Lessons Learned: Community Mobilization & the ‘HIV-Positive Sero-Status Disclosure Intervention’

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Presenter Disclosure

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Presentation Outline

• Digital Story Telling Videos on HIV Disclosure
• Exploring common HIV Disclosure barriers
• Development and Background of the HIV Disclosure Model
• Community Mobilization & Lessons Learned:
  1) The importance of partnerships
  2) The need for tailored strategies
  3) The importance of peer support
Common HIV Disclosure Barriers

- Disclosure and criminalization
- Racism
- Privacy concerns
- Culture
- Ignorance and Stigma
- Fear of Rejection
- Internal Stigma
- Isolation
- Sexual Orientation
- Gender
- Lack of Support Network and Resources
- Setting or Timing
- Relationship
- Abuse
- Testing positive through the Immigration process
Introduction

• Criminalization of HIV non-disclosure has been the main focus
  – Focusing solely on an individual’s responsibility to disclose obscures the social, systemic, and structural factors that influence HIV-positive status disclosure
  – Disproportionately affects Black men and women

• Managed properly, disclosure has major benefits for BOTH those living with and at risk of contracting HIV
  – It can be an effective HIV prevention and support strategy
The aim of the model is to provide a systematic way of supporting people living with HIV through the process of disclosure.

Everyone experiences disclosure differently however, most will undergo similar stages of disclosure each time the disclosure process is initiated.

The model provides a template that outlines the stages involved in the disclosure process in which an individual seeking support is able to explore the challenges, barriers, and possible strategies associated with their HIV status disclosure in a collaborative and person-centred approach.
Research Process

1. DEVELOPMENT
- Literature review of disclosure studies, models, theories
- 2 focus groups (women who had and had not disclosed their status) and 4 in-depth interviews with ACB HIV-positive women
- 2 focus groups with service providers working with ACB women
- Total n=30

2. PILOT TESTING
- May-September 2010
  - 22 Women, 5 service providers, 4 peers, 1 counsellor
  - Women participated in 8-10 sessions with their service provider and peer support worker
  - Data recorded in tracking forms filled by the participants, peer support worker, and service provider

3. EXPANSION AND ROLL-OUT
- 3 Focus groups in Toronto with: Heterosexual Men (n=13), MSM/Gay Men= 9, Youth (n=6)
- 8 in-depth Interviews in Cambridge, Kitchener, and Waterloo area and 5 in-depth interviews in Niagara
- 2.5 day training with 40 service providers and 20 peer support workers
HIV Disclosure Model Steps

1. Acceptance & Empowerment
   - Coming to terms with an HIV-positive diagnosis
   - Adjusting to being a person living with HIV (PHA)
   - A continuous process of personal growth, self-assessment, recognition & struggle to accept the new self-identity of being a PHA

2. Establishing Motivation for Disclosure
   - Knowledge of HIV 101
   - Comfort level discussing HIV/AIDS
   - Availability, awareness, & accessibility of services
   - Understanding the potential repercussions of disclosure & non-disclosure

3. Evaluating the Disclosure Environment
   - Determine reason(s) why the person wants to disclose and to whom:
     - Is it driven by a need to access resources/services, or additional support?
     - Is it due to a sense of personal responsibility?
     - Is it driven by legal obligations?
     - Is it necessary?
     - Is it voluntary?

   - Identify the social support available to the person, will culture, community, or faith impact the disclosure environment?
   - Determine safety & wellbeing: will disclosure threaten the person’s/family’s safety?
   - Lead to a possibility of violence, stigma, rejection, or family problems?
   - Develop a safety plan if necessary

   - What are the potential reactions?
   - Is safety & wellbeing accounted for? Is a safety plan ready?
   - Do the benefits outweigh the risks associated with disclosure?
   - How will disclosure affect a person’s: Future? Health? Wellbeing? Family?

6. Finalize safety plan
   - If not ready continue preparations, support & revisit previous steps
   - If ready implement action plans ensuring all support systems are in place
   - Where? Who will be present?
   - Who will support the person being disclosed to immediately & long-term?
Community Mobilization & Lessons Learned: The Importance of Partnerships
Community Mobilization & Lessons Learned:
The need for tailored strategies

“There's first of all, culture. So culture... that sometimes there's a way that we talk to each other culturally, so if there's no space within that interaction to even approach an issue like HIV, then it's not possible, culturally speaking, literally.”

“... It's a function of where they come from, you know their ethnic base, what you know, how they identify, whether or not they are you know gay, lesbian, transgender, and so I think disclosure issues when you are trying to help somebody - there is no blanket coverage - it has to be tailored to specific groups because the need of certain individuals that come from different cultural backgrounds.”

“For me, the big issue, my HIV status is not an issue with me. What is an issue with me, and I have evolved over time, is fear of rejection. And that fear of rejection has taken on many different levels and types. Fear of rejection because of my ethnicity, fear of rejection because of my sexual orientation, fear of rejection because of my colour, I mean there's so many different levels of fear of rejection for me. And as I said, before it affected me a lot, it's affected me less as I'm growing and so on. But it was a huge deal for me.”
Community Mobilization & Lessons Learned:
The importance of peer support

“I think for me what supported me in my disclosure, just as the brother here, I think meeting people who are like me. In this process, when we're meeting and we're all positive, and just sharing our stories, our pains and sufferings, how we're discriminated at home or at work, that process gave me a lot of strength. It didn't happen in one day or one week, it took several months. And so, that journey supported me to say "you know what? I think I can disclose but as a process”.

“Someone living with HIV. Who knows me, who knows that okay, this is beyond: this is like a brother, this is like a sister. And to me it has given me a lot of power to acknowledge and to appreciate the fact that, you know, I am not alone in this struggle.”
Where are we now?

- Conducted 2.5 day training February 17-19, 2016 to 40 service providers and 20 peers from across the province to implement the HIV Disclosure Model
- Rolling out the HIV Disclosure Intervention in Ontario
- Finalizing training toolkit and tracking forms
- Will be doing additional training and evaluation
WHIWH UPDATE

#GLADITESTED - Encouraging HIV testing amongst African Caribbean and Black women

Mercy Gichuki, MPH
Women’s Health in Women’s Hands CHC
Community Health and Wellbeing: Shift the Conversation

June 8th, 2016
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Presenter Disclosure

Presenter: Mercy Gichuki

Relationships to commercial interests:

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Women’s Health in women’s Hands CHC (WHIWH CHC)

- WHIWH CHC provides primary healthcare to racialized women living in Toronto and surrounding municipalities.

- We are population based CHC and prioritize women from Black, African, Caribbean, Latin American and South Asian communities.

- WHIWH CHC has been involved in HIV advocacy, treatment, prevention & research for over two decades.
The ‘African, Caribbean and Black Women Taking Control over HIV/AIDS and Sexual Health’ initiative

- Is a three year project that is part of a broader HIV Program running at WHIWH which focuses primarily on treatment, support and care for women living with HIV (WLWH).

- Targets ACB women over 16 years in Toronto and aims to enhance the existing ‘Care Cascade’ by including HIV education, testing, diagnosis and linkage to primary healthcare as part of a holistic ‘Care Cascade’ continuum.
We have expanded OHTN’s HIV Care Cascade framework for our program to include components of community mobilizing/engagement, education and testing to identify women living with HIV.
Holistic Approach

- WHIWH CHC trained 4 staff members from various departments, in addition to 3 trained staff members to deliver the Anonymous POC testing.

- The complete staff now includes 2 physician, 2 nurses and 3 health promoters to administer the HIV Anonymous POC testing.

WHIWH CHC was designated an Anonymous HIV Testing Site that same year.

We are 1 of 50 Anonymous HIV Testing sites in Ontario and 1 of 16 Community Health Centres that provide anonymous HIV POC testing.

Anonymous HIV POC testing has consistently resulted in more HIV positive tests, than standard or nominal testing.
Anonymous HIV POC TESTING
What is Anonymous HIV POC Testing?

- Involves a 30 minute appointment
- Pre Test Counseling
  - Tailored to clients and their specific experiences
  - Review risks, HIV transmission, & HIV/AIDS, etc.
- Testing
  - Finger prick test
  - Result within 5 minutes
- Post Test Counseling
  - Provide result and follow-up with any additional questions
  - Reactive tests require additional time and support
ANONYMOUS HIV TESTING PROGRAM
AT WHIWH CHC

- In 2015, began to expand our already existing Anonymous HIV testing program and trained four new staff members

- Comprehensive training:
  - AIDS Bureau training & shadowing at Hassle Free Clinic
  - Train the trainer model – group and one-on-one training

- Promotion of our Anonymous HIV testing program
  - Internal promotion
  - New client promotion

- Testing has increased five-fold in the last year
WHIWH CHC TESTING APPROACH

- Follow our mandate and work from a feminist, anti-racist anti-oppressive, LGBTQ and trans-inclusive lens

- We take into consideration the many intersections of women’s lives

- We tailor the sessions to allow for natural conversation to take place

- We encourage questions to be asked throughout the session
WHIWH CHC Testing Goals

- Clients that test Reactive:
  - Link them to care
  - Reduce viral load with treatment
  - Connect them to support and community

- Clients that test Negative:
  - Make different choices as a result of new knowledge
  - Making HIV testing part of their routine medical care
#GLADITESTED - Encouraging HIV testing amongst African Caribbean and Black women

- #GladITested Campaign consists of five individual posters and one group poster with different statistics on them including a youtube video.

- This video has been viewed over 300 times on youtube and it has reached over 7000 individuals on our facebook page.
Success of the campaign

- The biggest success has been the extent to which we have been able to penetrate ACB communities to reach women we would never have otherwise reached with the support of the community ambassadors.

- We have also been able to increase the number of women accessing HIV testing services, through development of a more targeted and community-based HIV testing strategy. Raising the profile of HIV testing outside traditional health institutions.
Places for Outreach

- Universities
- Cultural events and festivals
- Pride

Anonymous & Rapid HIV Testing

Thursday, March 17th
10am - 3pm | Student Centre | Room 150

Know your HIV status, get an anonymous test!
#gladitestated

Point of care HIV testing is done by a painless finger-prick and results are ready in a few minutes. Anonymous HIV testing uses only numbers to keep track of results. You do not have to give your name or address.
HIV Testing Campaign

#GLADITESTED

Females aged 30 to 39 had the highest proportion of new HIV diagnoses.

"Book your Anonymous HIV test at WHIWH CHC
416-593-7655 or visit whiwh.com"
#GetTested

#KnowMyStatus

#GladITested