls, including those who are themselves HIV positive, also bear the physical and psychological burden of HIV and AIDS care. Women thus carry a 'triple jeopardy' of AIDS: as people infected with HIV, as mothers of children infected and as carers of partners or parents with AIDS (Paxton and Welbourn 2004). A UNAIDS report in 2004 showed that 90 percent of care for people living with AIDS takes place in the home (UNAIDS 2004:118) and is provided overwhelmingly by women and girls, who are frequently unpaid and receive little support or training from the State. Home-based care is often perceived as a 'cost-effective response' to the epidemic, yet in reality it is exploitation of women's unpaid labour, only made possible because care work is seen as 'women's work' and is thus accorded less recognition and value than the work undertaken by men (Voluntary Services Overseas 2006). Women and girls are especially vulnerable to HIV infection due to a host of biological, social, cultural and economic reasons, including women's entrenched social and economic inequality within sexual relationships and marriage (Esplen 2007).

A study by Bharat et al., (2001) conducted in Mumbai and Bangalore, many health care providers and facilities were found to deny care, treat patients poorly, and stipulate conditions for agreeing to treat people living with HIV/AIDS. Another study undertaken by the International Labour Organization (2003) of India in Delhi, Manipur, Maharashtra and Tamil Nadu further highlights the various forms of discrimination in a health facility include refusal of treatment, discriminatory precautions and lack of confidentiality. Doctors often refuse to assist in the delivery of a HIV-positive pregnant woman, despite minimal risk of contracting the virus. Another study undertaken by UNDP (2006) reveals that 25% of people living with HIV in India had been refused medical treatment on the basis of their HIV-positive status.

So far no systematic study on barriers to avail health related services by the women living with HIV/AIDS in Manipur. Keeping this view in mind it is hereby proposed to take up "study on barriers to avail health related services by the women living with HIV/AIDS in Manipur".

The main purpose of the study is to obtain an integrated picture of the nature and severity of the barriers to avail health related services around care, treatment and support, sexual and reproductive health and RTI/STI infections etc. by the women living with HIV/AIDS, against the background of the existing medical and sanitary facilities available so as to discover the main health provisions and necessary measures of bringing about improvement in the health care system.

2. Methodology

This is a qualitative study conducted in four districts viz., Imphal East, Imphal West, Churachandpur and Ukhrul of Manipur, one of the north-eastern states of India bordering Myanmar (Burma). Manipur is geographically very close to the notorious "Golden Triangle", which geographically composed of northern Thailand, northern and eastern Myanmar and Western Laos.

The study has been conducted eight Focus Group Discussions (FGDs) in the four districts (Imphal East, Imphal West, Churachandpur and Ukhrul) – two in each district, among the infected mother having children. The number of participants in each group was 10 women having similar age group of their children. Another 20 Case Studies were undertaken in the four districts (Imphal East, Imphal West, Churachandpur and Ukhrul) – five in each district, from the infected mother having infected children to understand their peculiar and significant problems. The study participants were selected through convenient sampling method as detail database of women living with HIV/AIDS was not available for random selection.

For the collection of the study population, different Drug abuse and HIV/AIDS epidemic relevant NGOs/CBOs/FBOs (Non Governmental Organizations/Community Based Organizations/Faith Based Organizations) in the study areas (Imphal East, Imphal West, Churachandpur and Ukhrul) are selected purposefully. Informed consent was obtained from every participant in the research. The field work for the study took place between March 2010 and March 2011. The Focus Group Discussions and Case studies were recorded on tape with due informed consent obtained from the respondent and later transcribed for analysis. Mainly, the data was collected at the office of HIV/AIDS related organisations and few were collected at the place of convenience of the participants. The interviews were carried out by an interviewer and a co-interviewer. Each focus group lasted approximately 90 minutes.

During the focused group discussion, women were first asked general questions about themselves, such as, their age, location, community, marital status, number of surviving children and family size. After building rapport, women were asked more specifically about their experiences of being HIV-positive, whether they had faced stigma or discrimination in health care settings. Discussions also covered their access to care and support services, their association with HIV/AIDS relevant networks and suggestions for addressing problems faced by the women living with HIV/AIDS.

2.1. Study Limitations

Mobilizing the individual respondents for focus group discussions were quite difficult, especially in the difficult tracts of Churachandpur and Ukhrul districts.

3. Result

3.1. Characteristics of Study Participants

A summary of the main characteristics of the participants is presented in Table 1 and 2. Table – 1, summarizes the profile of focus group discussion's women participants (N=80). Participant's age ranged between 20 and 45 above. Most of the sample women were in the age group 35-39 years, which is followed by the age group 30-34 years. It can be assumed that the worst affected are those in the age group of 30-39 years, which is the most productive group. 42 women (52.50%) out of 80 participants belong to this group. Their marriage profile shows that out of 80 participants 38 were currently married and another 38 were widow and remaining 4 were separated/divorced. Table – 1 also shows that 38 out of 80 participants have 2 children. Only 4 participants have 5 and above children. Their health profile shows that 45 out of 80 participants are undergoing ART treatment while 35 participants are not On ART. Prevention of Parent to Child Transmission (PPTCT) treatment was taken by few participants. Only 11 out of 80 participants had undergone PPTCT treatment. In the case of contraception used, 54 out of 80 participants ever used contraceptive method to delay or avoid getting pregnancy. 26 participants never used contraceptive method. Table – 1 also presents information on the reported source of HIV infection. Except one respondent, all women reported that they had contracted HIV from their husbands. One woman reported that she had got the infection as a result of blood transfusion.

Table – 2 summarizes the profile of case studies women's respondents (N=20). The general age groups of the respondents are 30-34 (8/20) and 35-39 (7/20). It is found that 13 respondents out of 20 are currently married and another 7 are widow. It is also observed that majority 45% (9/20) of the respondents have 2 children closely followed by 35% (7/20) of the respondents who have 3 children. From table, it is seen that 70% (14/20) of the respondents are undergoing ART treatment. 25% (5/20) of the respondents had undergone PPTCT treatment. In the case of contraception used, 85% (17/20) respondents ever used contraception. Table – 2 also presents information on the reported source of HIV infection. All respondents reported that they had contracted HIV from their husbands.

3.2. Key Themes

Three major themes were identified. 1) Barriers in seeking treatment for general illness. 2) Barriers in seeking reproductive healh services. 3) Barriers in treatment related to RTI/STI symptom.

3.2.1. Seeking Treatment for General Illness

Participants described their experiences vis-a-vis the denials of basic services in seeking treatment for general illness. These impediments included early discharge from hospital, delays in treatment, slow service, postponed surgery, conditional treatment, unwilling to do any job which involves blood.

" …. I had a swollen at appendix and it was necessary to remove it. Immediately after learning I am on ART, doctor did not want to perform the operation so he postponed the fix time by saying water is not available in the facility and referred to another facility." (FGD Imphal East)

"…. I had a fibroid at womb and it was necessary to remove it. The doctor in the District Hospital asked for operation. After knowing my HIV positive status the doctor said no operation could be done and sent me away after prescribing some medicines. Doctors refused hysterectomy because of my positive status". (FGD Imphal West)

"…. I had a dental problem; by thinking it is compulsory to disclose my status I disclosed my status to the concerned doctor. Immediately after knowing my HIV positive status the dentist refused dental surgery". (FGD Imphal West)

"…. Sometimes doctor treat us conditional treatment (e.g. only on the condition that the patient will come for follow up and collect ART medicine). Sometimes doctors do not check the patient's body and sign the case sheet thinking that it is not necessary to check the patient body for every month". (FGD Churachandpur)

"…. I had an affectation to access professional medical care for my treatment. After some months of started on ART, I was injured my big toe on the way to go to hospital for taking ART drug. After reaching there the doctors/nurses were not ready to give first aids and dressing my injured, it might be because of frequent visit at ART centre". (Case 10)

They also spoke to how medical staff refused to touch them and gave oral medicines rather than injections and denied medical treatment such as administering insulin, vitamin and drip injection. There were instances; many a times denied medical treatment such as administering insulin, vitamin and drip injection.

"…I called upon a nurse from my locality for my Drip-Injection. At that time the father of the nurse scolded me by saying 'you had an incurable disease so I cannot give permission to my daughter for your injection'. The nurse looked at me and kept silent." (FGD Churachandpur)

"…. A nurse from my locality who is employed in government hospital refused injection due to my HIV positive status". (FGD Ukhrul)

"…People treat us badly once they come to know. It has happened to me once. I had gone to the hospital for health check up. When I gave my case sheet they just put at the end of the bundle and told me to wait. They could have worn gloves and treated me. Nurse does not want to touch my body and used glove while giving injection and show afraid of me. There they treat me as untouchables. It is very insulting." (Case 2)

3.2.2. Seeking Reproductive Health Services

A high number of respondents reported that they had undergone abortion more than once**.** It has been noted that fertility appears to be lower among women living with HIV/AIDS because of the number of spontaneous abortion (miscarriages), still births and induced abortions they have. Poor maternal health results in low birth weight and premature babies, still birth, neonatal deaths, low birth weight babies. Heavy work during pregnancy can lead to premature labour and, when high energy demands are not compensated by increased caloric intake, the health of their unborn children suffers as well to still births and low-birth weight babies.

One area in which stigma and discrimination affect women living with HIV/AIDS (WLHA) is reproductive health.

Positive women often have limited reproductive choices however, as decisions may be made for them by their husbands, in-laws or health care staff. In relation to this circumstance a participant of FGD Imphal East mentioned that, "I had four daughters and unluckily two had died now I am currently pregnant because I do not have a son. I do not want more children but my husband and parent-in-law expected to have a boy child".

Young HIV positive women participants of the FGDs and Case Studies have reported that doctors often refuse to assist in the delivery of HIV-positive pregnant women, despite minimal risk of contracting the virus.

One respondent of FGD Churachandpur responded that, "Doctors/nurses do not want to touch my body, they delayed in delivery".

HIV positive women often get caught between pressures from health workers not to have children and pressures from family members to have children. Newly child birth respondents of FGD Churachandpur responded that, "Paramedical staff asked for not for another pregnancy".

Another participant of FGD Churachandpur narrated her experienced at the time of her last child gave birth. "…. When I went to gave birth to my last child, a lady doctor there spoke badly. She said that I should be sterilized because they do not want to carry out the delivery of HIV positive cases. It was really painful".

Talking about the current forms of stigma and discrimination and systemic problems that prevail, women from FGD and Case Studies reported that in the case of HIV positive pregnant women doctors are hostile and government hospitals immediately sent them to private hospitals saying that requisite facilities are not available with them. A woman of FGD Ukhrul said that she was refused admission at the government hospital for delivery because of her HIV status, "… I was pregnant. It was my fifth month, I remember well. I went for a check up at District Hospital. The doctor said they would check my blood. When they got my HIV report and it was positive the doctor said the hospital would not take me for delivery and told me to take to private hospital. Again, next time when I went to the doctor he said the hospital would not take me for delivery and told me to take to private hospital. Due to money problem I took my delivery at home".

Another Case Study respondent of Ukhrul responded that, "…I had an experienced of affectation to access professional medical care for my last but one and last son's delivery cases. At the time of my last but one son's case we went to the District Hospital but the doctors and nurses there said that the case was complicated and they would not look after my delivery and referred me to do at Private Hospital. Then we went to Comprehensive Health Research Centre (Private Hospital) and my delivery took place. After one year I conceived my last son. At that time also at first we went to the District Hospital but the doctors and nurses again asked my delivery to do at Private Hospital. Our family is not financially sound. Due to money problem I had done my delivery at home. At that time the nevirapine treatment of the child was given by a worker of Kaphung Reisang Long (an HIV/AIDS related NGO".

Again, another Case Study respondent of Ukhrul reported that, "…. I had an experienced of affectation to access professional medical care for my last son's delivery case. At that time we went to the District Hospital but the doctors and nurses there said that they would not look after my delivery and recommended us to another hospital. We went to Comprehensive Health Research Centre (Private Hospital) and my delivery took place".

Once again a Case Study respondent of Ukhrul narrated same experienced that, "… I had an experienced of affectation to access professional medical care for my last child's (daughter) delivery case. At that time we went to the District Hospital but the doctors and nurses there said it is very risky to carry out the delivery of women living with HIV so they would not look after my delivery and referred us to do at Private Hospital. Then we went to Comprehensive Health Research Centre (Private Hospital) and my delivery took place. The charge for delivery is high, so we borrowed money from money lender which we have still to repay".

3.2.3. Barriers in Treatment Related to RTI/STI Symptom

From the FGDs and Case Studies it was found that most respondents had at least one or more than one symptom related to reproductive tract infection/sexually transmitted infection (RTI/STI). Most respondents consult with the concerned doctor of their respective NGOs/Networks (Drug Abuse and HIV/AIDS relevant), some consult with pharmacist and few of them also do self medication.

In relation to this condition, some participants of FGD Imphal East reported that they had the different problem of abnormal vaginal discharge, itching or irritation over vulva, boils/ulcers/warts around vulva and pain during urination or defecation. And also reported that, "we had consulted the relevant doctors of our respective NGOs (Networks) or do self medication by applying warm water diluted with salt to the affected area".

Again, some participants of FGD Imphal West also reported the experienced of different problem of abnormal vaginal discharge, itching or irritation over vulva, and boils/ulcers/warts around vulva. And also narrated that, "we had consulted the concerned doctors of our respective NGOs (Networks – SASO, ORCHID-Project and KRIPA etc) or do home remedies like washing up genital parts using hot water".

Another woman of FGD Churachandpur expressed that, "I had the problem of abnormal vaginal discharge and itching or irritation over vulva. I had consulted the doctor of STI clinic through LRRC worker".

Two participants of FGD Ukhrul reported that, "We had the problem of abnormal vaginal discharge, itching or irritation over vulva. We had consulted the concerned doctor of ART Centre".

Another two participants of FGD Ukhrul reported that, "We take the medicines from pharmacy and suppress the problem".

Another Case Study respondent of Imphal East mentioned about her treatment, "It is difficult to seek sexual health services for all women living with HIV (especially widows). I have a menstruation related problem. My monthly period is irregular; it is three times in two months. I am consulted to gynaecologist indirectly through my sister-in-law, because I think that I am a widow so people will laugh at to visit to gynaecologist. Nowadays different HIV/AIDS related NGO workers expressed a wish to sit gynaecologist at every ART centre for solving the problems for women especially for widow". (Case 10)

Again, another Case Study respondent of Churachandpur reported that, "At the period of menstruation I felt abdomen-ache and back-ache since the last 6/7 years. I had not done any consultation/treatment for this problem. I also had itching or irritation over vulva and boils around vulva since the last 6/7 years. In this case also I had not done any consultation/treatment. I had taken pain killer drugs from pharmacy when I felt unwell. As a HIV positive woman I did not want to treat the problems". (Case 11)

4. Discussion

It is seen that the age group 30-39 years is the worst affected by the disease, i.e. 52.50% in FGDs and 75% in Case Studies. Since the worst affected age group is the most productive part of life, the impact of the disease in the socio-economic condition of the individual and the society is devastating. It could change the age and sex composition within the family – the family may lose an earning member or the child could become orphans if both husband and wife are HIV-positive. Their marriage profile shows that out of 100 respondents 51 were currently married, 45 were widow and remaining 4 were separated/divorced. Most of the widows and separated/divorced were lone breadwinner of their family. It is also observed that majority 47/100 of the respondents have 2 children followed by 22/100 who have 3 children. Their health profile shows that 59 out of 100 participants were undergoing ART treatment. Prevention of Parent to Child Transmission (PPTCT) treatment was taken by few participants. Only 16 out of 100 respondents had undergone PPTCT treatment. Except one all the women (99/100) reported that their husbands (former or current) had transmitted the infection to them. Most women (83/100) were generally infected from their husbands who were injected drug users. Some women (16/100) reported that their husbands had pre-marital or extra-marital relationships, and linked their husbands' sexual relationships outside marriage to their current positive status. One woman reported that she had got the infection as a result of blood transfusion.

In the FGDs and Case Studies, most of the respondents are aware of the availability of health services in their respective areas such as government hospital, private hospital, and clinic and concerned doctor of Drug Abuse and HIV/AIDS related NGOs/Network offices.

Some go to private doctors, government hospital, private clinic, pharmacies for treatment when they suffered from illnesses. Some of them also opted for self medication. This is because either they do not have the money for treatment or lack of awareness of importance of their health or danger of the disease they suffered.

The health care sector is perhaps the most conspicuous context for HIV/AIDS related discrimination, stigmatization and denial. Regarding discrimination at health facilities in Manipur, participants mentioned that the government doctors and health care workers discriminated much more. Again, they opined that it is much less in the capital city of Imphal (Imphal East/Imphal West) but very common in the interior and hilly regions.

Responses in the Focus Group Discussions and Case Studies indicate that in non-hospitalised illness episodes some of them had sought treatment from the concerned doctor of "Drug Abuse and HIV/AIDS" relevant NGOs/Networks rather than government and private health care centre. The NGOs/Networks give them the prescribed medicines of worth Rs.200/- for one illness episode. It indicates the important role played by the NGOs/Networks in providing care and support to the HIV and AIDS infected persons in Manipur.

5. Conclusion

This report summarizes the barriers and discrimination that women living with HIV/AIDS face in Manipur to avail health related services based on the results of eight (8) semi-strctured focus group discussions and twenty (20) case studies carried out with 100 women living with HIV/AIDS in four districts viz., Imphal East, Imphal West, Churachandpur and Ukhrul of Manipur.

Most of the participants described their experiences vis-a-vis the denials of basic services in seeking treatment for general illness. Early discharge from hospital, delays in treatment, slow service, postponed treatment or operations, conditional treatment, unwilling to do any job which involves blood. They also spoke to how medical staff refused to touch them and gave oral medicines rather than injections and denied medical treatment such as administering insulin, vitamin and drip injection.

Another area in which stigma and discrimination affect women living with HIV/AIDS (WLHA) is reproductive health. It is also observed that HIV positive women often get caught between pressures from health workers not to have children and pressures from family members to have children.

Most of the young respondents reported doctors/nurses were not willing to perform delivery on them. Many a time when they revealed their status the doctors/nurses hesitated to handle them. Some respondents responded that at the time of their delivery government hospital's staffs (doctors/nurses) immediately sent them to private hospitals saying that requisite facilities are not available with them.

The findings from this study show that the home remedial measures and self medication were common in relation with STD/STI treatment. Some respondents had sought services for treatment from the concerned doctor of 'drug abuse and HIV/AIDS epidemic' relevant NGOs/Networks.

We hope the present report can improve care and support services to women living with HIV/AIDS. It can help the government to assess health and information needs and to plan better health services. It can help to prevent HIV infection, improve access to HIV treatment, care and support, and lessen the impact of HIV/AIDS, particularly among the most vulnerable and marginalized section.

Characteristics	Number	Percentage
Age (years):		
20-24	3	3.75
25-29	13	16.25
30-34	17	21.25
35-39	25	31.25
40-44	15	18.75
45-above	7	8.75
Marital status:		
Currently married/Remarried	38	47.50
Separated/Divorced	4	5.00
Widow	38	47.50
Number of surviving children		
1	15	18.75
2	38	47.50
3	15	18.75
4	8	10.00
5-above	4	5.00
Number of undergoing ART treatment	45	56.25
Number of ever used PPTCT treatment	11	13.75
Number of ever used Contraceptive	54	67.50
Source of HIV infection		
Women who indicated husbands as the source of infection:		
a) Husband injected drug user	68	85.00
b) Husband had extramarital affair	11	13.75
Blood transfusion:	1	1.25

Table 1: Profile of focus group discussion's women participants (N=80)

Characteristics	Number	Percentage
Age (years):		
25-29	1	5
30-34	8	40
35-39	7	35
40-44	4	20
Marital status:		
Currently married/Remarried	13	65
Separated/Divorced	-	-
Widow	7	35
Number of surviving children		
1	2	10
2	9	45
3	7	35
4	1	5
5-above	1	5
Number of undergoing ART treatment	14	70
Number of ever used PPTCT treatment	5	25
Number of ever used Contraceptive	17	85
Sources of HIV infection		
Women who indicated husbands as the source of infection:		
a) Husband injected drug user	15	75
b) Husband had extramarital affair	3	15
c) Husband had premarital sex	2	10

Table 2: Demographic Profile of case studies women respondents (N=20)

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