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The Black, African and Caribbean Canadian Health (BLACCH) Study: Phase I Preliminary Findings

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The Black, African and Caribbean Canadian Health (BLACCH) Study: Phase I Preliminary Findings

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Abstract

The Challenge: Most studies of HIV and health in African, Caribbean and Black (ACB) communities have taken place in large urban centres and rarely examine how the interactions between racism, gender, HIV-related stigma and multiple forms of oppression affect health and HIV vulnerability. This lack of information negatively impacts HIV prevention and health promotion efforts for ACB communities.

Our Approach: The BLACCH Study uses a community-based approach to collect extensive information about the health of ACB communities in Middlesex County, Ontario. The first stage of the project consists of semi-structured interviews to collect information about the breadth of health-related experiences in Middlesex County's ACB communities. A purposive sample of 30 persons will be interviewed—seven (7) persons providing health or support services to the local ACB communities and twenty-three (23) ACB community members. ACB persons involved in the interviews are from diverse backgrounds and represent a cross-section of these communities. The interview topics include: gender; migration; general health; religion; nationality; HIV-related beliefs, behaviours, knowledge, experiences, stigma and services; social network characteristics; socio-economic status and housing. The interviews are being analyzed using a modified grounded theory approach to identify emergent themes based on lived experiences.

Key Findings: We learned the following: health is viewed holistically, and participants largely classified themselves as healthy; diabetes and HIV are important health issues in the community; many people obtain health information through the Internet; most participants believe their risk of contracting HIV is quite low; ACB persons are not utilizing HIV services; there should be more of an ACB presence in HIV/AIDS, health and social service organizations; organizations need to have multiple employees from ACB communities with different ethnic backgrounds; health and social service organizations need to build trust with ACB communities; and rather than asking ACB persons to seek services and information, service providers should bring services and information to ACB communities.

Impact on Policy and Practice: This first phase of the study builds the capacities of community members, academic researchers and organizations in Middlesex County to mobilize to address the needs of ACB communities. In the long run, the BLACCH Study will help interested parties gain a better understanding of the HIV-related experiences of ACB persons who reside in areas with small ACB populations and limited HIV/AIDS resources.

Background

The Black, African and Caribbean Canadian Health (BLACCH) Study is an interdisciplinary, mixed-methods, community-based study focused on better understanding health and HIV in African, Caribbean and Black (ACB) communities in Middlesex County, Ontario. To date, studies concerned with health and HIV in ACB communities have taken place in large urban centres like New York City, Toronto and Montreal, and smaller urban centres receive considerably less attention. The BLACCH Study will provide much needed information about the understudied urban-rural regions in the rest of Ontario.

ACB persons are over-represented in Ontario's HIV-positive population and are a priority population for prevention efforts. Studies show that the social context of the lives of ACB persons is responsible for this unequal burden of disease [1,2]. There are over 8,200 Black persons in Middlesex County [3], and London, Middlesex County reportedly has the third highest HIV infection rate in Ontario, behind Toronto and Ottawa [4]. It is imperative to develop effective programs to reduce HIV transmission in London. The BLACCH Study has the potential to simultaneously assist HIV prevention efforts in London and for other Black communities in Ontario.

Principal Aims

- ❖ To better understand of the lives of ACB persons in Middlesex County, Ontario.
- ❖ To inform the development of the BLACCH survey instrument.
- ❖ To provide evidence that will enable health and social service providers to design more effective HIV prevention and care programs for ACB communities in London, Ontario and other small cities.



Figure 1: Mixed Methods Integration Strategy

Data Collection

Target Populations and Sample

- ❖ One service provider who caters to AC communities from each of these seven (7) organizations:

London Cross Cultural Learner Centre
AIDS Committee of London
Infectious Diseases Care Program at St. Joseph's Hospital
Options Clinic for Anonymous HIV Testing
Middlesex-London Health Unit
Assemblée de la francophonie de l'Ontario London-Sarnia
London Inter-Community Health Centre

- ❖ 23 African, Caribbean or Black persons who: reside in Middlesex County; are at least 16 years old; and speak English and/or French. HIV status will not determine eligibility.

Sub-Sample in These Data

- ❖ The first 12 of 30 interviews
- ❖ 1 non-ACB service provider; 2 ACB service providers; 9 other ACB community members
- ❖ 16-57 years old; 9 females and 3 males
- ❖ African, Caribbean and Black Canadian ethnicities
- ❖ All English-speakers who reside in London (except one service provider)
- ❖ Have lived (or provided services in London) from 1-40 years
- ❖ Have resided in Canada from 8-57 years
- ❖ 1 homosexual PHA; everyone else identifies as heterosexual
- ❖ All Canadian citizens
- ❖ Household income from <\$5,000-\$100,000+
- ❖ All, except one person, identify as Christian

Recruitment

- ❖ Purposive sampling is being used to recruit a diverse sample of community members.
- ❖ Sampling will discontinue once saturation is reached and theoretical constructs are developed.

Interview Topics

- General Health
- Migration
- Social Determinants of Health
- Health Behaviour
- Service Utilization
- HIV
- Social Network
- Gendered Experiences
- Research Methods
- Concluding Thoughts

Conducting Interviews

- ❖ Interviews are:
 - ❖ Approximately one hour long
 - ❖ Open-ended
 - ❖ Guided by probing questions
 - ❖ Recorded (and will be transcribed)
 - ❖ Conducted in a private room on a one-on-one basis
- ❖ Community members receive honoraria of \$10

Data Analysis

- ❖ Content analysis of the interviews is being performed using a modified grounded theory approach to identify emergent themes
- ❖ Individual interviews are summarized independently by two coders, and then the summaries are compared and discussed
- ❖ Interviews are analyzed on a question-by-question basis, and all responses to each question are grouped
- ❖ Interviewers take detailed field notes of each interview

Findings

Health is viewed holistically, and participants largely classified themselves as healthy

Participants defined health as being both physiological and psychological. Some focused on overall balance and well-being, and some affiliated health with diet. Most participants considered themselves healthy or moderately healthy.

Diabetes and HIV are important health issues in the community

Majority of the participants believed diabetes and HIV are important health issues in the Black community, but many participants do not know about HIV in Canada.

Many people obtain health information through the Internet

The Internet and word-of-mouth (friends, health care providers, news media) were the avenues through which most people received health-related information.

Most participants believe their risk of contracting HIV is quite low

Many of the participants did not think HIV was a personal health concern due to being married or abstinent.

ACB persons are not utilizing HIV services

Some of the reasons for not utilizing HIV services included: stigma and discrimination from service providers; lack of trust between community members and service providers; service providers being judgemental; stigma within ACB communities; inadequate services for ACB communities; and lack of HIV education.

There should be more of an ACB presence in HIV/AIDS, health and social service organizations

ACB persons need to be represented in organizations. This includes hiring ACB persons to provide services and including images of ACB persons in publications and promotional materials.

Organizations need to have multiple employees from ACB communities with different ethnic backgrounds

Some persons will not access services at an organization if someone from their ethnic community is present in the organization. This is too close for comfort, as many persons are isolated within their ethnic communities.

Health and social service organizations need to build trust with ACB communities

Many ACB persons are reluctant to access services because they do not trust that their information will be confidential, or that the service providers will not be judgemental. This trust can be built by having more ACB representation in organizations.

Rather than asking ACB persons to seek services and information, service providers should bring services and information to ACB communities

Since there is a lack of trust between ACB communities and service providers, many ACB persons do not access services and do not believe service providers are sincere. By bringing services and information to these communities, service providers will build trust with ACB communities.

Implications

This phase of the BLACCH Study will provide information useful for designing culturally appropriate research methods and content for a population-based survey that will reach larger samples of ACB communities. Additionally, information gathered from the interviews will help inform the design of a comprehensive knowledge translation strategy. Findings will be shared with ACB communities and organizations serving these communities using a combination of media. The BLACCH Study's overall purpose is to provide evidence to guide the creation and implementation of culturally-appropriate health promotion and HIV prevention and care programs for ACB communities, especially those outside of more well-resourced urban centres.

References

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Research participant quotes below,
please take.

The Black, African and Caribbean Canadian Health (BLACCH) Study: Phase I Preliminary Findings (Selected Quotes)

Baidoo-Boonso S¹, Longman R¹, Bauer, G¹, Nleya-Ncube M^{2,3}, Pugh D², Lawson E⁴, Abdelkader M⁵, Jasnos, J⁵, Hussien S⁵

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Health is viewed holistically, and participants largely classified themselves as healthy

Participants defined health as being both physiological and psychological. Some focused on overall balance and well-being, and some affiliated health with diet. Most participants considered themselves healthy or moderately healthy.

"Health means to me... a lifestyle, it always relates to a lifestyle... your diet. It could also mean what your blood pressure is; what your sugar levels are; if you have any sicknesses or diseases or things like that."

"Health means being in a good, healthy condition; feeling well; the wellness of your body, mind, and also your psychological security. You feel secured."

Diabetes and HIV are important health issues in the community

Majority of the participants believed diabetes and HIV are important health issues in the Black community, but many participants do not know about HIV in Canada.

"I was doing a clinic placement with Lawson Diabetes Center, now it's St. Joseph's Centre... for a period of about 6 months... at that time, I saw about two Black clients, one aboriginal client, and one Hispanic [client]... [D]uring that time, as part of presentations [I] talked about diabetes, it's prevalence and stuff like that, and I remember a part of my presentation [to] a group; everyday, we would have a group of about 6-10... and every time I would say that 'diabetes is prevalent in blacks like me, in Hispanics, in Aboriginals' and stuff like that... [A]fter being there and doing these presentations for quite a while, it dawned on me... 'where are all these Black people? Diabetes is prevalent in these populations... [yet] I've only seen these 4 people... where are they?'"

"[HIV] is a big problem in our community. It's just as a taboo, we don't talk about it. It's as if it's not there, but it affected me back home; so many of my cousins, my relatives died of HIV. Here, [friends of mine] go back home... and it's easy to get contracted with HIV. They don't talk about it. It's a taboo, so of course I worry about that."

Many people obtain health information through the Internet

The Internet and word-of-mouth (friends, health care providers, news media) were the avenues through which most people received health-related information.

"If I need [health information], I go online. I talk to people because when I do research, I do run around asking people their experience with a certain issue, and I do go to the doctor and ask them too sometimes; and the urgent clinic..."

Most participants believe their risk of contracting HIV is quite low

Many of the participants did not think HIV was a personal health concern due to being married or abstinent.

"I don't believe I'm at risk for that. My greatest risk would be whether or not my husband had sexual intercourse with people I don't know about and contracted it elsewhere; as someone who has been married for seven years it hasn't come up yet, so I'd like to believe that there are no ghosts hiding, waiting for me. So, it's not something that's on my radar... it's not something that I'm concerned about, but you never know."

"[My risk] is quite low, because, at this point in my life, I'm practicing abstinence right now, but had I not been I think it would be quite high because obviously the only potential mates that actually approach me... are of the Black community ... and I just know, at the back of my head, that we have a high HIV prevalence rate... but for now it's quite low."

ACB persons are not utilizing HIV services

Some of the reasons for not utilizing HIV services included: stigma and discrimination from service providers; lack of trust between community members and service providers; service providers being judgemental; stigma within ACB communities; inadequate services for ACB communities; and lack of HIV education.

"They face the discrimination, they face the stigma of whomever is providing that service thinking, 'oh my gosh you have AIDS'. They just face all those preconceived notions because they just see a Black person and 'if they want information about AIDS then they must have AIDS'... They just face all of that preconceived notions and judgmental thoughts that will [seep] into the person's response to their questions whenever they are trying to access information about AIDS."

"The barriers, I would say, is mostly themselves because [of] the stigma associated with being identified as an HIV patient... plus awareness; [they need] to know that there are other people like them... and probably not enough facilities... and I don't know if they have enough support financially."

"...I think it's a lack of education and also the stigma related to that, and people looking down on them because they have HIV. I think those are the two big things that might prevent people from coming forward and seeking help."

There should be more of an ACB presence in HIV/AIDS, health and social service organizations

ACB persons need to be represented in organizations. This includes hiring ACB persons to provide services and including images of ACB persons in publications and promotional materials.

"The easiest answer is to have people of varied cultures working for their organization. That's my solution... it sure makes a difference... Their [service providers'] intention is genuine and sincere, but they just don't get it, and it's very frustrating because you can't say it, 'cause if you say it, it's like you're offending them and they're pissed off, because they're just like: 'we're here, extending ourselves to you and it's still not good enough' ... that's not what we're about. I can't be bothered to sit down there and pussy-foot around your feelings to make you feel good about attempts you're making that really don't cut it. The bottom line is within our own communities, we have to train people to have the education to provide the services, and people hate hearing that, it's like you become sort of segregationalist in how you're speaking, and that's not what I'm advocating, but the bottom-line is there's certain things that I understand and know because of who I am as a Black woman that I bring to the table that isn't explained to me. It's not described to me. It's not something I studied in school, it's just part of who I am and it's, it's what I bring to the table, in the same way that what a Latino or White colleague brings to the table is an experience that no matter how much I may like their food, or the way they look or dress, and think it's neat; I could try to immerse myself 'til the cows come home in their culture; I'm still not gonna be them, and I'm not gonna bring that to the table, so you gotta have the actual people in place."

Organizations need to have multiple employees from ACB communities with different ethnic backgrounds

Some persons will not access services at an organization if someone from their ethnic community is present in the organization. This is too close for comfort, as many persons are isolated within their ethnic communities.

"I think a lot of the barriers are around stigma... the stigma that is presented within these communities... the difference between how a Black person from the Caribbean or Africa views HIV, as opposed to the Caucasian Canadian. Someone made an appointment; he came in, he saw me, and you know I recognized his accent, I knew he was from my country but I won't say anything unless he says something, but I think what that did to him, I think it shut him down... [it] would have taken a lot of courage for him to come in, in the first place, and then to be met by someone from his country, well it made it very uncomfortable for him and he shut right down. He said to me, 'I'm not going to tell you anything'. So for someone from the Caribbean, if it's me... (someone from [the Caribbean] community)... then if [the person] were to test HIV positive... even though I'm bound by confidentiality... [the person] would still be afraid that somehow, it's going to get back to [the person's] community and [the person] does not want anyone to know."

Health and social service organizations need to build trust with ACB communities

Many ACB persons are reluctant to access services because they do not trust that their information will be confidential, or that the service providers will not be judgemental. This trust can be built by having more ACB representation in organizations.

"I didn't want to go to a pre-natal class [held at] the organization within which I worked. I didn't want to have everybody all in my personal business, which tends to be a characteristic of many of the people in our community. We are very private people, but those classes were quite beneficial to me and the health of my unborn child."

"[E]verything in this life is about relationships and if people don't trust your organization. If people don't know your organization, and or trust them, they're not gonna avail themselves of your services, no matter how good those services might be."

Rather than asking ACB persons to seek services and information, service providers should bring services and information to ACB communities

Since there is a lack of trust between ACB communities and service providers, many ACB persons do not access services and do not believe service providers are sincere. By bringing services and information to these communities, service providers will build trust with ACB communities.

"They have it set up for the North American people. It's just set up for the way it's acceptable in this society I guess. So anyone else that feels like their culture is not accepted, kind of has to suck it up, because they've already set up everything [the health care system] how they want it."