REPORT

Qualitative Research conducted among Female sex workers and Multidisciplinary Care Team on

HIV positive Female Sex Workers' Adherence to HIV Medication

Prepared by: Ms. Lovette Byfield
Consultant
December 2017

CONTENTS

Background	**3**
Methodology	**5**
Detail Findings	**9**
Summary & Recommendations	**25**
Appendices	**30**

Background

The HIV/STI/Tb Unit of the Ministry of Health has conducted work with female sex workers (FSWs) and has achieved significant success especially in relations to the reduction of HIV rates among population. The HIV prevalence has been reduced from 12% in the 1990s to 4.1% in the 2004 and now stands at 2.9% according to the last survey conducted in 2014.

Female sex workers have been identified as one of the populations which are particularly vulnerable to HIV owing to specific social, economic and cultural factors in the society which, directly impact their lives. Owing to the nature of sex work they have been exposed to high levels of stigma within the society. The stigma faced by the female sex worker and the discrimination they frequently experience have also influenced their willingness to access health services and HIV treatment, care and prevention services in particularly. There is some amount of stigma associated with HIV disease and while there has been a positive shift in attitudes in more recent times, persons diagnosed with HIV are not always willing to access care for fear of being stigmatized. The FSW who is diagnosed with HIV may also experience an added layer of stigma which may manifests as; denial or delay of health care, breach of confidentiality, health care providers who are indiscreet, judgmental and stigmatizing. This stigma presents specific challenges for the managing the treatment, care and support for HIV positive sex workers.

The 2016 sex workers treatment cascade reflected the challenges relating not only to collecting data on the FSW but also indicated that the FSW are not achieving viral suppression at a rate comparable to other key population groups nor the general population. The data revealed that although 81% of self-identified FSW are retained in care, 34% are on ART, 28% had done a viral load test and only 14% are virally suppressed. On the other hand, among the self- identified MSM the data indicate that 85% are retained in care, 38% are on ART, 38% have done a viral load test and 31% are virally suppressed. The HIV/STI/Tb unit therefore needs to gain deeper insights into the needs of FSW populations and the challenges they encounter in adherence while striving to achieve viral suppression. The insights gained will guide the design and implementation of programmes to improve adherence among the FSW and support them towards achievement of viral suppression.

Against this background the National HIV/STI/Tb unit of the Ministry of Health has undertaken qualitative research with the population as guided by the following objectives:

1. To gain insights into the challenges HIV positive FSW are encountering in accessing treatment care and support.
2. To have an improved understanding of factors influencing adherence and viral suppression.
3. To propose strategies to address these challenges identified in the research

The specific themes explored with the FSW participants in this research were:

i. Knowledge and comprehension of the terms virally suppressed and CD4 test
ii. Factors facilitating adherence
iii. Barriers to adherence
iv. Disclosure of HIV status
v. Experiences accessing care at the treatment site
vi. Perceptions of the service delivered by the care team
vii. Suggestions to motivate their peers towards adherence.

Similar themes were explored with the clinicians and members of the care team:

i. Perceptions of the level of adherence among FSW
ii. Perception of factors which support or hinder adherence among HIV+FSW clients
iii. Perceptions of treatment literacy among the FSW
iv. Suggestions to improve care and management of the HIV+ FSW.

Methodology

Rationale: In-depth Interviews and Focus Group discussions with participants

A qualitative approach to the research was taken owing to the need for the exploration of the opinions, perceptions, the underlying reasons and motivations of the HIV positive FSW towards adherence to ARVs. The specific qualitative methods were in-depth interviews and focus group discussions (FGDs). The in-depth interviews were conducted with HIV positive FSW who were virally suppressed and those who were non-virally suppressed. This segmentation was necessary to gain insights into the practices of both groups and also to use the lessons learned from the virally suppressed groups to improve programs.

In the in-depth interviews the HIV positive FSW was regarded as a key informant. In this role the individual FSW was able to provide her opinion and perspective on the challenges of adhering to HIV treatment at the individual and group levels. The FSW was engaged in a non- threatening and confidential setting which is critical when seeking to explore sensitive issues and get information from stigmatized populations.

The research engaged a small section of the population, approximately 22 FSWs. The participants were purposively selected and were not intended to be a representational sample. The results from this group have provided useful insights into the challenges faced by the population and also guided the recommendations for achieving the objectives of the treatment and care of the HIV positive FSW. In-depth interviews with the FSW were conducted in the parishes with the highest number of sex workers and also high HIV prevalence that is, KSA, St. Ann, and St. James.

In-depth Interviews were also conducted with two clinicians, one each from the major treatment sites in KSA and in St. James. The interviews were conducted to gain the clinicians' perspectives on the challenges they have encountered in providing treatment and care for HIV positive FSW.

Focus group discussions were conducted with a mixed group of FSWs which included; HIV positive and HIV negative, also virally suppressed and non-virally suppressed. Participants were not required to state their HIV status in the group. The FGD allowed the participants to interact with each other and generated useful information which might not have emerged from the interviews. The FGD also allowed for clarification of some of the issues which had emerged from the in-depth interviews. Focus group discussions were conducted in KSA and St. James, the parishes with the highest number of female sex workers and high HIV prevalence.

FGDs were also conducted with members of the multidisciplinary care team in KSA and St. James. The main objective was to get their perspectives on the challenges relating to adherence to HIV medication among FSW clients.

Recruitment of participants

The Ministry of Health's focal point for the research informed the coordinators of the treatment and care and the BCC teams in three regions; South East, North East and the Western Region about the study and solicited their assistance to recruit FSW clients. They were asked to recruit both virally and non-virally suppressed FSW participants for the interviews and HIV positive and HIV negative FSW for the FGD. For the recruitment of clinicians and members of the multidisciplinary care team, the coordinators of the care teams in KSA and St. James were asked to inform care team members about the research and recruit at least one team member from each staff category for the FGDs. The clinicians for the In-depth interviews were identified by the coordinators based on their experience and availability. Recruitment of HIV + positive sex workers presented some challenges for the care team members as they were unable to readily identify the FSW clients at the treatment site. However this challenge was overcome with the assistance of the BCC team members who were more familiar with the FSW owing to frequent interactions with the group through outreach and testing interventions. The BCC team was also responsible for linking the HIV+ FSW with the care team.

In-depth Interviews (IDI)

Of the twelve (12) proposed in-depth interviews with FSW ten (10) were conducted that is, 4 in KSA, 3 in St. Ann, and 3 in St. James. The teams in St. Ann and St. James were unable to recruit the proposed number of FSWs as they were not as familiar with the population. Only three FSWs were interviewed in each of these parishes, i.e. St. Ann 3 and St. James 3. Although there is a database of the FSW clients in St. Ann it proved difficult to locate the clients. Also in St. Ann, although 4 FSW clients were scheduled for the interview one was unable to attend owing to child-care challenges.

The interviews were conducted with virally suppressed and non -virally suppressed female sex workers. The table below provides the details:

Table 1: FSW participants in IDI, location and health status

	Number of interviews proposed	Number of interviews conducted	Parish of interview	Number of Virally suppressed	Number of Non virally suppressed
	4	3	St. James	0	3
	4	3	St. Ann	1	2
	4	4	KSA	3	1
Total	12	10	3	4	6

The in-depth interviews with the FSW were conducted in private and confidential locations which allowed participants to be open and honest in their opinions. Participants were not

required to give their names prior to the interviews and to avoid using names during the session. No personal information was documented for the female sex workers participants.

Two (2) in-depth interviews were conducted with clinicians one in KSA and one in St. James were also conducted. The clinicians also worked in the treatment sites with a high volume of clients that is, Comprehensive Health Centre in KSA and Type 5 Health Centre in St. James respectively. Clinicians were interviewed in their professional work setting, their role in the health team was known. However privacy and confidentiality was maintained for the interviews.

Focus Group Discussions

Twelve female sex workers participated in the two FGDs conducted, one each in KSA and one in St. James. The groups comprised of both HIV negative and HIV positive sex workers. The participants were recruited by a member of the health team who was knowledgeable of their status. The participants were not required to disclose their HIV status in the group discussion.

Table 2: Location & Number of FSW participants in FGDs

Location	Number FSW participants
KSA	**6**
St. James	**6**
Total	**12**

A total of 14 members from the care teams; seven (7) in KSA and seven (7) in St. James participated in the two FGDs. The care team members include persons who provide psychosocial and other support to the HIV positive FSW, e.g. psychologist, adherence counsellor, social worker, contact investigators and others.

Table 3: Location, Number of care team participants & staff category in FGD

Location	Number of participants	Staff category
KSA	**7**	Social worker x 2, Psychologist, Contact Investigator, Adherence Counsellor x2 Treatment Liaison Officer,
St. James	**7**	Social Worker, Psychologist, Treatment and Care Officer, Contact Investigator, Adherence Counsellor x 2, Treatment Liaison Officer

Two separate focus group discussion guides were developed using open ended questions. The FGD guides explored the themes previously identified in the report as well as emerging issues from the In-depth interviews.

Prior to the focus group discussions participants were informed that all responses would be treated as anonymous and confidential and participants were assigned numbers. No names were used during the discussions. The sessions were recorded with permission from the participants, to ensure accuracy in transcribing.

All the recordings of the interviews and the focus group discussions were transcribed and analyzed and the findings are included in this report.

Detail findings:

Female sex workers (virally and non-virally suppressed & HIV negative)

Knowledge and comprehension of: virally suppressed, CD4 test

Although there was a measure of understanding among some FSW about the meaning of the term viral suppression and the benefits which will result from adhering to the medication, most of the participants were only able to articulate their ideas after much probing and they were generally tentative in their responses:

'When them say mi have a lickle bit a virus mi ask dem fi explain it, dem say mi have HIV but it no reach AIDS stage as yet an mi fi tek mi meds and eat food and exercise'.

'Your body a build up and you and you get strong and healthy, yes you look nicer and eat your food on time and take your pills on time'.

'The medication kill it, it nuh really kill it out, but it cut down the speed of it'.

'If you take your medication you can live couple years longer, but when you neglect it maybe yu guh faster.

'I have never heard about that, virally suppressed, is it the part where the virus goes to sleep, that's the part you're talking about, cause I've never heard it in that term before'

'Oh, viral suppress, I think its base on when I take my meds, it a lessen the virus….'

Participants in one of the FGD were more precise and confident in articulating their understanding of viral suppression. These were participants in the St. James group. It should be noted that although unsolicited participants in this FGD indicated that they were not HIV positive and that they had been tested for HIV within the last three months. They appear to be more knowledgeable;

'From what I know so far because I've done my workshop and stuff, you have HIV and you have AIDS, HIV is the virus …. So that can go to sleep so you don't go to full blown AIDS'

'When them say it put to sleep, let me clear this, a no say dem put it dung like how mi put dung di phone ya so, and it dead and it done, no, When they say put it to sleep them give you medication and you going constantly tek your medication, is a life time ting. So u go know say if a one pill every morning just like di vitamin….., you know say bam when you wake up …., you haffi jus tek your medication'

'You still have it, them put it to sleep that no mean say it gone outta yuh body, cause dem say yes dem gi you one vaccine or dem gi you antibiotic and it put you to sleep, you still have it but it cut down'

'Knowing that it's asleep, you still take your medication, you still use your condom, if you don't use your condom that is when it going to upgrade to higher doses which is AIDS'

Some participants also had a fair understanding of the purpose of CD4 test and why it was important for them to have it done.

'I've heard your CD4, if your CD4 is high, they won't start you on ARV. If your CD4 is low like 250, then they start you on ARVs'

'It is for viral loads, it tell you whether you are up or you're down, Basically CD4 is to make them know what medication to change you and put you on'.

'I do the CD4 test up by (name of facility), right now I'm having a discussion with her(the doctor) about my skin but it has been a challenge like for any person, coming to live with the situation,,,'

One virally suppressed participant had some confusion in explaining how the CD4 test relate to the viral load and also the purpose of the test. However she understood that she is virally suppressed and that her viral load has been reduced;

'Mi no really understand it so good but the viral load must be on a level, you CD4 no supposed to be higher than your viral load, because how me get da part deh lickle mi member one time me do one test and dem say mi CD4 a how much thousand so that mean say the virus active inna mi body. Me do one since year and dem say the viral load come down, mi non-reactive…and dem call me and a congrat me and a say mi fi continue on what me doing.'

Some of the participants had the tendency to delay in scheduling and keeping their appointments to do the CD4 test. One participant indicated that she had to work and also that she was presently experiencing ill health so she had been putting it off;

'Dem gi mi di CD4 to tek but through mi head a spin mi caan really tek it, mi walk wid the paper dem, but mi out deh a do di prostitution work'.

Another participant stated that she had been delaying and she planned to do it in December of this year which was 3 months away

'Dem always a tell mi… this white paper here…., but right now di CD4 fi do but, yeah, in December when mi come back mi do it'.

One participant highlighted that she had experienced some lengthy delays to get back the results from her last CD4 test owing to some problems at a particular clinic. She expressed her annoyance with the long wait. This delay she experienced may influence her willingness to do further CD4 tests;

> *'I couldn't get back my viral load the last time because they have problem at XXXX (name of clinic) suh when mi duh it, when mi duh the CD4 …mi did a wait pon it how much month suh mi couldn't get it, suh …… whole heap a month's past,'*

Factors hindering adherence – Non- virally suppressed FSW

i. Perceptions about eating & medication

Participants seem to have different perceptions about whether medications had to be taken with meals or by themselves. The challenge they experience to maintain the regime was sometimes related to the availability of funds to buy food.

> ***'***Sometime I don't eat anything, they say we can take it without eating anything but from mi inna di hospital all along, dem neva tell mi nutten like dat. Dem always mek mi get something fi eat first'.*

> *'Well the eating part now, mi a tell you the truth, sometime mi caan afford fi buy breakfast, mi nah tell yuh no lie, cause sometimes it kinda hard pon mi fi tek it at the right time'.*

> *'Sometimes mi haffi buy it (the medication), cause a nuh all the while the pharmacies have it, and mi haffi directly have it to take'.*

> *'Mi just duh wey mi know sey fi duh, mi know sey if a di one day more mi coulda live, mi know sey if mi tek mi medication mi maybe can live three more day, suh all wid hot water and drop salt in dey', mi drink dat and tek di medication. Cause I nuh like the begging part yuh nuh'.*

> *'I take it at night, after I read it, when you going to your bed, it did'nt say after a meal'.*

Ii) Alcohol and smoking

Participants acknowledged that the combination of drinking and smoking could lead to complications while on medication, but stated it was sometimes difficult to overcome this habit which they consider as a part of their coping strategy

> *'God is a awesome God, mi drink mi liquor, mi can tell say it a go about a month now and mi still deh pon medications'.*
>
> *'Well, sometimes when mi memba certain tings, mi ask mi doctor about the smoking him say mi can, but like bun one a day, but mi nah tell yuh no lie, a more than one day mi go, mi guh hard pon it all five.'.*
>
> *'When mi smoke mi hold a meds and think back how mi use to live when mi did small wid mi Grandmother. Cause a mi Grandmother raise m, now mi nuh dey roun me Grandmother, mi a big girl now a try tek care myself'.*
>
> *'This week mi will bun a "hundred" (dollars) bag ai di weed, it serve mi Monday, Tuesday, Wednesday, Thursday, Friday, Saturday, till Sunday morning. When the next week start, mi say mi nah go do weed this week'.*
>
> *'Alright, mi can avoid di drinking but mi caan avoid di smoking. Mi can go all over one year, two year without alcohol but di smoking mi no know how to control dat part deh'.*
>
> *'Mi drink mi liquor, mi can tell you say it a go bout a month now and mi still deh pon mi medication, dis dizziness though'.*

iii) Side effects of the medication

Some participants reported a range of side effects from taking medication and stated that this led to inconsistencies in following their prescribed regime.

> '*The challenge I have is sometime is that sometime when I take the meds, it make you have a low feeling, first when mi use to go pon it ,mi use to upset, mi use to vomit it, she tell me there are no medicine without side effects'.*
>
> *'Why mi no tek dem fi all a month, because everytime mi tek dem mi feel a way. Mi feel bad, mi feel like di house a spin so wid mi and mi nuh like how mi feel every minute'.*

'Yu si the first one that mi was on, when mi tek dem, dem mek mi feel drowsy and mek mi feel like mi drunk, suh mi guh back to the clinic to the doctor, and she gi mi a new set'.

One participant stated that she had made adjustments in taking the medication so that she could cope with the side effects and fit in with her work schedule. She seemed to regard taking her medication as a normal part of her routine;

'Nothing, just normal, If mi a work, when mi come a work at 4 o'clock, I tek it cause mi a gi it time fi di bad feelings pass. But if mi nah work, mi tek it regularly before mi guh a mi bed a night time'

iv) Mobility of the population

Participants explained that their working situation is highly mobile. This includes working at locations both locally and abroad. It was therefore difficult to carry and take the ARVs or keep appointments at the same clinics.

'Mi work a Hanover, mi work a St Catherine, mi work a Westmoreland, mi work St James, mi work a St Mary, mi work all over'……guh a St Martin one time guh dance, cause mi travel like eleven times, one time to England, Bahamas six times a nuff other country, Cayman, whole heap a cuntry'.

'More time yu dey some wey and yu nuh memba, yu a sey yu know sey mi should a walk wid it, now and again mi miss it'.

'Every time mi move go a next house, and when mi move mi caan find mi appointment card, so mi go clinic and dem check it from 1989 and mi wi say, "Miss you can write a new one give mi, and dem write I" …'

'Dem say dis yah woman nuh tan one place; dis minute mi deh deh, so dis minute mi deh deh so, dem say (name of FSW) mek you tan one place'.

'To tell yuh the truth sometime when appointment fall pon di 7th and mi deh way a Hanover or mi deh way a Westmoreland mi can go badda come'.

v) Work site challenges: privacy, competition, club operators

Participants revealed that it was challenging to preserve their privacy and HIV status while working at the Clubs under the scrutiny of the Club Operators and the competitive jealousy of other Female sex workers. The club operators were demanding to see the results of their HIV test results after the outreach test has been conducted at the site;

> *'You have xxxxx (name of club) down there by the xxxxx (location of club), di boss is sticking out and when the AIDS people them come im want to see the yellow paper or the white paper'*

> *' I dweet 2 times since I've been there and everytime I dweet I haffi show him'*

> *'if he request a HIV test, fine, but if him no ask mi fa, mi nah carry it go gi him, cause a no fi him business*

> *' For where I work, the owner is different, sometimes you have to present, they always come there to do the testing, so when he calls and you have to present that paper before you can do no form a business wid anybody up there. As soon as you want to do business you have to present it at the window, him don't even want to see the result as long as you have the piece a paper in your hand. But that was first time, now, mi no know if a something him hear or what,…. he want to see it directly, and as soon as I heard that I just took out my paper and use my phone and send it'.*

Participant also suggested that the lack of privacy at the sites was compounded by jealousy and competitiveness among colleague sex workers. They reported that FSW would resort to any action to get a perceived rival out of the club;

> *'Wey dem duh, dem go behind yu back and try fi get yu out, because them realize every club mi guh, mi can dance suh mi boss dem love mi, so dem nuh like that'.*

Some of the actions taken by the rival FSW would include intrusion in the personal space or searching the personal property of co-workers to find items such as ARV medication which, would justify a fellow workers' dismissal from the club if the boss is made aware of the workers' HIV positive status

> *'I don't think it is fair for me to have my medications and others who don't have it a fast inna u tings and report it to Boss'.*

> *'One girl weh mi send fi mi face powder in mi bag, she no see di bag tie up and lef it, she jus go in a dash out mi tings, mi have to leave dung deh completely'.*

One other participant reported that to avoid detection she resorted to hiding her medication when she was working at the club;

> *'Mi did hide and carry mi pill, a so mi haffi hide and carry dem now. Mi no upfront like one time'.*

Some of the HIV positive who were still working or had worked at club sites provided suggestions to assist other HIV positive sex worker to preserve her privacy and take her medications in these settings;

> *'Lots of girls I know went through problems at the clubs them all war to because of it. But they are not smart, they are not clever, because them can eat and when dem finish eating, dem go one-side and tek dem tablets, and nobody don't even suspect'.*
>
> *'No listen, you walk wid two pills, you don't live there, you don't have to take the bottle with you'. If I'm going to my fren for two or three days, I put the pills inna a little bag and write vitamins, argument done'.*

v. Female Sex workers attitudes to HIV positive sex workers

The club based sex workers gave their perspectives on having a HIV positive sex worker in their work site. Most of them felt that the sex worker should discontinue work since it would be bad for business and also increase their risk of HIV infection;

> *'Because you're working as a sex worker knowing that you have a virus just like number 6 said earlier, a condom can burst, you pass it on to that man and the same man pass it on to somebody cause sometime you deh a certain club and you see one man a do business wid all 3/4/5 dancer fi di one night and you don't know who have it. '*
>
> *'Mi woulda stop her, if me own a club and find out say a dancer have AIDS cause you a put other dancer life at risk right there so'*
>
> *'Dem a go talk bout it and she nah go mek no money and mi a go feel bad as a owner fi di club, mi nah go mek no money cause people nah go buy certain things'*
>
> *'For me, the only way mi would a say alright then mek she stay in the club, unless she not having sex, she just dancing, that's the only way I let she stay in the club'*

vii. Stigma and discrimination

Some participants complained that they faced stigma from their own family and in some instances from community members. Speaking of family and community members participants stated;

> *'I don't let my family know, my sister only assuming so I just mek she gwaan assume'.*
>
> *'Yeah, but mi tell them a lie, as I told you mi tell them mi have sugar'.*
>
> *'How mi see dem treat mi and how dem use to treat mi mother and suh mi just stay wide a dem'.*
>
> *'One chile inna di community did a sey mi have AIDS and I told her look here, if I reach this point now I am grateful because when I bought my house for $4.5 million and I didn't ask you for one dollar'.*

On the other hand other participants shared that they had received positive support from members of their family.

> *Mi sista, ma big sista she always encourage me, one of my sista have it too, but she did'nt know she have it'.*
>
> *'Yes Miss mi tell mi children and dem nah tell nobody'.*
>
> *'I sit down and tell like my Aunt and Uncle, because my Aunt is same thing as me'.*
>
> *'My Mother, she is supportive, she is good, cause basically she just have like me and my little sister and I am the only one that's here'.*

Factors facilitating adherence

I. Internal motivation, support from family, children, care team

*T*he virally suppressed female sex workers revealed that there were a number of factors that influenced them along the journey to achieve adherence and viral suppression. They listed that becoming self-motivated and building relationships with family members and with members of the Health Care team, played critical roles in this respect.

One of the participants' spoke of being motivated to keep healthy having experienced the rapid deterioration of her mother's health owing to cancer;

> *'My mother had cancer and she stayed long to get help, she end up inna Hospital and her hair falling out and she died, So I don't want my life to be like that' Well just looking at myself and say I don't sick and I don't want to be sick, so I have to get up and find something to eat'.*

'They never treat me no harsh way. I tell them, they help me, because my mother gave me some money and I bought land and I build a house'

Another stated that her motivation was internal and she was determined to live;

> *'I was given a life-changing illness and I'm able to stay on top of it you know and not to let it get me down and you and you know don't let it define who I am'*

One other participant indicated that she felt good to be virally suppressed and she was determined to remain virally suppressed;

> *'It feel good, but mi try fi nuh have unprotected sex cause although me might non-reactive and a person might have something and pass it on back to me same way.'*

Several participants referenced the support from family and being concerned about their children as important to their being virally suppressed;

> *'Sometime mi will get something to do, the money no enough, so mi really hah do nutten now, but sometimes mi have a cousin him will drop in more time or will send something for har'(her daughter).*

> *'Anytime mi look pon mi two daughters dem, one 15 and one six, and think back pon people wi mi know die leave children an the treatment dem get from family members. Sometimes mi daughter would call me, mommy tek your medication, di 15 year old one, cause she understand'.*

> *'Not everybody know, no one hasn't broken it out, they keep it good and they ask me if I'm taking my pills;.*

> *'You have to find somebody who you know by name and you talk to face to face or on the phone and you have to trust that person'.*

The support from the care team was also mentioned;

'The social worker is helpful, if you don't have a bus fare she will give you bus fare, if you want food she will give you, if you want clothes she give you clothes'

ii. Interactions with other PLHIV

Participants acknowledged that there were valuable emotional benefits to be derived from attending seminars and workshops organized by the health team or civil society partners as well as interacting with person who are living with HIV.

'Now in the PLHIV community, people look upon me as a leader and I can't be leading people and they are not seeing me do well'.

'Yeah I am more at ease cause sometimes being at sessions over and over with JASL, dem boost me more'.

'Just like how Jason would a come out and me use to say a act Jason a act, till I met Jason baby mother and she say a no act him a act, she positive too also.

Mi use to go a (name of health centre)' , the man work there (name of worker) him say him HIV positive for how much years but mi always tell him sey him lie, and a him was my greatest motivator'.

'I have to do better cause people out there depending on me to do good so they can do good. Yea I'm attending a PLHIV support group at JASL'.

'Rosie Stone is my big motivator, sometime mi call her like at 2 o'clock, she say you not stopping, I say remember I have obligations like you and if it going take until my son done college, I will, because him must help the smaller one fi pass the barrier'

Experiences accessing public facilities-interactions with the health team

Female Sex Workers operating in Kingston and St Andrew commented that accessing the services at the public health facilities was very uncomfortable for them primarily because of the attitude of the health care team including the non- clinical staff e.g. security guard

'You don't have to behave a way to get disrespected over this clinic; some of the nurses are very feisty. On a whole public facilities, certain nurses and doctors talk to you a way for nothing at all'.

'You cannot speak softly to them you need to talk up loud but you are scared, you want to talk softly, you don't want nobody else to hear what you are saying'.

'Some time di security have a problem, them going tell you say yu frack too short, yu arm outta door, the security might deh pon him wrong side that day, and yu depend pon yours and unno ketch up'.

'Some a doctor and nurse very nice, but some a dem aggressive, you have to know how to deal wid di public when dem get aggressive'.

One participant spoke to fact that the clinic has sections which are known by all who attend the clinic. She thinks that clients in section 3 are likely to be embarrassed or attract unwanted attention

'*The sections them at the clinic, it label, so if you deh ova deh ova di part weh say number 3 and dem know say da part d a fi disease, dem a go see you and carry on bare excitement'.*

Another participant highlighted the long hours of waiting at the clinic;

'Yu come and you get a number and you siddung, you siddung, you siddung fi di whole day and, yuh number naw call and yu get miserable an start to deal wid di public, it kind a complicated'.

Care team and Clinicians Perspectives

Assessment of adherence among HIV+FSW

The clinicians and the members of the multidisciplinary care team indicated that it was difficult to assess adherence among the sex workers as they were generally unaware of these clients. They noted that the HIV+ sex worker didn't willingly and readily disclose their involvement in sex work and this created a barrier to provide early and specific care for them;

'I think there's going to be a challenge in actually singling out these persons, because when they come to the clinic, there is no record of them as sex workers'

'When they don't identify themselves when they come to you, your treatment management or education or the type of care that would be specifically geared to them, you wouldn't be able to give them'.

'Maybe is when you are going through their sexual history, based on some of the information that they give you, you start giving advice and trying to deal with any issues in terms of sexual activity'.

'Part of it is that some of them have to keep hiding their HIV status, so because of the hiding they are not very stable'.

Both the Clinicians and the care team underscored that it would be more beneficial for clients if they disclosed that they were sex workers, as this would facilitate more flexibility in management, scheduling and referrals for these clients to be more aligned to their work schedule and mobility;

I think if they admit then we can work with the issues that they have, but if they don't admit then you treat them like one of the regular patients and expect them to come in at the regular time,'

'Which is why I said disclosure is important because if we know within reason, I think people will try and accommodate patients'.

'That is why we have a multi-disciplinary approach but team members have a schedule… sometimes only one (team member) for the parish and she covers another parish as well, sometimes so if we know the clients we can make more flexible appointments'.

Factors influencing Non- Adherence

The care team members and Clinicians pointed out that adherence remained a serious challenge for the clients particularly in respect of maintaining their privacy in the home and work settings and managing the nutritional demands associated with adhering. The Clients also had to confront the perceived stigma attached to attending a STI clinic for treatment:

i. Privacy in the home or place of work, nutritional needs, stigma associated with the health facility;

'I think it's across the board, the adherence issue, whether they are from the key population or from the general population. So if they have to disclose it to their partner, taking pills or pretty much storing pills in the house is going to be a challenge',

'They work with other sex worker in confined places, most of the times say 3 ,4 girls are in one room and say they have a set time to take their medication if they are getting dressed at 7 o clock when it's due and they are due to go on to dance or whatever they do, those who dance, they would not be able to take their medication in front of everyone'

'If they are in a financial bind then definitely food is going to play a major role'.

'They tell you I never take my pills because I never had anything to eat'.

'Some of them will miss their appointment or don't come to the clinic, so they don't want anybody pretty much to see them at this clinic, especially since over a period of time people know that this the STI unit'.

'Most of them will have their clients passing through or may even be co-workers here so they don't want to access care'.

'she was at a another facility and she doesn't want to continue care there she wants to come here but her fear now is that a co-worker here is her regular client and she doesn't want to be revealed"

ii. Mobility of the population, hours of work, relationship with health team

The Clinicians stated that the clients were not always able to keep their appointments because of their work schedules and so the Clinicians tried to be flexible in offering treatment;

'So they move around a lot and it is often cause a break in care. Now often times when a patient is attending a treatment site, and that patient is on treatment when they turn up at another treatment site sometimes, not all the time but sometimes they are treated as new in which they may go through an adherence process again and this causes a break in their ARV treatment. So those few months that they might be out of the clinic and also the few months that they might take them to get back on treatment that's a break in treatment and the adherence is not consistent for a long enough period for them to be suppressed and remain suppressed overtime'

'Difficulty attending appointments, so they tend not to keep up, we say try and come in the morning, early enough so we can get you registered and try and accommodate the person'.

'They are not able to keep the 8:30 -5pm appointment and some of them work Monday to Friday, is only a weekend so you find they miss their appointment, so I was saying I sometimes work on the weekends, on a Sunday so you can give her an option'.

Also there are very mobile, you have to think of, and I also find that you have to tailor the choice of medications to their lifestyle. Some might have an issue with the a particular pill cause of the drowsiness at night, you may say ok if you work and night but sleep in the day then u take the pill in the day, so you have to adjust the treatment, choose, based on the lifestyle'

One clinician also indicated that some of the patients despite being mobile were able to keep their appointments owing to the relationships with the health care team

> *'Like I said sometimes it is difficult to really pinpoint that this person is but for the ones that we can identify some of them are pretty good, some of them do come. And if they're not able to come some will reach out to if they have a close relationship with the Care member or the BCC team, they usually contact. I know for one outreach worker XXXX she always contact me and say nurse I have one of the patient want to come in when can they come. So I know she will have that relationship with some of them'*

Iii) Financial responsibilities to support the family, children

The Clinicians suggested that financial needs that is, the need to survive and to support r children pushed their clients to remain in sex worker. The FSW may be preoccupied with these needs and consequently adherence to ARV and being healthy maybe regarded as secondary to daily survival

> '*even though she looks like she is deteriorating physically ….. she would go out on the road anyhow and for her she is saying this is her only means of survival and when she takes the pills it makes her drowsy and she can't work while she is drowsy she can't work while she is sick and so she also has a partner at home who encourages her to go out and engage in these activities'*
>
> *'Cause we do encourage them to try and keep a job, you are more independent, you* can meet your daily needs and I think economics is a major role for a lot of them'.
>
> *'they say well money must come , whether it's going to come from a healthy vagina or an infected vagina it has to come, because if I don't get any money the children not going to go to school and the family is going to suffer'*
>
> *'Most of them are not comfortable but they just doing it because of the circumstances, cause a lot of them are from rural parishes, they tell their family they are working in the tourist industry they don't want to go home and they have to send up the money cause the children are there',*
>
> *'Sometimes when I am speaking to them a lot of them burst into tears and them say Miss mi no really waan dweet, but mi haffi eat, mi children haffi go a school'.*

Factors facilitating adherence

Concerns about image, skin conditions, concerns about children acceptance of status

Some of the clinicians and participants also suggested that FSW were motivated to adhere to ARV owing to the need to maintain a clean, healthy image to attract clients;

> *'… when they start telling you about how they having these skin rash and how it start look bad and the customer might start get suspicious, well I say look here, you have to understand that it is important to take your pills and they work. A lot of these things that are showing up will not go away if you don't take them'*

> *'Jamaicans are very concerned about their skin, their look; they don't want any rash and they come to you and they say doc I have a skin rash, I say don't worry about your skin rash if you take your pill it will go away, trust me'*

One participant suggested that concerns for the welfare and the future of their children was crucial motivator for the HIV+ FSW;

> *'I think their family, like their children and so, their children motivates them too because many of them have children and dem sumting dey. If they take the medication they will live a little longer to see their children past the best or past the worst or give them grandchildren or so, so that also and motivate them too'*

Another care team member highlighted the role of accepting your status and being internally motivated;

> *'She accepted her status and she know what she needed to do because when she would tell you about the kit that she uses she will always walk with her kit, have her hand sanitizer, her condoms, her lubricant and everything is packed in there and she doesn't miss her pills. So she knows the time when she is to take her pills, she takes her pill in her kit and she makes sure everything is packed'*

Suggestions to improve management of the FSW client

The Clinicians suggested that it would help to strengthen the adherence programme if sustainable relationships could be established with members of the BCC team;

> *'So BCC would be our leader when it comes to key population. So they would have from my standpoint have the bulk of the work responding to them. Cause our case manager wouldn't be able to go to a club and find them like that, so she would be led by the BCC team'.*

Participants suggested that the care team members should also be involved in outreach testing;

> *' I think as health care providers we could be a little more visible at nights, during their work hours, now it wouldn't be a case where you will be out there to identify who those persons who are positive , but you would be there in general, giving talks, giving brochures, giving information, if you having any challenges you can contact such and such, be a little more visible, because we all know the areas where they operate from, we do*

> *'I have been out to different population the MSM population workshops at night and yes it does assist and help when they know somebody at the treatment site'*

The clinicians and the care team members identified some challenges at the operational level which they think were also affecting the management of the HIV+ FSW client and the quality of service being delivered. These included the size of care team, physical spaces and limited options to meet the nutritional needs of the clients;

> *'And we try with the nutritional support that we get but sometimes I don't think it's adequate, cause if we just get the rice and the peas, you not going to eat rice and peas or cornmeal. So if we could give them a little more, at least to keep them'*

> *'Right, physical spaces are beating us badly. The team is willing, even though the man power might not be the quota that we would have wanted it to be but the man power that we have now, persons are that motivated and that into HIV & STI management, we can still get the job done, but is just the little nicks that pretty much needs to be ironed out so that we can definitely zoom in on the needs that we have identified'*

> *' so if they turn up one of the day when the psychologist is not there then you that's gonna be a problem; so if they miss their appointment, so we have asked folks to have a psychologist more often so that we can deal with those issues, so yes there will be a fall in through the cracks with that kind of thing if they cant keep their appointment for the psychologist'*

Summary & Recommendations

The research findings indicate that there are several issues relating to the female sex workers' ability to be adherent to their ARV medication and therefore achieve viral suppression. The most critical issues have been summarized below based on the reports of the interviews and discussions with the FSW and the care team members.

Knowledge and comprehension of: virally suppressed, CD4 test; there was limited understanding among some of these participants about the meaning of the term viral suppression and the benefits which will result from adhering to the medication.

The participants also had a fair understanding of the purpose of CD4 test and why it was important for them to do it. However among the HIV positive sex workers there may be some lingering confusion about the link between viral suppression and CD4 test. Some of the HIV negative FSW who participated in the FGD in KSA were not familiar with either of the terms i.e. virally suppressed or CD4 test

Factors hindering adherence: for the non-virally suppressed FSW several factors hindering adherence were identified by the sex workers themselves as well as by other participants. These included factors specific to treatment literacy such as;

i. Perceptions and practices about eating food and medication,
ii. Behaviours relating to alcohol consumption and smoking and taking ARVs
iii. Coping with the side effects of the medication.

Factors specific to the sex work industry were also raised these included;

i. Mobility of the sex workers to seek work locally and overseas made it difficult for them to access services regularly.
ii. Lack of privacy at the worksites – sex workers operate in small confine spaces it is difficult to avoid scrutiny from co-workers
iii. Club operators demanding test results prior to employment as they seem fearful that their establishment will be stigmatized and they would lose business. Club operators have maintained close relationships with BCC outreach testing team and have initiated testing request for sex workers on a regular basis.
iv. FSW at the club sites are highly competitive for clients and this seems to engender negative attitude towards HIV + FSW. Consequently the HIV+ FSW in this setting is less likely to adhere to her treatment regime for fear of losing employment.

The fear of being stigmatized by family members and members of their community was also stated as a factor hindering their adherence**.**

The health care team identified similar factors but also shared some additional factors from their perspectives such as;

i. Sex workers tend not to disclose their involvement in sex work to the clinician or care team. The health care provider is therefore challenged to provide the specific support for adherence to the HIV positive sex worker.
ii. Privacy in the home settings especially if the client has not disclosed HIV status to family members makes it difficult for the client to take medication and support nutritional needs
iii. The sex workers tend to work late hours and the clinic hours of operations are not flexible. This affects the ability of the FSW to keep appointments especially if these appointments are in the early morning. The FSW may also work in one parish and attend clinic in another parish.
iv. The sex workers find it difficult to confront the perceived stigma attached to the STI clinic/HIV treatment site and therefore some may not attend the clinic or may visit inconsistently.
v. Fear of encountering clients in the health care settings who may disclose that they are sex workers or become suspicious of their HIV status
vi. Financial needs that is, the need to survive, to provide for children and to support family members are likely to drive persons to overlook the need to adhere to their medication, keep their appointments and generally attend to their nutritional needs or practice unprotected sex.

Factors facilitating adherence: The main factors facilitating adherence identified by all participants that is, sex workers, clinicians and care team are as follow;

i. Internal or self- motivation, personality and a willingness to accept HIV status
ii. Disclosing HIV status to someone either family member or friend and the support they receive from these persons
iii. The desire to support and protect their children is a possible motivation for the sex worker to stay healthy
iv. Building relationships with members of the care team especially, the clinicians and the social worker and the treatment and care officer
v. Experiences of interaction with other persons living with HIV especially those who are living for long periods. These include public figures such as; Ainsley Reid, Rosie Stone and support group members.
vi. Concerns about image especially skin conditions. The presence of skin rashes can arouse the suspicion of clients and make it difficult for the sex worker to earn as having a 'clean' appearance is a critical in sex work. The FSW are more likely to adhere if they recognize that taking the medication consistently will reduce or remove the skin rashes.

Accessing care at the health facilities; participants had mixed experiences when accessing care. The HIV positive FSW who are known to the care team and clinicians reported positive experiences when interacting with the health teams. They have established relationships over the time and the team has supported them, accommodated them outside regular schedule appointments and facilitated their access to other social services.

On the other hand some FSW in KSA who were not HIV+ but were accessing STI services were concerned about the treatment they received from different categories of staff i.e. the security guard, registration personnel and some clinicians.

Recommendations:

The following are being proposed based on the findings of the research and the critical need to urgently address the current situation of less than optimal levels of adherence among HIV positive female sex workers.

1. **Implement a strategy to improve treatment literacy among the population:** Build the capacity of the health care team and BCC team members to engage clients in interactions around treatment. The relevant modules of the Positive Health Dignity and Prevention (PHDP) curriculum can be used as training resource in this area. Provide cues to action and user friendly tools to support the HCW provider to include the information in their routine interactions with the clients. Include treatment literacy information in the client waiting area and utilize various media to present the information in these settings.

2. **Review mechanisms to increase the awareness among the multidisciplinary team of the identity of female sex worker;** in an effort to improve the management of HIV+ sex worker ensure that key players are sensitized and have access to the parish treatment data base and also have an increased appreciation for its role/usefulness in client management.

3. **Strengthen the link between the BCC team and the care team;** Institutionalized the inclusion of the peer navigator in care team meetings as well as the inclusion of care team members in outreach activities to reach the FSW at their worksites. The presence of care team members at the sites will assist in reducing the fear of meeting an unfamiliar face if the sex worker needs to access care at the facility.

4. **Although there is some effort at introducing flexi time at the clinics, this is on an ad hoc basis. Full attention should be given to institutionalizing the implementation of flexible hours to accommodate the FSW and other members of the key population:**

the introduction of flexible hours may help in reducing the fear of being stigmatized among FSW. The FSW would be able to access the service at irregular hours when fewer clients may be present.

5. **Expand the Adherence strategy to assist FSW to reduce their vulnerability owing to financial and other social challenges:** the HIV positive FSW is faced with financial challenges and encounter difficulty in meeting basic nutritional and other needs relating to children and family. The strategy to increase adherence has to provide options and opportunities for the sex worker to meet these needs. Mechanisms to improve their access to social services and social inclusion as well as alternatives to sex work are integral to this strategy.

6. **Revise the system for providing HIV results at sex work sites;** Refrain from providing paper –based results for HIV outreach tests conducted at sex- work sites, inform participants of result and devise suitable mechanism for follow up and linking to services

7. **Scale up and maintain site-based sensitization sessions with club operators;** to discuss the practice of club operators requesting FSW HIV status as a basis for employment. The sessions should provide information on confidentiality and HIV testing, basic HIV transmission and prevention, risk reduction in sex work settings and stigma and discrimination and its implication for reaching sex workers who are in need of care. Collaborate with civil society partners to maintain consistency in messaging and conversations with club operators.

8. **Increase the involvement of PLHIV community and implement a strategy to structure opportunities for interactions with other PLHIV;** this will allow the sex worker to meet with other PLHIV in different settings i.e. one to one, small groups or larger workshops. Explore ways to further integrate the PHDP community facilitator and or sex worker peers in a buddy system for the sex worker. Also increase the visible involvement of established public PLHIV persons that is, Ainsley Reid and Rosie Stone as spokespersons to support the adherence programme.

9. **Continue to encourage HIV positive FSW to disclose their status to some trusted person who will be able to support and encourage their adherence and consider expanding the size of the multi-disciplinary team at the clinics.**

10. **Intensify strategies to work with families and communities to reduce stigma and discrimination and encourage support for family members;** if the possible care team members should explore increasing home visits.

11. The Female sex workers provided the following suggestions that the client can do at the individual level to improve their adherence;

i. Find somebody you can trust at the clinic and exchange phone numbers so that you can be supported
ii. Find somebody a family or friend or community member you can talk to face to face
iii. Try to keep your appointment dates at all times
iv. Repackage medication by placing them into regular pill or vitamin containers to avoid detection and scrutiny

Appendix 1

In-depth Interview & Focus Group Discussion Guides

Appendix 2

Transcripts of Interviews & Focus group Discussions