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# The Black, African and Caribbean Canadian Health (BLACCH) Study: Laying the Foundation for Conducting HIV Epidemiologic Studies with Ethno-Racial Minority Communities in Understudied Urban-Rural Locales

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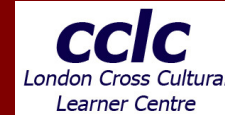


## The BLACCH Study

Laying the Foundation for  
Conducting HIV Epidemiologic  
Studies with Ethno-racial Minority  
Communities in Understudied  
Urban-Rural Locales

## Research Team

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## Overview

- Introduce the BLACCH Study
- London and Middlesex County
- Goals and Research Methods
- Conclusion

Here is an overview of this presentation. I will first provide some background information about the BLACCH Study, then I will provide some information about London, Ontario in order to contextualize the BLACCH Study. Next, I will present each of the major goals of the project and the methods used to reach those goals. I will conclude by discussing the impact our methods have had on the research, the team and the community as a whole.

## The BLACCH Study

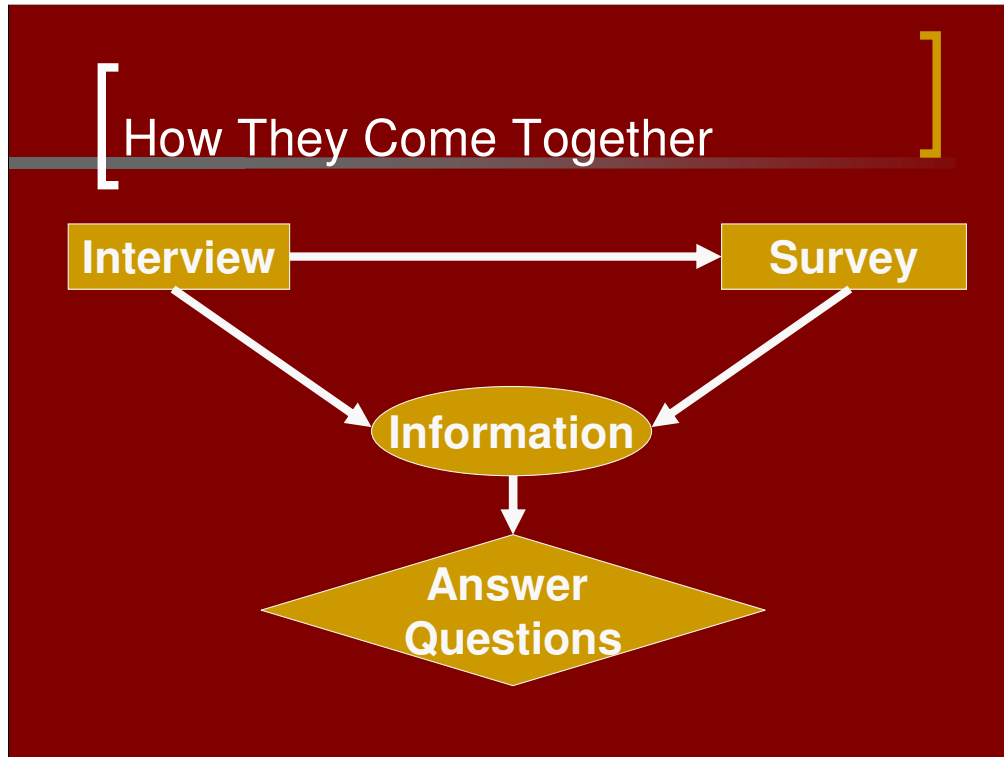
- Response to the impact HIV has had on ACB communities locally
  - 22.8% of new diagnoses in 2007<sup>1</sup>
  - Estimated prevalence of 1.7%<sup>2007</sup><sup>1</sup>
- Focused on program development
- Community-based research framework
- Social Determinants of Health
- Multi-disciplinary
  - Women's studies, social justice studies, psychology, public health, epidemiology, education, social work, physical education
- Mixed methods
  - Semi-structured interview
  - Survey

The Black, African and Caribbean Canadian Health Study, also called the BLACCH Study is an epidemiologic study that was started in response to the overrepresentation of African, Caribbean and other Black (ACB) people in incident HIV infections in Canada, and more specifically in London and Middlesex County. For instance, according to reports, ACB people accounted for 22.8% of new HIV diagnoses in Ontario in 2007, and the prevalence of HIV among the ACB population in Southwestern Ontario (the region where London and Middlesex County are located) is 1.7%.

Since we are focused on informing the development of HIV prevention, treatment and care programs, we are taking a community-based approach. Our research partners are a settlement service organization that is funded by Citizenship and Immigration Canada, an AIDS service organization, and research university. We also work with other stakeholders who serve as advisors and provide feedback throughout the research process.

Our team of 10 includes people with a diverse knowledge base. In addition to having people with degrees in a number of disciplines, we also have people with rich lived experiences. For instance, some of us are immigrants and refugees while others were born and raised in Canada.

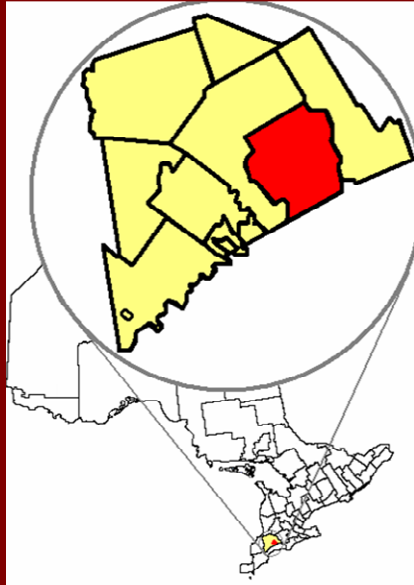
Lastly, we are using a mixed methods approach. Specifically, we have conducted semi-structured interviews and we will be launching a cross-sectional, self-administered survey.



We will use the interviews to help us design the survey. Both the interview and survey will give us information that we can use to answer questions about HIV and health.

## London, Ontario

- Largest city in SW Ontario
  - >350K in London (2006); >480K in CMA (2009)<sup>2</sup>
- Black population
  - 3<sup>rd</sup> largest visible minority group in London; 7,600+ (2.2%) & Largest visible minority group in CMA; 8,200+<sup>3</sup>
  - 50% born in Canada, and many others are from Africa and the Caribbean<sup>4</sup>
  - HIV primarily spread through heterosexual contact<sup>1</sup>
  - Underutilization of HIV prevention services
  - No specific services for the Black population



London is the largest city in Southwestern Ontario, and the 4<sup>th</sup> largest city in Ontario. The city itself had over 350,000 residents in 2006, and the metropolitan area was estimated to have over 480,000 residents in 2009. London is about half-way between Toronto and Detroit, and is surrounded by rural areas.

At only about 2% of London's population, the Black population in London is much smaller than those in Ontario's three larger cities. There are over 7,600 Black people residing in London proper, and over 8,200 residing in the Metropolitan area that includes London. It has been reported that 50% of London's Black population was born outside of Canada, and these persons are primarily from African and Caribbean countries.

As in other Black communities in Canada, HIV is primarily spread through heterosexual contact in London's Black communities. Additionally, despite the high infection rate among the Black population, HIV prevention services are underutilized by this group.

At present, aside from a Multicultural Outreach Coordinator at the local AIDS service organization, there are no health or social services directed specifically at Black people in London.

## Getting to Know Black People in London: Networking

- Networking with community members, service providers and academic researchers
  - Informal conversations, attending meetings, volunteering
    - History of Blacks in London: 1700s & 1800; 1850s; 1960s to now
    - Identify key persons: Multiple well-known individuals



Very little is known about Black people in London, so our first goal was to increase our knowledge of local Black communities. Since there is not a lot of information published about this population, and very few people have researched this population, this goal was accomplished by networking and doing some very simple semi-ethnographic work.

As part of our networking efforts, we connected with community members and followed-up through informal conversations. We also attended meetings with groups, and volunteered to help with events. For instance, we volunteered to wait tables at a local Ethiopian restaurant during an HIV/AIDS Fundraiser, we participated in the annual AIDS Walk, and we attended meetings with the Black Diabetes group.

Networking helped us to do two key things:

- 1) We learned about the history of Blacks in London and surrounding areas. For instance, there are three different migrations of Blacks to the region (this does not include slaves). The first migration occurred in the 1700s and 1800s, and these migrants were mainly British Loyalists. Then, in the 1850s, many escaped slaves from the U.S. came to London through the Underground Railroad. After the U.S. Civil War, many of these people returned to the U.S., and during the Gold Rush many Blacks went West. Since the 1960s, most of the Blacks who have settled in London came directly from Africa or the Caribbean. This information was useful for understanding the different groups in our population, and appropriate questions for those groups.
- 2) We were also able to identify influential members of the different communities and other stakeholders who should be included in the study. Some persons decided to serve as research partners and are members of the team, others serve as advisors, and others serve as participants who inform the development of the project.



## Getting to Know ACB People in London: Semi-ethnographic Work

- Semi-ethnographic work
  - Attend in community events, visit businesses and other organizations
    - Identify: businesses, organizations (service and social), media, group relations, community practices



We also did some semi-ethnographic work to learn about patterns in the community. For instance, we located key businesses and other organizations and local media outlets. This work helped us to see how groups relate to each other and how strong in-group bonds are. For instance, we learned that African communities were generally more cohesive and collectively active than other Black communities. On the other hand, Caribbean communities are more likely to have relationships on a one-on-one basis and generally do not have community organizations. Also, once you meet one person in a Caribbean community, you will be connected with others from that community.

## [ Building Capacity ]

- Immersing team in health research with Black communities
  - Learn about Black communities
  - Training in interview research
  - Experience in research processes
    - Data collection & analysis, grant writing, ethics, study design



The majority of our research team had very little research experience, but we all came to the table with rich life experiences. To build the capacity of our team to conduct health research with Black communities, we:

- 1) Built the team's capacity to work with local Black communities by sharing knowledge we gained through personal experiences, networking and semi-ethnographic work with the team.
- 2) Taught interested team members to conduct interviews for research purposes.
- 3) Improved the team's understanding of the research process by providing team members with opportunities for involvement in various stages of the research process. These included assistance in data collection and analysis, grant writing, the research ethics process, and study design.

Each of these tasks were performed to provide the team with the knowledge and skills needed to engage in additional health research with Black communities and answer questions of interest to Black communities.

## Identifying Community Concerns and Research Methods

- Semi-structured interviews
  - Open-ended responses
  - 22 Community members; 8 service providers
  - HIV, general health, social determinants, experiences, discrimination, research methods
  - Identify topics to be included in the epidemiologic survey, language and appropriate recruitment methods



After preparing ourselves to undertake the project, we needed to bring the project back to the community and solicit input from community members and other stakeholders. To do this, we conducted 30 semi-structured interviews. We asked participants a pre-determined list of questions to which they provided open-ended responses. The interview participants were 22 community members, and 8 service providers representing 8 service organizations that serve Black communities. These organizations were: the AIDS Committee of London, the Cross Cultural Learner Centre, the Infectious Diseases Care Program, the Options Clinic for Anonymous HIV testing, the London Inter-Community Health Centre, the Muslim Resource Centre, the Middlesex-London Health Unit, and the French-Canadian Association of Ontario. Whenever possible, we interviewed service providers who were also community members in order to capture their unique experiences.

The interviews covered topics related to HIV, general health, the social determinants of health, life experiences, experiences with discrimination and research methods.

From the interviews, we were able to identify topics for the survey, learn the language used in the community to discuss certain topics, and identify recruitment methods that would be comfortable for community members. For instance, we learned that people would rather complete a general health survey than just an HIV survey, and as part of health, people wanted to talk about diet and exercise. Participants seemed more comfortable using medicalized language instead of slang to discuss health topics. Also, participants were willing to pass the survey onto their friends as long as the survey was not only focused on HIV.

## Conclusions: Research Benefits

- Although these methods are unusual in epidemiologic research, they have been very rewarding thus far
  - People engaged and anticipating the survey
  - Community input and ownership
    - Language, topics, writing questions and answer choices, recruitment methods
  - Interesting promotional and KTE opportunities
    - Performances during Black History Month, presentations
  - Build relationships and identify influential persons
  - Learn about ACB communities

In the end, these methods provided many benefits for the research project as a whole.

They allowed us to engage community members and service providers in the project from the very beginning, and many are looking forward to the launch of the survey.

The community was able to provide input into the project, and the community also has a sense of ownership over the project. Along with the research team, community members and service providers helped to determine the language used in the survey, identify survey topics, write questions for survey along with the answer choices, and identify appropriate recruitment methods.

We have also been able to engage in some unique promotional and knowledge translation and exchange activities. For instance, we were able to share interview themes and quotes during scripted readings performances during Black History Month events. We were also able to promote the study while performing in events. Additionally, we have been asked to give presentations to community groups, and individuals have asked for presentations about the project as well.

These research methods also helped us to build relationships with community members and other stakeholders, as well as learn about the Black communities in London.

These benefits will likely manifest in: 1) a stronger survey instrument, 2) a larger sample size, 3) and more opportunities for KTE in the community.

## Conclusions: Community Benefits

- Capacity-building for the research team
  - Learn from each other and draw on our strengths
  - Foundation for future research projects
  - Provide practical experience, including “Canadian experience”
- Benefits for broader Black communities
  - Health promotion and education
  - Activism and advocacy
  - Building coalitions and networks
  - Informing community members about available resources

In addition to research-related benefits, the methods we have used provide benefits to the research team and broader Black communities as well.

For one, the team’s capacity to conduct health research with Black communities has increased, and will continue to increase. We have been able to learn from each other and draw on each other’s strengths to create a strong research team. As a team, we are better than the sum of our individual abilities. We have also provided the team with the foundation needed to initiate and execute future research projects. Lastly, team members have gained practical experiences in day-to-day activities related to research, and new Canadians on the team are gaining “Canadian experience”, which will help them in the labour market.

The research has raised awareness about health issues in local Black communities; people have begun to think about health more. Additionally, some community members have begun to speak about using the results of the study for advocacy and activism for Black communities. Much of the talk has been focused on creating more programs and services specific for Black communities. We have also been able to connect groups and individuals who have similar interests so that they can work on projects to bring Black communities together and advocate on the behalf of Black communities. Lastly, as we learn about resources, we are providing community members with information about these resources and ways in which they may be accessed.

## References

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[ Questions? ]