

To Disclose or Not to Disclose?

The Factors Influencing HIV Disclosure Among African and Caribbean Women

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Background

In recent years, non-disclosure of HIV-positive status has become a legal offence in many countries, including Canada. A lack of socio-cultural and gender specific disclosure frameworks presents a missed opportunity for providing women with the information and tools required to navigate the disclosure process. Effective disclosure strategies also reduce the likelihood of legal prosecution and the frequency of secondary transmissions. Within the context of African and Caribbean Diaspora communities, race, gender, social networks and criminalization are factors that must be considered when developing strategies to address voluntary and involuntary disclosures. We present an evidence-based disclosure intervention adapted to the unique challenges and opportunities faced by HIV-positive African and Caribbean women living in Toronto, Canada.

Methods

1. Developing the Disclosure Intervention

- We reviewed the literature for relevant disclosure studies, models and theories, focusing, where possible, on studies that explored the experiences of Black women.
- Two (2) focus groups and four (4) in-depth interviews were conducted with HIV-positive women from the African and Caribbean Diaspora
- Two (2) focus groups were conducted with service providers working with women from the African and Caribbean community.
- Data were analyzed thematically using relevant qualitative theories.
- A model for the disclosure intervention was developed by drawing from literature, focus group and interview findings. Service providers and key HIV stakeholders provided additional recommendations.

2. Pilot Testing the Disclosure Intervention

- Service providers and peer support workers were recruited to provide guidance to women participating in the pilot testing phase.
- Peers received training relevant to issues of disclosure and support work
- Pilot testing conducted with partner agencies who serve African and Caribbean women, under the guidance of service providers, peer support workers and a counselor.

Demographics

Twenty-five (n=25) women participated in the focus groups and interviews. Participants mostly consisted of heterosexual women between the ages of 35-44. Nearly 75% of women identified as being African with a smaller proportion indicating that they were Afro Caribbean (24%). The demographics suggest that most women received their HIV results from a family doctor, during immigration medicals, and during hospital visits (Figure 1). Approximately 35% of women received little or no counseling following their positive diagnosis.

A large number of the participants had disclosed their positive status to partners (77.3%), while the proportion of women disclosing to their children was smaller (27.7%). Nearly 60% of the women disclosed to a family member, with 36.4% of women sharing their serostatus with their parents. Half the women disclosed to friends, support group members and service providers. Every participant had disclosed to at least one person (Figure 2).

Figure 1. HIV Diagnosis
The conditions under which a woman learns about her HIV status and her ability to access support following diagnosis can have implications for the way she negotiates future disclosures.

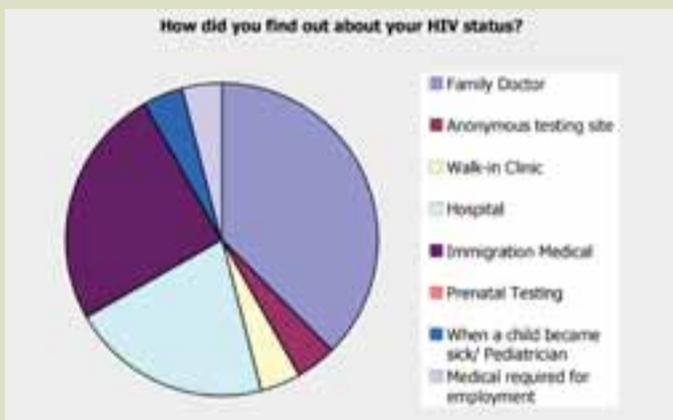
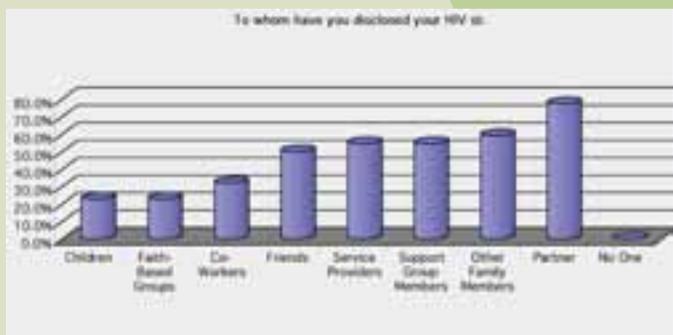


Figure 2. Disclosure Experiences
Low disclosure rates to children and faith-based groups seem to indicate that additional support and resources may be required in these areas. Partner disclosure figures as a prominent theme.



Results

The following were identified as factors influencing disclosure among African and Caribbean women: education; empowerment and self-acceptance; internal and external sources of stigma; support systems; treatment and disease progression; violence and safety; legal and ethical issues; culture and community; as well as spirituality.

Education

"Before I received my status I was already participating in all kinds of groups and workshops... If I hadn't participated I would not understand what I do now about HIV, such as treatment side effects".

– African Woman

Support Systems

"I first disclosed to my family because I needed support to carry on. Their reaction was very supportive...very loving. So because of that, I didn't care so much about the reactions of outside people."

– Caribbean Woman

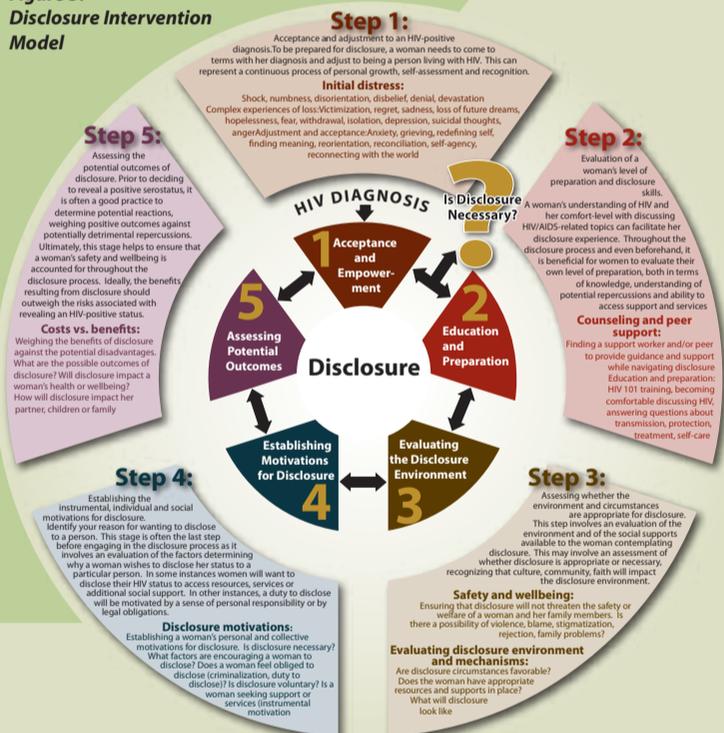
Legal Issues

"It's a hard thing because if you don't disclose you can get into trouble...you know it's in the law, they say that if you, even if you use a condom, and then the person get to find out after, they can still criminalize you because they can say, what if this condom had broken?"

– Caribbean Woman

We present an HIV disclosure intervention that addresses these principle factors. The intervention contains various disclosure scenarios, descriptions of the disclosure process and relevant resources, as well as a peer-support training package. A step-by-step schematic is also included, representing the various phases a woman may undergo each time she engages in disclosure (Figure 3).

Figure 3. Disclosure Intervention Model



Next Steps

The implementation of this intervention hinges on a deeper understanding of the multiple overlapping issues facing African and Caribbean women navigating disclosure. At present the disclosure model is being pilot tested with a group of women in Toronto, Canada. Following the pilot testing phase, a community Think Tank will be held to discuss findings and recommendations. Outcomes will be used to develop an evidence-based disclosure intervention that will be tested for effectiveness and adaptability on a national scale.

Conclusions

An effective HIV disclosure framework should encompass a low-cost and widely applicable intervention that can be adapted to the social, economic and cultural realities faced by women living in various contexts. We present an evidence-based disclosure framework that can be used to further support African and Caribbean women as they work through multiple HIV disclosures.

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