

EXPERIENCES OF CARE AND SUPPORTS

INTRODUCTION TO THE STUDY AND OUR FINDINGS

There is little research on the experience of immigrant women living with HIV and their social supports in Canada. We found that among a group of women meeting at the Sexuality Education Resource Centre MB (SERC), in Winnipeg, this was a common topic of conversation. **These conversations were so frequent, that they ended up inspiring a process of community-based research.**

RESEARCH QUESTIONS

With the aim of understanding and sharing their experiences of care and support, we wanted to know:

- + What care and support do women seek or have accessed?
- + How do women use available care and support?
- + How does this shape women's lives?
- + How do women assess their care and support?

METHODOLOGY

As the project took place with a group of women who met regularly, we chose to frame this qualitative research project within an ethnographic participatory approach.

"Working together [in this project] it is a good thing. Once you join hands with somebody it's better because two hands are better than one."

- + The meetings became an important place to conduct our research, and notes were taken whenever the women discussed their care and supports.
- + We conducted individual interviews using the Life Story Board (vidaview.ca). This consists of a play board, cards and notation system that can help share personal and relational aspects of a person's lived experience.
- + A few women chose to bring photographs representing their experiences.

ETHICAL APPROACH

- + We were careful in the analysis and presentation of the stories shared by the women. No identifiable details of their stories are revealed. We used pretend names which the women chose for themselves.
- + We did not associate the women with any particular country or community of origin. Identifying their communities may foster further stigma towards and within these communities. We felt this was essential as HIV non-disclosure has been criminalized in Canada, which affects racialized communities to a greater extent.

*"Understanding our experiences
is a very good idea, a vital idea.
People would know what's
going on [in our lives]"*

FINDINGS

This study draws from the experiences of the participating women in SERC's women's group. Seven women participated in interviews and group discussions, and a few additional women only participated in group discussions. Arriving from a number of African countries, the women had settled in Canada within the past 7 years. Their ages ranged from their early 20s to their mid-50s. For the most part, the women struggled with poverty, access to education, access to gainful employment, childcare, stable housing, and having to send remittances back home.

Based on their stories, we identified the following main themes:

- + Engagement with clinical care and treatment
- + Seeking or receiving settlement and other social services
- + Relationship with other women living with HIV (SERC's women's group)
- + Engagement with religious institutions and communities

- + Engagement with local communities (seeking support in the face of HIV stigma), and
- + Family relationships (in Canada and transnationally).

We have developed a number of fact sheets on these topics that are available online at www.serc.mb.ca

Thank you to the women in this project for sharing their stories in this research and helping us to gain such valuable insight. For more information please contact **Simret Daniel, Project Coordinator at 204-982-7816, simret@serc.mb.ca** or **Paula Migliardi, Research and Evaluation Coordinator at 204-982-7813, paulam@serc.mb.ca**

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ENCOUNTERS WITH THE HEALTHCARE SYSTEM

Most of the women had received HIV medical care prior coming to Canada. **Grave illness or prenatal care prompted HIV testing** followed by regular engagement with under-resourced medical services in their home countries. **These experiences became points of comparison.**

ACCESS TO MEDICAL CARE WAS IMPORTANT FOR ALL THE WOMEN.

- + Most of the women arriving to Canada with a HIV diagnosis were quickly connected to health care soon upon settling in Winnipeg
- + Access to "lifesaving" drugs and treatment was key for the women, who compared it to the poor access to treatment they had back home.
- + Women with less English proficiency or those relying on language interpretation, focused on their need to access HIV medication.
- + Access to reliable treatment meant that the women could achieve a "normal" life.
- + The costs of medication were a concern for some of the women in working poor families, which had a negative impact within their family relationships.
- + Some of the women had to find creative ways for taking medication without disclosing their HIV status within their current living arrangements.
- + Women's relationships with their medication was key to the maintenance of their health.

Taking medication was not a simple mechanical act.

- + Maintaining a treatment regime was not an easy task for most of the women. The women often shared ways of ensuring the efficacy of the medication. Types of food, meditation, timing, and other techniques helped them with their regimes.
- + The women believed that being stress-free helped with the efficacy of the medication.

"Comparing to back home, you did not have access to up-to-date medication, you know. At least I know, now I get my medication and my status rarely even comes up in my head."

“It’s very challenging. And it affects somehow my health when it comes to HIV status because with the medication you need to be holistically okay so that the medication can work. You need to have a peace of mind, you know?”

- + The relationship with medical personnel was highly influential in the women's acceptance and relationship with their medications, and the maintenance of their health.
- + Stigma and discrimination were commonly experienced, and even expected within their exchanges with the healthcare system prior to coming to Canada.
- + In Canada, the women found that HIV health professionals were very respectful and non-discriminatory.
- + The women who had achieved a strong relationship with their care providers tried to comply with their regimes, not only for their own health, but for the health of the relationship with their doctors and nurses.
- + However, establishing a good relationship with healthcare professionals was a long and difficult journey:
 - ✧ Inability to speak the same language affected clear communication
 - ✧ Receiving care from people with similar ethnic or national background caused a great deal of stress because of fear of disclosure of their status in their community.
- + Some women found that having an advocate by their side helped them when treated poorly in healthcare facilities not specializing in HIV care or with non-HIV specialists.

“I think that’s what one needs, that’s what I discovered, you need friends, you need someone to advocate for you”

“I think that personally it took me 3 years to start building trust even with health providers. Whenever I would go to [the clinic] and at the lab, at the lab I just look if it’s an African, my heart will pound. They’ll be, oh no, she will go and tell people (...) It took me sometime to realize not all people are the same.”

IN SUM, THE WOMEN SAID...

The first priority for the women was to have access to HIV medication. With time, the women improved their relationships with their care providers to better understand their medical care. Their medical needs drove them to accept their regimes, but also to find ways to make these regimes fit to their complex social realities. For the women who had limited English proficiency or who used interpreters, the outcomes of the encounters with the medical system were more instrumental and less holistic.

RECOMMENDATIONS

- + Invest in educating healthcare providers about HIV in settings outside exclusive HIV care.
- + Ensure that notions of confidentiality and privacy in the healthcare system are well explained and understood within the medical encounter, and beyond.
- + Assist with the complications and uncertainties of daily life in managing complex medical regimes.
- + Investigate the impact of medication costs in treatment adherence and family relationships.
- + Support comforting healthcare environments, and building relationships between healthcare providers and people living with HIV seeking their services.

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PERSPECTIVES ON SOCIAL CARE SERVICES

Over the years, this group of immigrant women living with HIV have received very diverse social care services. **Their stories reflected on their experiences with settlement, education, home care and housing, among other services in Winnipeg.**

Sometimes their experiences of living with HIV shaped their assessment of these services.

- + For those who received them, settlement services were instrumental in helping access HIV-related services and other needs (e.g., housing, employment, language classes).
- + Women with different immigration statuses had different access to settlement services, and possibly to other services. Some were not aware of services available.
- + Sometimes these services were inadequate because of limited options to their diverse needs and interests.
- + Finding gainful and secure employment, with benefits to fall back into when ill, was a major struggle. Most options offered to them in employment services did not seem to account for their health concerns.
- + Precarious employment prevented women from gaining access to affordable, reliable and safe childcare options.
- + Among those who received home care services, the women believed that there was a breach of confidentiality, and that they were discriminated against because of their HIV status.

“But it was not easy (...) when it came to look for a house, the person in charge of housing kept on taking me downtown to get a house and I was like ‘I don’t like this house. I can’t stay here.’ I looked around and was, it’s not a safe place for my kids..., and I only had three chances. If I refused that house, they’d say ‘That’s it. We can’t get you another house.’ I was like, ‘fine.’”

“I feel like hardship is weighing over good things, you know. I have to push through, I have to work so hard.”

- + Sometimes the women were not sure if they needed to disclose their HIV status to access services. Eager to obtain services, or believing that they would be in trouble for not disclosing their status, the women chose to disclose their status and faced sometimes unnecessary stress.
- + On the other hand, at least in one of the cases, HIV non-disclosure with school staff may have left a young woman's rights unprotected. She skipped school to avoid being bullied because of her HIV status.
- + Limited English language proficiency, and no access to interpretation, restricted the women's access to supports.

"I don't know why they do that [tell their workers of HIV status]. I'm scared. But I took her, she didn't cook for me, didn't clean the house, just sat on the couch. I changed for another one. She came for only one day. They didn't come to [do] what they were supposed to. One even used gloves around, she didn't want to come near me, and I mentioned to her that that was not right, why wouldn't she say 'I'm sorry?'"

"When I went for surgery, I went to transit, handi-transit, and my [relative] was interpreting for me. And she [the clerk] asked me 'what medication are you taking?'" I had to tell her that, because of HIV. So, when [my relative] heard, he was just silent, and he cried. That was the moment that he knew."

CONSIDERING ALL THIS...

The diverse stories women told illustrated the complex social needs, and their difficulties in gaining access to proper services. Sometimes the women found the services adequate; however, in many more cases the services were unable to meet their needs. Lack of awareness of services, HIV stigma and discrimination, lack of language interpretation, and lack of knowledge on when and how to disclose their status influenced their access to social services.

- + Address stigma and discrimination in communities at large.
- + Address stigma and discrimination, training, and human rights abuses in service provision (including the very need to know the HIV status of clients).
- + Put in place mechanisms to rectify human rights violations.
- + Ensure people living with HIV know when they HAVE to disclose their HIV status when seeking social services.

"... when [CFS] took over my kids (...) I got a phone call from the school, they told me 'your child had come to school only for 10 days in the entire year' and that really broke my heart (...) The main reason is the language barrier. Like other parents, when a child is not going to school or if the child is not doing well in school, parents will go and will discuss, but for me, I don't know what to say. There is no translator. I don't say anything. So it was the language barrier that what it was a huge problem."

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ENCOUNTERS WITH THE CHILD WELFARE SYSTEM

These findings come from experiences with the child welfare system where some **women have had their children "taken" or have "lost their children" to the system** or who have been in-care (e.g., foster families, group homes, hotels)

THE MOTHERS

An inability to fully care for children, due to poor social supports available, was the main factor in some of the cases. HIV stigma was largely associated with the lack of supports. Inappropriate supports contributed to these scenarios, including

- + No common language or or non-existent interpretation services, which prevented women from understanding the processes involved in their children's apprehension and future
- + Not having significant community support due to HIV stigma
- + Worker' who are not knowledgeable about experiences of living with HIV, and the types of supports needed under these circumstances
- + Lack of support in communicating with children in care
 - + Late realization of the implications of poor communication with children in care
 - + Loss of common language and limited daily contact, leading to an inability to communicate
 - + No interpretation available during visits

"I would get confused... when they took away the kids, they told me that they will give them back to me in 6 months, and I patiently waited .After six months they told me 'you know what? We are not going to give you the kids (...)' . A year passed, two years passed, then we went to the court. So meanwhile the kids forgot the language, and even up to now they only speak English, and I cannot communicate with them. I need someone to translate when I am with my own kids and I am in such a pain.

"When I came to Winnipeg I was so happy, but again when they took away my kids I was in my house by myself, alone, no help, nothing. I, and the walls. Even when they sent me those letters from CFS I didn't know how to read them. I could open them and look at them."

THE CHILDREN

A different perspective came from a young woman who had been in care. Many stories revealed consistently inadequate supports while in care, including

- + Shaming and humiliation experienced when children were "watched" while taking their medications by foster parents, or when not allowed to participate in programs or for recreation.
- + Inadequate access to culturally appropriate meals due to restricted access to group home kitchen facilities to prepare desired meals or bringing outside food.
- + Lack of accommodations made for "prescribed" diets within their meal plans was a major concern. This resulted in skipping meals or developing an intolerance to medication.
- + Excessive surveillance over young women's sexuality. Because of "criminalization" of HIV transmission, youth were questioned over their sexual behaviours while no sexuality education was provided
- + Ongoing questioning of youth's potential mothering abilities based on assumptions on the youth's perceived mothers' parenting (in)abilities

THE WOMEN ALSO TOLD US

The women also told us that at times they felt heard and appreciated when some of the workers were there for them and listened. However, it appears that even in these situations, the outcomes were not what the women expected. Family reunification was a long and arduous road or a dead end for these women.

The stigma of living with HIV, and the additional stigma of becoming involved with the child welfare system added to the experiences of isolation these women felt. The resulting emotional stress left many women with depression and feelings of hopelessness.

Motherhood was of central importance to the women in the study and highly valued

I went a whole week without taking my meds. There was no food in the house. I told them I needed African food. They don't understand. They cooked pork all the time. I don't eat that, I could not eat that. I asked about rice, I could not cook my rice! (...) They didn't allow to cook for myself. I didn't want to be there. I could not take my meds with this small food. (...) I was trying to go to school, but it was hard for me. I did not see any help. It was hard to go to school with all this, with my emotions like that. This was supposed to be a nice place. I had a nice bedroom. But I didn't have freedom in that house.

in their communities. Amidst the many hardships these women faced, motherhood encouraged and motivated them to move forward with a new outlook on life. However, the lack of supports at both the community and services level got in the way of these women's dreams.

- + Must develop service delivery models that meet the social, cultural, gendered and linguistic needs of immigrant women living with HIV, and their families
- + The child welfare system must acknowledge the impact of, and design services that respond to, HIV-related stigmatization
- + The child welfare system should provide services that adequately address HIV care needs, and support women's autonomy in their own care
- + Communities and caregivers should address HIV-related stigma, and stand up for women and families affected by HIV
- + A stronger network of support for immigrant women living with HIV

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THE WOMEN'S GROUP: TOGETHER FOR CHANGE

This group of immigrant women not only face a multitude of challenges, faced by any newcomer settling in Winnipeg, **they have the added struggle of living with HIV and its stigma.**

The Women's Group, as the women are used to call the group, brings together immigrant women from many African countries to learn from each other, and to learn from guests to the group. Some time ago, a few women asked SERC to provide a space for coming together. Other women in this group were told about it by their health or social care providers, or through their peers.

Often, the women talk about their experiences of care and support. They want to share these with other women living with HIV, with those who provide care or support for them (even if they do not know that they are positive), their communities, and the public in general.

"It's like I'm home (...) I can tell everyone my problems. I enjoy this and it's really nice. I feel how much you take care of (me) and how much I love you. You guys are like my other family, my other parents. You helped me with another step I'm going through."

WOMEN'S GROUP FEELS LIKE HOME & FAMILY

- + The group was described by the women as a "family". In this family, the women were able to rely on each other, whenever they needed.
- + This "family" or "home" facilitates openness and a sense of full autonomy to share one's ongoing struggles with living with HIV.
- + The women's group plays an important role in providing emotional support.
- + The women received HIV related services; however, this was a significant space where they could figure out how to resolve day-to-day challenges, and share experiences with other women living with HIV.
- + Despite busy schedules and daily challenges, the women connected with each other regularly outside the organized activities of the group.
- + Some women found that the group allowed them to find new ways of participating in society.

NEW OUTLOOK ON HIV

- + Caring about and for each other has led to a renewed or enhanced sense of self for individual women.
- + Coming together has helped the women to regain a sense of "confidence."
- + Sharing experiences of living with HIV has changed the women's outlook that HIV is a "deadly" disease, and helped them feel like "normal" people.

"People in the outside may not accept me as I am, but here, my sisters here, I know they accept me, they are a shoulder to lean on."

LOOKING FORWARD

- + The women appreciated their leadership role in shaping what they wanted to see happen in their group.
- + They tried to find opportunities to learn new skills that would result in gainful employment.
- + Sharing helpful information about managing their illness with group members is one of the group's activities.
- + Many of the women in the group were passionate about the political stance that the group should take. However, faced with stigma, the women struggle with becoming visible as a group of women living with HIV.

PARTICIPANT 1: IT IS GOOD TO DO A DEED [COMING TOGETHER INTO A SAFE SPACE]; HOWEVER, WE NEED TO LEAVE A LEGACY!

PARTICIPANT 2: THIS IS A VERY IMPORTANT GROUP. LET'S TRY TO DO SOMETHING WITH OUR GROUP.

PARTICIPANT 3: IT IS A GOOD THING TO HAVE A PLAN, TO TAKE THE GROUP TO ANOTHER LEVEL.

PARTICIPANT 1: THE FIRST PRIORITY IS TO LOVE, HAVE UNITY, EASINESS, LOVE, HAVE A PROJECT THAT [IMPARTS] LOVE.

- + Based on the benefits, the women wanted to promote the group amongst other women.
- + Believing that gossip and fear kept people from talking about HIV or seeking services, the women in the project wanted to:
 - ✧ Invite other women living with HIV to their group.
 - ✧ Tell service providers that supporting the coming together of women living with HIV is helpful and meaningful to women.
 - ✧ Tell organizations that they need to check if or how their services may contribute to HIV stigma and discrimination or inadvertent disclosure of one's HIV status.
 - ✧ Tell the community at large, and their own communities, that they want everyone to work towards making HIV stigma disappear.

"I liked what you did for me 'cause you brought me up, you made me feel like I was somebody (...) Because you were tapping into what I did, you know what I mean? You knew I have these skills and you were trying to connect me to..."

"I become more confident the more I talk with the group. I feel good when I am talking with the women. (...) Before I used to think that I am different from other people. And I used to feel like people may know my situation. But now, I am a normal person (...) and you are some of the people that gives me hope also. I have learned many things from you."

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STIGMA, GENDER AND HIV (NON-)DISCLOSURE

In our research, **HIV-related stigma permeated the conversations** with the African immigrant women living with HIV. This was seen to affect each of the care and support topics discussed. The women felt stigma was a part of their encounters with **health and social care systems**, other **social institutions**, the **community**, and **society at large**.

Research shows that people with HIV from racialized communities face multiple forms of stigma. In our research we learned:

- + The deep stigma the women faced back home influenced the stigma suffered in Canada.
- + Except for HIV specialized services, the women experienced stigmatization and discrimination because of HIV, and because of their racial and immigrant background in their encounters with other services.
- + In face of the silence around HIV in society at large and their communities, as well as their own experiences with stigma, the women struggled with keeping their status secret.
- + Being a woman living with HIV was strongly associated with "promiscuity" and dishonourable social practices (e.g., sexual relations outside marriage or sex with many partners).
- + HIV was believed to be the women's own fault.
- + Keeping the secret helped women maintain a good reputation, as well as much needed supports in their small communities and social networks.

"If I go to Nine Circles (Community Health Centre) and then I find a black person there, it's like 'Oh God you're gonna know why I'm here.' But now, I even don't think about it. I just go 'Hey, Hi, Hi, how are you doing?' We talk about anything else. But why you are here is none of my business."

"Whenever I go to church (there) is so much trouble. I prefer to stay home and there is no gossip (...) it is because "[name] HIV positive, [name] goes out with too many people." They don't know anything about me, but they are talking. I'm not going to sleep with a person and then oh, ... I don't want to have that, I don't want to go to jail for what I am doing, no."

“Women -they are looked at as the source of evil. When it comes to HIV, men are, the frustration men go through, it’s lighter than what women go through. Your in-laws- they will mistreat you. Your own people will mistreat you. This community says that woman is a prostitute. They don’t look at the man. They look at the wife as you know...”

“(...) my friends they attacked me (...) I don’t want to stay like this, people judge me. Because that time people talked about me, like ‘[name] has this’ day after day, whenever they saw me ‘don’t talk to that girl, she has this’ it was like ‘how am I going to live in this country?’ People keep talking about me (...) someone put on facebook I have HIV, and I didn’t say that, and that would hurt me. And I found out who said it. Why people hate me like this? I went and beg them. Then I went to ask them ...I don’t know it hurts.”

“People are not informed about what HIV is, and those ones who are infected, they don’t want to come forward. Why? Because of the stigma. Like many times I think of different people who are so okay to tell ‘This is what I am’ and I’m like ‘I admire those people, I will want to do that’.”

“Many times when I look at it, [HIV] is not the killing part (...). The bad news is not the disease; the bad thing it’s that’s confidentiality thing. It hurts so bad when you disclose your status and by the time you know it, the whole community is talking about it. That kills you.”

- + Disclosure was a difficult task with unknown consequences. Most had disclosed to small circles of friends and families with positive consequences. Sometimes intentional or unintentional disclosure had damaged relationships.
- + Disclosing HIV would have consequences in accessing social supports in Canada, and affect their relationships back home (as many women had not told their families about their status).
- + Gossip and fear about HIV in their social networks, including their religious community, was a major barrier with disclosure, and even talking about HIV in general.
- + According to the women, fear of HIV, and its strong association with death, fuels stigma.
- + Among women's experiences of HIV stigma, HIV non-disclosure criminalization had a great impact on women's intimate relationships.

MORE NEEDS TO BE DONE

The women felt that "not enough" was done in Canada to address stigma. They suggested:

- + Support initiatives that reduce isolation of members of the community affected by HIV
- + Create opportunities to build knowledge in the community about HIV and to address stigma, including the multiple forms of stigma affecting individuals and communities
- + Address barriers to services, including attitudes towards HIV
- + Ensure that confidentiality and privacy of people living with HIV is protected