



Optimizing the Health of Ontario Women Living with HIV through Knowledge to Action

Authors: Mubnii Morshed¹, Wangari Tharao¹, Mona Loutfy², Carmen Logie³
1. Women’s Health in Women’s Hands, 2. Women’s College Research Institute, 3. University of Calgary

Background

The main purpose of KTE in HIV research is to improve policies and practices by mobilizing relevant data through a variety of methods. It is a critical and participatory process that allows for decision makers and stakeholders to engage with timely and relevant data.

Objective

To demonstrate the process of utilizing findings from a community based research (CBR) project to tailor effective and meaningful KTE strategies for diverse stakeholders, while simultaneously strengthening relationships and trust between researchers, service providers and HIV+ women.

The WCBR Project

The WCBR project “Involving Ontario HIV-positive women and their service providers in determining their research needs and priorities” (2007 - 2009) was undertaken as a result of the increased rate of HIV infection among women in Canada. **The project consisted of two phases:**

Phase 1: qualitative component of 15 focus groups (n= 104). Participants were self-identified Aboriginal, African, Caribbean, South Asian, Latina, sex workers, injection drug users, lesbian/bisexual/queer and transgender women.

Phase 2: Based on findings from phase 1, a survey (n=166) was conducted among one of the groups of women highly impacted by HIV in Ontario: African, Caribbean and Black Canadian (ACB). It was designed to assess the relationships between independent (HIV-related stigma, sexism, racism, social support, resilient coping) and dependant variables (quality of life, access to care, depression).

Key Results from the WCBR Project

The main themes that emerged from the data:

1. Poverty

Because of poverty you have housing issues, and then you have lack of access to adequate nutrition. You have lack of transport... increased costs going back and forth between doctors and pharmacists... people making decisions about whether they have enough money for milk or to take the bus to see the doctor... you rely on AIDS service organizations. They’re so under-funded we can’t rely on their programs, because one year they have this program and then the next year they have that program.

HIV Positive Participant

2. Employment barriers

3. Mental Health & Emotional Issues

Loneliness, you’re lonely, depressed.... Even when you go to see a psychiatrist or psychologist, they don’t really address my issues as a women living with HIV. ... You’re told, okay you’re depressed, go take this medication. You take the medication and it doesn’t help so I think more needs to be done. Having support groups, yeah, where you can go and talk and ease your stress.

Young HIV Positive Participant

4. Social isolation & fear of disclosure

I can’t even see a church talking about HIV or AIDS. Which is kind of sad because I think that would be a really good place to discuss it. Like we went on a spiritual retreat on Monday. And I just feel that like if there was a group that was religious that talked about that, I think it would benefit a lot of people who have HIV or know someone with HIV. Because God’s a strong presence in a lot of people’s lives.

Sex Worker

5. Need for gendered & women

Maybe you can help us out, have workshops open just for lesbian, queer, and – so that people won’t really be so afraid to talk about what they want to talk about, and get help from there, other than just shutting down, you know, keeping everything into your heart and causing stress. ... With your own people you don’t have to be stressed.

Queer Participant

Target Populations for KTE

Five (5) target populations for KTE were chosen due to their position as “decision makers” in their communities, and their ability to engage with and mobilize the data:

- 1. Service Users/Potential Service Users
- 2. Community Leaders/Advocates
- 3. Service Providers
- 4. Researchers
- 5. Policy Makers

The KTE Strategy

The WCBR KTE strategy focuses on delivering information directly to the targeted populations in a memorable and engaging way. The strategy includes 3 KTE mediums designed to reach multiple audiences.

1. Digital Storytelling (DST) Videos

One of the main findings of the WCBR project was the participants’ mistrust of research. Thus, the KTE medium had to capture and express individual experiences and impacts of the WCBR project of HIV+ women, peer-research assistants (PRAs) and the researchers themselves. DST videos are unique in that they are not interviews or documentaries, but a powerful multi-media tool utilizing poetry, images, video clips, photographs and more to follow an individual’s story through their lens. The DST videos serve as both a KTE tool to be shared at conferences, events and forums, and as a stigma reducing intervention.

2. Regional KTE Forums

The aim of a KTE forum is to disseminate and generate action plans based on the results of the WCBR project, while simultaneously strengthening partnerships between researchers, and the HIV community. This method is in keeping with the recommendations provided by the WCBR participants to reduce mistrust of researchers, and increase transparency of the research

process. The forums provide opportunities for community members, leaders, and advocates to create dialogue on WCBR findings as well as brainstorm about future directions for the data.

3. Community Report

The development of a community report containing key findings from the WCBR project is important for accessibility of data to a wide audience. This report uses laymen’s language to communicate what the WCBR project adds to current gaps in HIV knowledge, and uses the stories of the participants to speak to service providers, policy makers and community advocates. This report will be distributed both in print and electronically, and will utilize multiple electronic resources (social media, listserve(s) as an important complementary strategy.

Conclusion

The KTE strategies outlined above follow the participatory nature of the WCBR project, and works with researchers, PRAs, and participants throughout the process. The initiatives effectively translate the WCBR findings into the development of effective policies and programs that promote the health and well-being of WLWH and improve their health outcomes. The KTE strategies encourage co-ownership of the research process, and addresses major barriers that have been identified. The KTE strategies will have high uptake. Mobilizing communities to become engaged in the HIV/AIDS response and taking individual and collective responsibility is a viable strategy for shifting the HIV discourse towards a health promoting direction.

Acknowledgements

Research participants; Peer Research Assistants; Community Advisory Board

Funders: The Ontario HIV Treatment Network (OHTN) and the Canadian Institutes of Health Research (CIHR)

Conflict of Interest Disclosure: We have no conflicts of interest.