

The Personal Development Needs and Realities of HIV Positive Women in Jamaica



A FOCUS GROUP REPORT



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Executive Summary

This report documents the experiences of 43 HIV-positive women from 12 parishes in Jamaica. The study was conducted in the four regional health authorities: Western Regional Health Authority, North East Regional Health Authority, Southern Regional Health Authority and South East Regional Health Authority. The study drew on the experiences and perception of positive women to document their personal development and prevention and treatment needs. Recognising the need to give women living with HIV themselves a voice in programme design, participants were also asked to identify the priority needs of HIV-positive women and to suggest ways to address these needs.

Common themes and patterns emerged from the discussions with the women. The vast majority of women (72%) were unemployed, a finding that underscores women's vulnerability to HIV. Further findings indicated that the women's vulnerability was further compounded by violence and stigma and discrimination. From the data, it appears that women in Jamaica are more likely to be discriminated against than their male counterparts at all levels. A key point raised was that women tend to be blamed for HIV and are therefore called derogatory terms such 'whore'.

Further, the women indicated a difficulty to access loans or grants to start their own business but these have not materialised. Based on the current economic situation, the majority prefers to work for other people rather than themselves.

Another key pattern that emerged was that women are not routinely examined when they attend treatment sites, despite the fact they are women and , that they have a sexually transmitted infection. Further, women are not counselled around sexual and reproductive health and rights as the programme caters to a large extent on halting and preventing HIV.

Several women indicated that their relationship with their husbands and partners had become strained following diagnosis or disclosure of their status. This has resulted in a vast number of children being cared for by their mothers only.

Despite the stigma, discrimination, isolation, lack of employment, less than adequate health care that many women experience, most respondents reported that they are able to cope because they want to see their children grow into adulthood. Some stressed the positive role of organisations such as Jamaica AIDS Support for Life (JASL) and Eve for Life in helping them come to terms with their lives and addressing many of their critical needs, including medical treatment and empowerment. Women also identified their priority needs and ways to address these needs in future programmes. Findings indicate that providing financial security for positive women and ensuring a secure future for their children were major concerns. Participants noted the need to impart livelihood training linked to job opportunities, ensure that HIV-positive women continue to have access to free medication, ensure gynaecological care and comprehensive sexual and reproductive health services are provided.

Recommendations

There is a critical need for research that seeks to understand the relationship between women's reproductive health, gender and economic inequalities and HIV prevention and treatment. Programmes that are designed to reduce the risk of HIV and other sexually-transmitted infections need to be improved to explicitly address the empowerment of women in its totality including economic empowerment. Programmes also need to address disparities in poverty among women. Research is needed that will help provide the data necessary to make those improvements.

There is a critical need for increased involvement of HIV-positive women in the design and implementation of programmes and services. HIV prevention and treatment programmes must include the growing numbers of adolescent and adult women who are becoming infected. This would prevent the need to develop programmes considered to be "one shoes fit all" programmes that rarely benefit women

Integrate women's reproductive health and poverty alleviation programmes to reduce vulnerability to HIV and other sexually transmitted infection (STIs). To alleviate poverty and reduce the transmission of HIV, attention needs to be focused on how sustainable livelihood and income generating initiatives can help women lead empowered and productive lives that result in improved health outcomes. Some training suggested by the women include money management, business plan development, skills certification and financial and literacy improvement.

Increase HIV-positive women's empowerment programmes. This can be a four-pronged approach:

1. Give women the information they need about their bodies and sex, the skills they need to use a condom and skills training to communicate about sex in order to encourage inter partner communication.
2. Improve women's access to economic resources. Provide women with the skills needed to access loans, that they have the financial, marketing and business skills necessary to start or improve their businesses and have access to employment in the formal sector,
3. Ensure that women have access to health services that cater to their needs.
4. Increase knowledge and skills around violence against women. This is a violation of women's rights and can have significant negative implications for the health of women.

Increase Advocacy opportunities for HIV-positive women. A number of women-specific issues require HIV-positive women to play a leading role in advocating for change. These include advocacy for comprehensive sexual and reproductive health services, gynaecological services and elimination of AIDS-related stigma and discrimination in the health sector. In order to do this, training is recommended in advocacy, gender and HIV and sexual and reproductive health and rights.

Introduction

UN Women is funding a project being implemented jointly by Jamaica AIDS Support for Life (JASL) and the National HIV/STI Programme entitled: *Supporting Gender Equality in the Context of HIV and AIDS*.

The project was initiated based on evidence that globally, efforts to address and integrate gender equality dimensions remain inadequate. Women and girls still do not have equal access to services, resources, and decision-making processes when it comes to the national response to HIV/AIDS. It will focus on:

1. Building the capacity of HIV-positive women's groups and advocates and promoting their leadership so that they are better equipped to be meaningfully involved in all decision-making that affects their lives.
2. Target policy makers and programme staff in government, as well as the international donor community to ensure understanding of gender equality priorities are realized and commitments to inclusiveness of HIV-positive women is developed.

The approach of the programme will be:

- (a) Building institutional and individual capacities
- (b) Development of common goals and priorities on gender equality
- (c) Operationalizing and delivering on commitments to these priorities
- (d) Developing political advocacy strategies and skills for HIV+ women.

The broad objective of the project is to ensure that gender equality and human rights are integrated into key policies, programmes, and actions to address HIV and AIDS at the national level.

The specific objectives are:

1. To promote the leadership and participation of HIV-positive women's organizations and women affected by HIV/AIDS in shaping the policies, programmes, and resource allocations that address the HIV/AIDS epidemic in 5 selected countries (Kenya, Rwanda, Cambodia, Papua New Guinea, and Jamaica).
2. To develop core capacities of national AIDS coordinating mechanisms to promote human rights and gender equality in the HIV/AIDS response in Jamaica

For these objectives to be achieved, it was determined that focus group discussions would be conducted among women living with HIV and AIDS to obtain information about their personal

development (including economic) and priorities in order to develop programmes that address these needs. The information gathered in these focus groups is to be used as a basis for advocacy around the development of programmes that address these needs. It will also serve as a determinant of the areas that must be addressed in HIV positive women's empowerment efforts and the types of activities that are most likely to be beneficial to the prevention, treatment and care outcomes of positive women in Jamaica.

Methodology

Focus Group Instrument Development

A 35-item focus group discussion guide (Appendix A) was developed by consultants from the non government organisation, Eve for Life. The guide was reviewed by staff at Eve for Life and a monitoring and Evaluation consultant to the organisation. A draft was also submitted to Jamaica AIDS Support for Life for review.

A 7-point item guide participant profile form consisting of demographic information was developed (see Appendix D). Participants in each focus group discussion were asked to fill out the form prior to the discussion.

Participant/Organisational Selection

Participants were selected through NGOs and other entities working with persons living with HIV. The organisations selected to be approached were Jamaica Network of Seropositives, CHARES, National HIV/STI Programme, Jamaica AIDS Support for Life, Eve for Life and the Parish AIDS Associations in Kingston and St. Andrew, St. Ann, Manchester and St. James.

Jamaica AIDS Support for Life hosted three of the four focus group discussions in Kingston, St. Ann and St. James. The fourth was held at the Rural Agriculture Development Agency (RADA) office in Mandeville Manchester. The sites were selected based on cost effectiveness.

Participant Recruitment

Participants were recruited by Ms. Paula Samuels, advocacy Officer at Eve for Life. The selected organisations were contacted and asked to provide two women living with HIV who could serve as potential focus group participants. The suggested criteria used for selection was that participants should:

- be aged 15 to 65 years old
- be comfortable voicing her opinion

Sixty women who met the criteria were initially screened for participation. These were then screened a second time in an attempt to create equitable distribution across parishes. Potential participants were offered travel and lunch stipends to increase the likelihood of their participation.

Focus Groups

Four focus groups were conducted in Kingston and St. Andrew, Manchester, St. Ann and St. James between March 29 and April 6, 2011.

Table 2: Focus Group Details

DATE	LOCATION	PARTICIPANT NUMBER
March 29, 2011	Kingston	10
April 2, 2011	Manchester	11
April 4, 2011	St. James	11
April 5, 2011	St. Ann	11
Total		43

All focus groups were conducted in 1 1/2 to 2 hours. Each focus group discussion was tape recorded and later transcribed.

DEMOGRAPHICS

Forty three women participated in the focus groups. Of this number, approximately 83 per cent of the participants ranged in age from 25 – 49 years old mirroring the age range that is most affected by the HIV epidemic in Jamaica. Table 1 delineates these ranges.

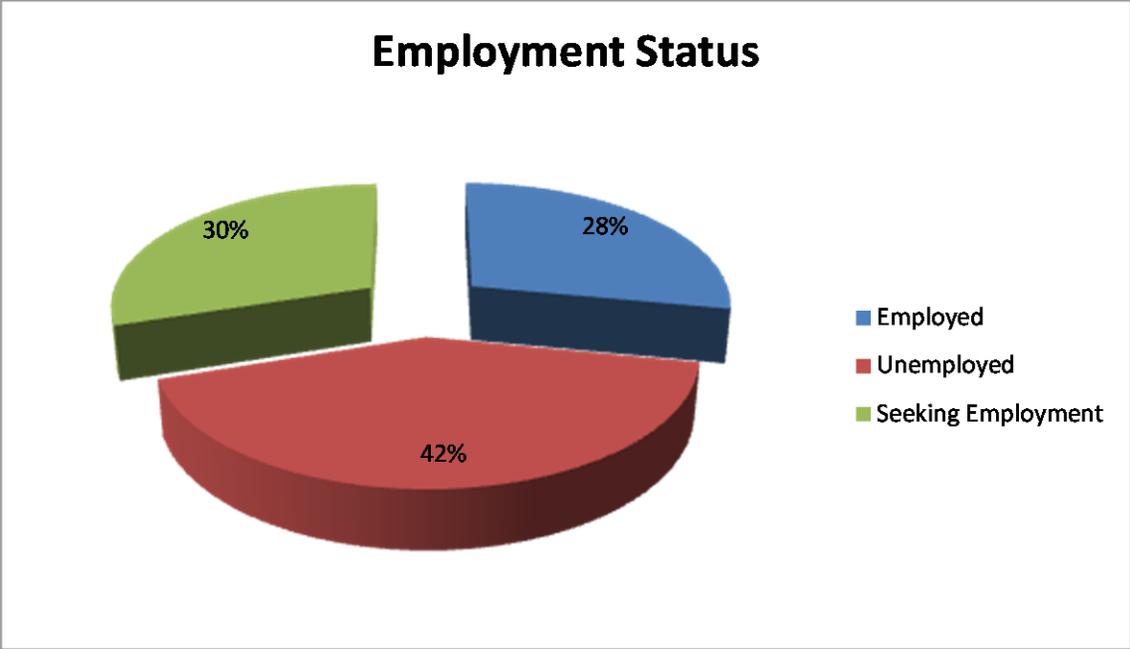
Table 2: Participants' Age

AGE RANGE	Number
15 - 24	3
25 – 49	36
50 and over	4

The highest number of participants was from the parish of St. Ann accounting for nine. It was followed by St. James with eight, Clarendon six, St. Elizabeth and Kingston and St. Andrew four each, Portland three, Westmoreland, Manchester and St. Mary two each and St. Catherine, St. Thomas and Hanover one each.

The number of years living with HIV ranged from one year to twenty years.

Chart 1: Participants' Employment Status



Marital Status and Number of Children

Thirty three percent of the participants indicated they were in visiting relationships (males visit but do not live at the home), 28 percent were single, 21 percent lived with their partners, nine per cent were married and another nine per cent were either divorced, separated or widowed.

The number of children that the participants had ranged from none to seven (see Appendix XXX). The highest number of children (34) was from the South East Regional Health Authority, 32 from the Western regional Health Authority, 30 from the North East Regional Health Authority and 28 from the Southern Regional Health Authority.

Focus group discussions - Results

Section 1:

Personal Development Issues

1.1. Situation of Women Living with HIV in Jamaica

The researchers postulated that in order for the women to adequately address their needs and realities as positive women, they should be able to identify, name and discuss their experiences and perceptions as positive women. In so doing, it was expected that the women would identify their own needs and solutions to some of the issues affecting them.

The participants were generally highly responsive when answering "How would

you describe the situation of women living with HIV and AIDS in Jamaica?" Very few people hesitated or chose not to answer. Several of the women, began their response by saying, "It is a challenge", "It is worse"; "It is hard" or "It is rough".

Stigma and discrimination

The most common responses were related to stigma and discrimination. It appears that across all four regions, women's social and economic vulnerability and gender inequality accounted for the stigma and discrimination experienced. Indications are that HIV positive women in Jamaica bear a double burden: being infected and being women.



"It is worse for a female to be infected than a male. They say bad things about us and not the same to the men. They call us whore, sketel, dutty gyal and they don't call the men names." – Respondent from South East Health Authority (SERHA)

"I sell on X street and everyday people come there and sey, 'Whey yu a talk to her for. She have AIDS!' They even class me as AIDS gal." – Respondent Western Regional Health Authority (WRHA)

"You have to keep it a secret. I can't get any taxi to carry me. A lot of times I suffer for hours because I can't get anyone to take me out of my community or into the community." – Respondent from SERHA.

"It is not an easy road, for example, I have a friend who is afraid to come out of her house. She cry every day, because nobody talks to her and they sey all sorts of things about her." – Respondent from Southern Regional Health Authority (SRHA).

“My sister came in the church and can take part in any area and I am in the church before her and I am treated less. Because I have the rash, they assume it is HIV, but I do not admit it. I sing on the choir and when my gown is there and I am not present in church my sister says no one wears my gown.” – **Respondent from North East Regional Health Authority (NERHA)**



Younger HIV positive women appear to suffer more severe acts of stigma and discrimination than women aged 25 and over.

“Younger women are treated worse. I know a 16 year old with two kids and the way the people in the community class her, I feel sorry for her. They tell her sey ‘you don’t reach nowhere, but you tek up man. It serve you right.’” – **Respondent from SRHA**

“When you go to the clinic, they class you any way they want as if you have no rights because you are young.” – **Respondent from SERHA**

Violence

Violence or the threat of violence also ranked high as a key issue for women living with HIV in Jamaica. The issue was common among three of the four regions.

“It is hard when you live in a garrison (poor, violence prone communities usually headed by a ‘don’ who wields power through gun). I have to stay away from my home because the men on the corner tell me ‘we have been watching you – if you don’t deal with someone in the community we will rape you’. I am very scared because I don’t want to sleep with any of them.” – **Respondent from SERHA.**

“My man every time we have an argument he threatens to tell people in the community about my status. If I was not HIV positive, I wouldn’t stick wid him. Right now I would be in a better position than I am in right now. It rough.” – **Respondent from SRHA**



Economic vulnerability and dependency

A key challenge put forward by the participants is the economic vulnerability of women in general. A significant number of positive women in general report that they are unemployed, and thus unable to care for themselves or their children.

“It is very stressful, mi nah work, mi have mi daughter to care for, can’t find food. It is really hard. It is hard.” – **Respondent from WRHA**

HIV positive women’s economic dependency figured strongly across all four regions. Indications are that due to the economic vulnerability of positive women, some opt to remain in relationships that are risky.

HIV prevents women from moving up and out of relationships. It forces you to stay with abusive men, because you cannot survive on your own.” – **Respondent from SHRA.**

“Women lack self esteem and self confidence and stick to abusive relationships because of their status. They are afraid to leave the man and try on their own.” – **Respondent from NERHA**



Single parenthood

Another common issue which arose in three of the regions related to single parenthood and the challenges associated with it. The women noted that on diagnosis, most of the men leave the family home and the relationships and the burden of care is left solely on the women.

“For some us, the men were the main breadwinners, but they leave as soon as they hear we are HIV positive.” – **Respondent from SERHA.**

“Men are not supportive of women. It is easier for the man to leave the home and the community to avoid discrimination, but not so for the woman. The woman has the kids and we have to remain and take the discrimination.” – **Respondent from SRHA.**

“It is rough for me. I am a single mother and it’s not easy. I have children going to school and paying rent and bills. I have nobody but my children and I have to be there for my children” – **Respondent from WRHA**



1.2 Reasons for situation of women

A number of reasons were put forward for the situation of women living with HIV in Jamaica. These include lack of jobs and an inability to support children, poverty, violence against women, educational level of women, ignorance about HIV and how it is transmitted, limited life skills of women and girls and limited information about their rights.

“Women in garrisons face a lot, if you are not sleeping with the men; they say you are a lesbian. This puts you at risk of being raped.” – Respondent from SERHA.

“Men leave as soon as they hear that we are HIV positive and we have to take care of the children on our own.” – Respondent from SRHA.

“Sometimes because parents cannot find it to give your children and you cannot support the children properly. So we go to as many partners as possible so you would say poverty and sexual favours for money. – Respondent from WRHA.

“Women have the information about how HIV is transmitted, but don’t have the life skills to prevent them from getting infected.” – Respondent from NERHA

A lot of us are not able to read and write and that makes us powerless.” – Respondent from SERHA

“A lot of women don’t want to accept that they are HIV positive, they don’t know how to deal with it. Every woman should get a women’s empowerment training. That is

what helped me to cope.” – Respondent from NERHA.

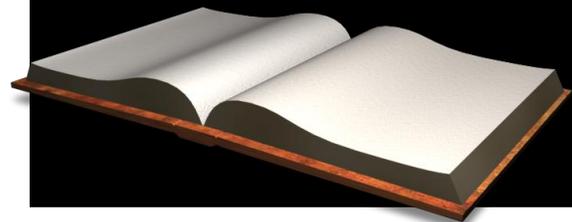
“Men leave as soon as they hear that we are HIV positive and we have to take care of the children on our own.”

Respondent from SRHA



“A lot of us are not able to read and write and that makes us powerless”

Respondent from SERHA



1.3 Motivation

Participants were asked what motivated them to cope with their HIV status. They indicated that they would cope better with HIV, if there was less discrimination and greater acceptance of people living with HIV especially women.

“I wish that if people who treat us bad could themselves walk in our shoes for a day, even those who are HIV positive and discriminate against each other.” – Respondent from SERHA.

“There are many different sickness way more deadly and dangerous than HIV but the discrimination is worst. If a person does not discriminate against you, you don’t feel down.” – Respondent from SRHA

In all four focus group discussions, although the women report high levels of discrimination, they note that they cope because of their children.

“The children them, because I don’t want them to suffer... so that they can be more comfortable when they get older.” – Respondent from SRHA

**“My faith keeps me going.
When I look at my life and
see that I am still alive and
that God has kept me, I
know that God has a plan
for me.”**

Respondent from WRHA

“My faith keeps me going. When I look at my life and see that I am still alive and that God has kept me, I know that God has a plan for me. The inner strength comes from my children. God bring me back and I think I am here for a purpose.” – Respondent from WRHA

“Sometime mi feel like give up, I am living with it for 18 years now, in some community the men expect you to deal with them, yes but I don’t deal with anyone there. I cannot give up because I have to stay strong for my kids.” – Respondent from SERHA

**“...If a person does not
discriminate against you, you
don’t feel down.”**

1.4 Job Opportunities

As indicated in the demographical data collected prior to the start of each focus group discussion, only 28 per cent of the participants were employed. Of the 72 per cent unemployed, 30 per cent were looking for employment. Some women noted that it was very hard to get employment as women generally due to the economic situation.

“I applied for security work several time and each time they turn me down. The last time was really bad, I was sitting beside a man who copy off even my name and he got the work and I didn’t. When I ask them about it, they sey they only hiring men!” – Respondent from SERHA

“I got a job with a man to wash his clothes, when the man come home to pay me my

money that I was looking forward to go home to buy chicken back if mi pickney them (for my children), the man strip himself naked and lay down in the settee and telling me how mi body look good so mi say you nah gi mi money, him say no, mi affi lay down an mi will get double on it. But since I don't want double or triple on it I went through the gate" – **Respondent from SERHA**

"It is just a woman thing. Basically when you go out to do domestic work, you have to do domestic favours as well." – **Respondent from SERHA**

But others feel that it is not only a question of gender when it comes to employment issues. They feel that women living with HIV are treated differently than other women. Some even lost jobs as a result of their status.

"I used to work at a gas station and someone who knew me came to the gas station and saw me selling inside the shop. He told the owner and he said I couldn't work there anymore as he was letting off staff. I was the only one who was let go." – **Respondent from WRHA.**

"I used to work as a domestic and although the lady was fine with it, her husband said he didn't want me to cook, so the wife made me do the washing, iron and clean. He then

said he didn't want me in the house, so I was fired." – **Respondent from WRHA.**

Even those who try to do business on their own are not immune to job-related stigma and discrimination.

"Once they know you are positive, you won't be employed, even when you are self employed, you still have problem."-

**Respondent from
NERHA**

"Positive women go through lot more than positive men. For instance if a man have a shop and he's HIV positive, you will just hear it for a couple of days and it run off. When you check it out, you see his friends and everybody in the community supporting him. But the women always loose business. Yu hear dem sey mi nah go ova Jenny shop because she HIV." –

Respondent from SRHA.

"The men seem to be able to get more support from their friends than women. Women discriminate against women more." – **Respondent from SRHA**

But despite the challenges faced, the percentage of unemployed women who were not seeking employment including self employment is cause for concern. Key reasons put forward by women in the SRHA for their unwillingness to seek employment were: fear of being asked to do HIV tests, fear of discrimination and lack of

"The men seem to be able to get more support from their friends than women. Women discriminate against women more."

Respondent from SRHA

national identification.

“I could get work you know, but I hear you have to do the test so sake of that I don’t even go.”-

Respondent from SRHA

It would appear that some of the information received by the women regarding job opportunities and HIV testing are hearsay. The veracity of the information is usually not confirmed, but fear of disclosure and discrimination appear paralysing. This seems to have been especially so in the SRHA.

“Somebody tell me that I have to do a blood test for my food handler’s permit, but another person sey I don’t do it. I am afraid so I don’t apply for it.” – Respondent from SRHA.

“My problem is that my age paper nuh right. Dem (potential employers) ask for it but I don’t have the correct one. I am not registered and dem do a search but couldn’t find me. They sey I need to find my father to verify me, but I don’t know which part to find him. Every time mi go RGD (Registrar General Department) dem turn me down.” –

.Respondent from SRHA

Most popular employment choices for HIV-positive women

- Housekeeping
- Caring for elderly people
- Office Attendant
- Receptionist
- Gardner
- Janitorial Services
- Home based care services for PLHIV
- Domestic Help: washing and cleaning homes
- Bartending

Most popular choices for income-generating projects

- Drapery making
- Fish mongering
- Poultry farming
- Dressmaking
- Wholesale business (to sell bleach, soap etc.)
- Phone card sale
- Higglering (buying and selling clothing)
- Bartending
- Hairdressing
- Shopkeeping
- Computer/Mobile phone repairs

1.5 Types of jobs preferred

Generally, participants were interested in working for others rather than creating their own employment. A key reason put forward is that due to the economic situation starting ones own business could prove risky. Instead, the women strongly leaned towards jobs that were mainly low paying.

A few wanted to work in the construction industry and some needed funds to use the skills they already had to make money. Among these were dressmaking, drapery making, jewellery making, poultry rearing and buying and selling.

“Right now I am on the street in the sun hot begging. If I could get some money to buy things I could be selling rather than begging.” – Respondent from SERHA.

Those who were willing to be their own managers were interested in drapery making, selling fish, raising chicken, dressmaking, managing wholesale business that sells items such as bleach, soap, higglering, hairdressing and selling phone cards

Almost all participants who were desirous of starting their own business indicated that they would rather do so in communities outside of their own due to fear of discrimination.

“I just started raising chicken and I was in a taxi when this lady say to me ‘you get sale for the chicken them and me sey yes. When me come off the taxi, the driver call me and tell me that she sey I have AIDS and nobody should buy from me.” – Respondent from SRHA

“I raise chicken, but I don’t sell to people in my community. Nobody comes to buy because they know I have HIV.” – Respondent from WRHA.

“I have my little business in the community and nobody buy from me. I sell only to people from outside the community.” – Respondent from SRHA

“Not everyone discriminates against people with HIV. I have no problem doing business in my community.”

Respondent from SERHA

There are those however, who have no problem doing business in their communities. This is reflected in one quote from a participant from SRHA.

“A the people in my community support me but me no know if them really know sey me positive. More time when they ask, I just switch to another subject.”

Another from SERHA indicated that: *“Not everyone discriminates against people with HIV. I have no problem doing business in my community.”*

1.6 Access to loans/grants

Accessing loans is highly challenging for women living with HIV especially if they had no history of saving with a credit union or other banking entities.

“You can get loan from the Credit Union if you have security. You can get the loan the same day or if you have receipt for your furniture, you can get loan. But how many HIV positive ladies in Montego Bay have them things?” – Respondent from WRHA

“I do not like to borrow money, but most of us not working and if you don’t have a job you can’t get a loan.” – Respondent from SERHA

“When you positive and everybody turn their backs on you, you just spend out the money you save. I borrow money from Jamaica National. I had to show them what me doing, me put up me fridge and me television for security. When I was not sick, me and everybody a friend but now me a the

‘AIDS gal’ a so them call me you know ‘the AIDS gal’’. Me own family don’t give me anything, once you become an positive them no give you anything.” – Respondent from WRHA

“The loan environment is just bad this year. The requirements are too high so it is not easy accessing loans.” Respondent from NERHA.

“It is not easy because if you are not doing anything they are not giving it to you and if

you don’t have a business you can’t get it. You can get a personal loan but you have to have a car, land, little or big house or some big furniture reach up into the top of the house.” - Respondent from WRHA.

Some of the women applied for grants through the National AIDS Committee (NAC) income generating programme, but were unsuccessful.

At least two participants in each focus group have had experience writing business plans, but none actually took the step to use it to apply for loans to start their own business. The majority indicated that they would love to have skills training geared at developing their own business and in money management. Others who are already involved in managing their own business indicated that they felt it was important to become certified and would appreciate certification thus improving their chances of earning more money.

Generally, women living with HIV do not have access to health insurance.■

Section 2:

HIV Prevention, Treatment and Care

2.1 Perception of services offered to women living with HIV

All participants from the four focus groups were accessing HIV and AIDS medical care and or support through the public health system. The participants describe the service in general as ‘ok’ mainly because they were receiving their medication.

Further probing indicates that treatment protocol in the various clinics and hospitals is ad hoc. Even within the same region, it appears some clinics and hospitals operate differently resulting in persons from the same region receiving varying degrees of access to treatment.

For instance within the SERHA, one participant from Kingston indicated she “missed appointments for one year straight” at a particular health facility, “and nobody nuh call to find out if I was dead or alive.”

Another from the same parish explained a different scenario where she noted that “Mr. X call me if I miss an appointment. He collects the medication for me so I don’t have to wait.”

In three of the focus group discussions (SERHA, SRHA, WRHA), participants indicated that they were able to access services that met the minimum basic needs of persons living with HIV, but not specifically geared at addressing the needs of women and girls. The basic minimum package of care as indicated by participants from the three groups was that on any visit, they see a doctor and receive prescription for a month’s supply of ARVs. Sometimes they will do a CD4 test every three months, but this is not the norm for all women. They are also supposed to do a viral load test every six months, but a number of the women indicated they have not done both tests in up to two years or not at all. On rare occasions, they see a psychologist, dentist, nutritionist, ophthalmologist and gynaecologist.

The situation in the WRHA appears to be the worst.

“Some of the doctors do not understand our condition, me feel say them scorn we. Dem

call in two people at a time then they spend the whole day. All they ask you when you go in to see them is if you having sex, if you using a condom and when last you see your period.” – Respondent from WRHA

“The treatment is not nice. I always have this pain in my vagina since last year (2010) and when I go down there, they never yet

say lay on the bed and let me examine you. I say doc, I feeling this pain over and over and when I pee it burns me. It is not inside, but on the outside. And every time mi go to see the doctor she keep writing the same prescription to insert and it is not helping me. I tell her she keep giving me the pills and it is not

helping me. She nuh do no examination, even though she know mi condition. All she do is just write prescription. Last month when mi go back and tell her she ask mi why a keep coming back for the same thing. It is only because I don’t have the money to go to doctor”- Respondent from WRHA

Indications are that patients are not routinely examined; instead, doctors prescribe medications based on what the patients tell them. This was confirmed by at least 30 participants in the FGDs.

In SRHA, participants pointed out that treatment and care is relatively good. They do physicals, CD4 tests, weight checks and

Indications are that patients are not routinely examined; instead, doctors prescribe medications based on what the patients tell them.

blood pressure tests. They also have access to a social worker on each visit. However,

they noted that the services are not specific to them as women and their specific needs.

“They tell us that we are not supposed to get pregnant. They say that if we get pregnant it will affect us. That is what they mainly talk to us about.” – **Respondent from SRHA.**

“Last week I had a pain in my belly bottom, like baby pain. I felt it move down my vagina and I went to bathroom and got a pan and pushed three times because I felt like I was having a baby. I felt something dropped out of me and when I looked down in the pan, there was a big stone. So we need to see our gynaecologist more often so we can know what is happening in our body.” – **Respondent from SRHA.**

In the SERHA and SRHA, participants indicated that prescriptions for women-specific issues such as mammograms and pap smears are referred, however, although referred, no follow up is done to ensure they are done. As a result, the women say they do not do the procedures as they have to pay for them and in many cases do not have the funds to do so.

A key problem encountered in the WHRA, SERHA and SRHA relates to limited or lack of access to gynaecological care. In WHRA,

all the participants indicated that doctors do not do routine examination of women, even when they complain of gynaecological problems.

Another key issue raised by some participants was the length of time they have to wait at the clinics to be treated. Monthly visits, where participants claim they spend less than 20 minutes with a doctor, are whole day affairs.

“I wake up from 3 a.m. and go to the clinic and get through by 9 a.m.” – **Respondent from SERHA.**

“I have 8:30 appointment and all 6 o’ clock in the evening you still sitting down waiting.” – **Respondent from the WRHA**

Another key issue highlighted by

participants from St. Elizabeth (SRHA) was the unethical practice of a contact investigator of contacting or visiting HIV positive persons armed with her igloo. Even after diagnosis, the participants indicated she still tries to visit them with the igloo to draw blood for testing.

“She visit me and cause people to find out that I have HIV. People in my community have her as the HIV lady. I had to move out of the community.” – **Respondent from the SRHA.**

“She visit me and cause people to find out that I have HIV. People in the community have her as the HIV lady. I had to move out of the community.”
Respondent from SRHA speaking about a Contact Investigator

“One day me see her in Black River talking to a man and she call to me. When I went to her and talk for a while she say to me that the man she was talking to was HIV positive. I cursed her and told her I was sure she also told the man that I was HIV positive. The next time she come to my house, I throw stones after her.” – **Respondent from the SRHA**

In the SRHA and NERHA, participants indicated that pharmacy service was very poor.

“The pharmacy only do a certain amount each day. If you reach there at 10, they tell you sey them can’t give we the medication.” – **Respondent from the SRHA.**

In the NERHA, indications are that treatment and care needs are highly satisfactory. The participants describe a situation whereby if the hospital or clinic is unable to fulfil some needs, these are picked up by Jamaica AIDS Support for Life (JASL), an NGO. It would appear that there is a continuum of care where doctors who work in the public health facilities also work with the NGO.

“Treatment from JASL is outstanding. We feel more comfortable here than at the health centre. We get adherence counsellor, access to social worker, access to a psychologist, liver function and

cholesterol checks, pap smear, routine STI screening, breast checks, dermatologist and nutritionist.” – **Respondents from NERHA.**

“The treatment from JASL is outstanding. We feel more comfortable here than at the health centre. We get adherence counsellor, access to social worker... and nutritionist”

Respondents from NERHA

2.2 Priority Areas for Women

During the focus group discussions, women identified their priority needs and suggested ways to address some of the challenges that HIV-positive women experience in their day-to-day lives. The three areas discussed most frequently are below.

2.1.1. Gynaecological Services

All regions except NERHA reported a lack of or limited access to gynaecological services.

The women explain that they are given letters to do pap smears outside of the clinic they attend, the cost of which is prohibitive for most women who are not working.

“They just give me a piece of paper that I need to get a pap smear, but when I go to the lab it cost J\$1,500 and I don’t have that kinda money.” – **Respondent from SERHA.**

The women suggested that government provide at least one gynaecologist at treatment sites in each region to provide the services needed.

2.1.2. Availability of Medicine

The shortage of medication was a major concern among the women, with some expressing genuine fear that the free access to ARVs will soon come to an end and without adequate warning from the Government. Many were fearful that the lack of ARVs could impact on the number of years they are able to spend with their children.

“My boyfriend medication run out because when we went to the pharmacy, they say they neva have one. Me ask them if they could give me the one they have and they said no. When me go back a week later they still nuh have it and another pharmacist give me the one available. By that time he was so sick with fever and pain in his joints. When me give him the one they give him, he start getting better. They need to give better information about the shortage.” – **Respondent from SRHA.**

Another woman who was in her eighth month of pregnancy had not started on ARVs to prevent mother to child transmission of HIV and was worried. According to her it is important that government explains what is happening to prevent undue stress.

“We are hearing information about the shortage of drugs through the health centre, but we do not know for how long.” – **Respondent from SERHA.**

In some regions, women report receiving only two weeks’ supply of ARVs at a time.

2.1.3 Information on Reproductive Health and Rights positive women

Sexual and reproductive health (SRH) services for HIV-positive women and adolescent girls appear to be limited in scope, access, and quality in treatment sites where they do exist. Respondents were of the view that HIV-positive women are getting pregnant because the National HIV/STI Programme is not focusing on health as it relates to reproductive health of the women, but on health as far as HIV is concerned. The key is preventing new infections and treating those already infected.

“They always tell us that we should always use a condom, they don’t talk to us about contraceptives, so as someone who doesn’t have a child, how am I supposed to have a child if I should always use a condom?” – **Respondent from SRHA.**

“Doctor don’t tell us anything about having children. Some persons tell us that when we are positive we should not get pregnant. That is why sometimes women tell lies about condom bursting. This creates a problem in the community because some women say they won’t use condoms because it will burst anyway, when the truth is the condoms don’t

Three priority areas identified by the women.

- Gynaecological services
- Availability of medicine
- Information on Reproductive Health and rights of positive women

burst that easily and it is just an excuse for getting pregnant. You can't tell them you did it deliberately because you wanted to have a child.” – Respondent from SRHA

Respondents recommend that it should become mandatory for HIV-positive women and girls to be given information and tools to protect their sexual and reproductive health.

Other needs highlighted were for psychologists, access to medical records (patients are not allowed to access docket with their records), youth friendly services for adolescent girls and reduction in stigma and discrimination by health care workers.

2.2 Participation in programmes and policy

Generally, the women in all four focus groups report that their participation in the HIV response is limited to being beneficiaries rather than active participants

in the development and implementation of activities.

“We bring our needs to the table, but we are not taken seriously. They just talk, talk today

and then it end right here tomorrow. We ask about the quality of doctors and nothing.” – Respondent from WRHA.

“We are not consulted about programmes and policies. They don't come to you and discuss alternatives like how to deal with ARVs with funding being reduced.” – Respondent from SRHA.

“Women are not engaged in decision making. Once you say something, by the next day other people can tell you what you said and they use it to treat you different.” – Respondent from SERHA

“Everybody is connected. You have to be careful what you say. Due to that, our voice is not being heard. A few NGOs talk to us – CHARES, Eve for Life and JASL.” – Respondent from SERHA

Limited participation is due to lack of or limited information from those who should know.

“Only persons up top know the information and those of us in the grassroots have only limited information.” – Respondent from SRHA■

“We are not consulted about programmes and policies. They don't come to you and discuss alternatives like how to deal with ARV's with funding being reduced.” Respondent from SRHA

Section 3:

Advocacy

Advocacy can be defined as an action directed at changing the policies, position, or programmes of an institution or organisation. It also includes persuading government officials to prioritise particular programme approaches or services. For the women involved in the focus group discussion, the three key advocacy issues arising from the discussions included:

1. Women's sexual and reproductive health rights
2. Access to gynaecological services at treatment sites
3. Elimination of stigma and discrimination in the health sector

Three of the regions highlighted the need for advocacy around HIV-positive women's health with emphasis on the provision of comprehensive sexual and reproductive health information and tools and on sexual and reproductive health rights. They also noted the importance of a gynaecologist on staff at clinics and health centres to deal with issues that are specific to women's health. A significant number explained that even though they were being treated for sexually transmitted infections, they are rarely examined.

The elimination of stigma and discrimination in the health sector was highlighted by two regions as an area that required advocacy. They noted that in some instances they are scorned by health providers, shouted at, disrespected through language used to describe them. At least at one pharmacy, participants report that they are forced to wait for long hours before being served even when they are the first to hand in their prescriptions. One participant puts it succinctly:

Stigma and Discrimination in the Health Sector

"I don't really experience discrimination in my community; it is only when I do to hospital.

"I was admitted to St. X Hospital this year as a result of cervical cancer. The nurse when she was doing her hand over to the other nurse read out loud my docket and said this is X, she is HIV+ and has cervical cancer. The workers who wear the pink heard and later in the day when they were serving food, she gave everybody on the ward glass plate and gave me plastic. I was served last.

"At dinner time, my friend who was in the bed beside me told me to go ahead and eat the dinner in the glass plate that she put down between us. When she returned with the dinner in the paper plate, she was very upset; she told me the dinner was not mine. My friend told her it was okay, she would take the dinner in the plate she brought.

"The next day, one of the women that wear the blue said, 'sister you not suppose to be on the seventh floor.' So they change me to the fourth floor. I get a better treatment there.

"On the fourth floor the nurse would say "Miss X did you take your medication? Do not let anyone see you taking it. That is confidential, it is your business." FGD Participant

“HIV a nuh nutten compare to the discrimination from the people who work at the clinic and hospital.”

Another important advocacy issue put forward was to lobby for HIV-positive mothers to be placed on PATH without having to undergo pre assessment. The participants indicated that high number of HIV-positive women is raising children on their own following the death or abandonment of the men in their lives. The other is access to non discriminatory employment. Again, unemployment was found to be high among the participants and could be a reflection of the wider society. Lack of employment could lead to reduced access to educational opportunities for children and poverty.■

Section 4:

Training Needs

Throughout the course of the discussions, several women noted that they were financially insecure as they had not been able to find employment. For many of the women, HIV had taken a toll on their livelihoods. Their diagnosis lead to loss of work and income and in one instance, a woman is on the verge of losing her home as she is unable to service a loan she took out while employed.

A number of the women who were self employed also expressed the need for certification in their area of expertise.

In addition to job training, a significant number of women highlighted the need for personal development training. The following were the top five training needs indicated:

Advocacy: Three regions indicated the need for training to advocate for the issues highlighted in the previous section.

Women’s Empowerment/Leadership: Participants from three of the regions indicated that the women’s empowerment training received from Eve for Life positively impacted their lives and enhanced



their coping mechanisms and self confidence. They recommend that all women living with HIV and desirous of leadership should receive similar training.

Money Management: Participants from three regions indicated that money management training would empower them financially. Many were desirous of starting their own businesses and this training would help them to start right.

Vocational Training: Participants in three regions wanted grants to do vocational training leading to certification.

Business Plan Development: This need was highlighted by participants in two regions. This was for women who wanted to start their own business.■

Section 5:

Conclusion

It is clear from the FGDs that HIV-positive women in Jamaica face some specific vulnerabilities and have specific needs that must be addressed. Given that a large majority of the women were unemployed and cared for many children, there is an urgent need for programmes that will improve the livelihoods of women living with HIV such as through income generating activities.

Moreover, the finding that women in the FGDs reported high levels of stigma and discrimination and were mostly displeased about the quality of women-specific services within the health sector, suggests that interventions should also focus on reducing gender related stigma and discrimination in the health sector and the

provision of services that are women specific.

Few women in the study underwent routine examinations to promote women's health such as for breast cancer, cervical cancers and sexually transmitted infections. Few women receive counselling on contraceptive options, child bearing and other reproductive health issues. This is despite policies that emphasise universal access to prevention, treatment and care.

Health workers need to be sensitised to the need for providing pre- and post-test counselling on HIV-related issues to HIV-positive women and to address their concerns in a non-discriminatory manner. At the same time, steps should be taken to protect women from seeking the services of unqualified health

providers and to ensure that they are made aware of available and accessible health care services in other parishes.

Further, the finding that many women experienced breakdown in their relationships on disclosure of status underscores the urgent need to address disclosure and couples' counselling.

Counselling services need to go beyond providing only information directly related to HIV. The results of the FGDs show that most women experience stress and feelings of hopelessness and therefore, counselling interventions should also focus on addressing the emotional and mental health needs of HIV-positive women.

Further, the finding that many women experienced breakdown in their relationships on disclosure of status underscores the urgent need to address disclosure and couple's counselling.

The data indicates that HIV-positive women faced stigma from family members, in health care facilities as well as in their communities. Efforts should be made to create an enabling environment so that HIV-positive women can lead their lives without being discriminated against in the various

settings. Sensitisation programmes at the community and health sector levels are needed that will allay misconceptions about positive people, address issues relating to stigma and discrimination, and stress the supportive role families, communities and the health sector can play in the well-being of positive women.

This report, which draws on perceptions and experiences of HIV-positive women, shows that women living with HIV face multiple vulnerabilities, ranging from physical health to concerns about financial security, family and peer support and securing the future of their children. The findings call, correspondingly, for multiple efforts that address positive women's health and well-being as well as empower them to lead their lives with confidence and dignity. ■

Section 6:

Recommendations

There is a critical need for research that seeks to understand the relationship between women's reproductive health, gender and economic inequalities and HIV prevention and treatment. Programmes that are designed to reduce the risk of HIV and other sexually-transmitted infections need to be improved to explicitly address the empowerment of women in its totality including economic empowerment. Programmes also need to address disparities in poverty among women. Research is needed that will help provide the data necessary to make those improvements.

There is a critical need for increased involvement of HIV-positive women in the design and implementation of programmes and services. HIV prevention and treatment programmes must include the growing numbers of adolescent and adult women who are becoming infected. This would prevent the need to develop programmes considered to be "one shoes fit all" programmes that rarely benefit women

Integrate women's reproductive health and poverty alleviation programmes to reduce vulnerability to HIV and other sexually transmitted infections (STIs). To alleviate poverty and reduce the transmission of HIV, attention needs to be focused on how sustainable livelihood and income generating initiatives can help women lead empowered and productive lives that result in improved health outcomes. Some training suggested by the women include money management, business plan development, skills certification and financial and literacy improvement.

Increase HIV-positive women's empowerment programmes. This can be a four pronged approach:

1. Give women the information they need about their bodies and sex, the skills they need to use a condom and skills training to communicate about sex in order to encourage inter partner communication.
2. Improve women's access to economic resources. Provide women with the skills needed to access loans, that they have the financial, marketing and business skills necessary to start or improve their businesses and have access to employment in the formal sector,
3. Ensure that women have access to health services that cater to their needs.
4. Increase knowledge and skills around violence against women. This is a violation of women's rights and can have significant negative implications for the health of women.

Increase Advocacy opportunities for HIV-positive women. A number of women specific issues require HIV-positive women to play a leading role in advocating for change. These include advocacy for comprehensive sexual and reproductive health services, gynaecological services and elimination of AIDS-related stigma and discrimination in the health sector. In order to do this, training is recommended in advocacy, gender and HIV and sexual and reproductive health and rights.■