PositiveWomen

Support and advocacy for women living with HIV

Needs of women from African diaspora communities in Victoria, Australia who are living with HIV

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Acknowledgements

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Background

- Positive Women Victoria
  - Advocating for all women living with HIV to help build resilience and enhance their lives
  - Health promotion, support and advocacy
- 250 women access our service
  - 20% Culturally and linguistically diverse (CALD) background, 10% originating from Africa

Gender, migration and HIV

- Globally, women account for 50% of all adults living with HIV
  - Particularly at risk in high-prevalence countries
- The majority of heterosexual people living with HIV in Australia are from a high-prevalence country
  - Majority of late diagnoses, and those who remain unaware of their HIV status
- Intersections of gender, migration and HIV – crucial differences in women's experiences of HIV in Australia

Research Setting

- In Victoria, percentage of women living with diagnosed HIV
  - Increased from 3.7% in 1990 to 8.4% in 2010
  - Projected to be 9.7% in 2020
- New diagnoses in first quarter of 2018
  - 13% were women. Increased from 11% in 2017, and 6% in 2016
- Limited information about experiences of African-born women

Research Question

What are the major structural and cultural barriers to accessing HIV community and clinical support for African-born women living with HIV in Victoria?

Objectives

- To explore the major structural and socio-cultural barriers to accessing HIV community and clinical support organisations experienced by African-born women living with HIV (WLHIV) in Victoria

- To understand perceived and experienced barriers by service providers when providing services to African-born WLHIV

- To identify opportunities for increased engagement and retention in care for African-born WLHIV in Victoria

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METHODS

Data Collection

- Ethics approval by Alfred Hospital Ethics Committee
- Qualitative study
- Individual semi-structured interviews
- Two participant groups
  - African-born women living with HIV
  - Service providers of HIV clinical and community support services in Victoria
- Interviews audio-recorded, transcribed verbatim

Data Analysis

- Thematic analysis
- Transcriptions coded individually by research team
- Codes grouped into emerging themes
- Decisions made by consensus

RESULTS

- Interviews from May – December 2017
- Eleven African-born women from Positive Women Victoria's membership (KI)
- Sixteen service providers from HIV clinical and community support services (SP)

Demographics of women

Age	Number of participants (n)
35	1
36	1
38	2
39	1
42	2
44	1
45	1
49	1
55	1

Region	Number of participants (n)
South	5
East	5
Central	1

Service Providers

Service Provider	Number of participants (n)
Monash Health	2
Refugee Health Dandenong	1
Multicultural Centre for Women's Health	2
Melbourne Sexual Health Clinic	1
Prahran Market Clinic	2
Family and Reproductive Rights Education Program (FARREP) service Royal Women's Hospital	2
HARP Complex Care and Bolton Clarke Service Royal Melbourne Hospital	2
Culturally and Linguistically Diverse (CALD) Community HIV support – Alfred Health	2
Alfred Health –Victorian HIV consultancy (Antenatal care)	2

Barriers to Access and Engagement

- Individual, community and structural barriers to engagement
- Shared barriers
- Barriers identified by only women
- Barriers identified by only service providers

Shared Barriers

Themes	Sub-themes
Individual	Isolation
	Perception of HIV by women
	Perception of HIV by service providers
	Cultural identity
	Fear of stigma
Community	Stigma and discrimination
	Cultural misconception of HIV (stigma vs knowledge)
	Fear of stigma
	Fear of disclosure
	Gender inequality – patriarchal beliefs and practices
Structural	Stigma/prejudice from clinical services
	Location of HIV specific services
	Lack of representation/monoculture in Australia
	Limited HIV friendly GPs / S100 prescribers
	Interpreter access

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Perception of HIV by service providers

"the initial doctor that I met which, his reaction was so like blank and he was my first contact. I came out of his office feeling like if this is - if a doctor can react like that then I'm in a bigger problem than I thought I was" – KI 5

"Most women go to their GP first, to access services, don't feel they have adequate information given to them … doctors don't really know how to start that conversation" – SP 3

Stigma versus knowledge

"They don't know that things have changed in terms of medications and everything. They just think that once someone has HIV it's death" – KI 4

"If they were really knowledgeable – what that virus is doing, how you could control it, they understand that. But I think there is no knowledge there's cultural stigma" – SP 7

Lack of representation/monoculture in Australia

"What is pulling African people back is there is no voice that is speaking for them. They want someone who can identify with them. This is where the problem is" – KI 2

"Shopping around for an S100 prescriber doctor would be a lot more challenging for a woman from an African background …compared to if someone is same-sex attracted, because in most of the GP practices same-sex attracted patients would get priority" – SP 8

Barriers identified by women only

Themes	Sub-themes
Structural	Unwanted disclosure from services
	Pressure to self-disclose
	Misinformation from clinical services

"It's a gathering and I'm new from Africa and the manager of the service provider was like oh we've got a new individual here and … she is HIV positive, we're just thinking that she will become one of our positive African speakers here in Australia. And then everybody was just looking at me…

… giving me pressure to go public yeah. Emphasising oh it's gonna be good for you and you know, you need to do this, you need to do this. The fact that I entrusted them with my status but I didn't actually want them to say to people even indirectly like that, you know?" – KI 9

"I was just looking for somewhere to get some information and to get some help… I went to the doctor and asked him to make a referral and send me to somewhere that he knows, and he was like he doesn't know anyone, he's never met anyone in my situation, and I can ship my drugs from home" – KI 5

"Yeah so I've told my GP most of the time this is not about surgery or anything so can you please not put the HIV status on there, but he always does it … he says he has to write it" – KI 7

"I went for my appointment to check for my child and I overheard the doctor saying that's the lady with the HIV and they come straight to me. So as soon as I saw the doctor I gathered that they were talking about me…

… they pretty much just kicked me out and said you have to have a termination of your child whether I was 36 weeks pregnant so it was just kind of like they kicked me to the curb … and when I got home I just think oh my god I just found out I've got this, I've got no support or nothing so I thought, I have nothing to live for" – KI 3

Barriers identified by service providers only

Theme	Sub-themes
Individual	
Experienced	Time
	Language
	Carer responsibilities
	Basic needs
Perceived	Racism
	Visa category
Community	
Experienced	Different languages and small groups
Structural	
Experienced	Cross-cultural miscommunication
	Visa category
Perceived	Racism
	Cost
	Model of care

- Majority of barriers identified were shared by both the women and the service providers
- Fear as a central theme and a significant barrier
  - Stigma and discrimination from services
  - Stigma and discrimination from their communities
  - Unwanted disclosure

Opportunities identified

Themes
Motherhood as a driver
Hope from support services
Desire to empower peers
Desire to have agency through increased knowledge and confidence
Interest in meeting peers from similar cultural backgrounds experiencing similar challenges
Need for HIV awareness and education

Conclusion and recommendations

- Contributes valuable insights to the currently limited body of information on lived experiences of migrant women seeking access to treatment and support within HIV sector in Australia

- Multiple barriers consisting of individual, community and structural factors
  - Affects women's ability to seek support and service providers' ability to provide best practice care

- Recommendations
  - Increasing HIV awareness within non-specialist services
  - Provision of culturally accessible and acceptable services
  - Meaningful engagement with culturally and linguistically diverse communities

What next?

- Community engagement with African women and their communities
- Engaging with service providers about what they can do specifically for future actions
- Develop partnerships with organisations that have worked with women from diverse backgrounds
- Design an implementation for working with an engagement plan for working with women from Africa living with HIV and women from other diverse backgrounds
- Develop future peer support resource for training & engagement for all WLHIV

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Stay connected

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