



African, Caribbean and Black Communities in Canada

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CIHR Social Research Centre in HIV Prevention

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THE ISSUE

According to the 2006 Canadian Census, Black communities account for 2.5% of the population of Canada. However, in 2005, approximately 12.2% of HIV infections in Canada were attributable to African, Caribbean and Black (ACB) communities. While ACB communities comprise just 4% of Ontario's population, they account for 16% of the 26,000 people living with HIV and 26% of all new HIV infections (2007). Moreover, it is estimated that only 56.3% of HIV-infected persons from ACB communities have been diagnosed. Men account for 60% of the estimated number of HIV-positive people in the HIV-endemic exposure category (i.e., people from HIV-endemic African and Caribbean countries) and 12.4% of all the men diagnosed with HIV. In Quebec, 15.7% of HIV infections were cases from endemic countries (2008). Most were from Haiti and sub-Saharan Africa.

Other Canadian provinces and territories also show similar trends: British Columbia, 4.4% of HIV positive tests reported in 2006; Alberta, 20.4% of positive tests reported in 2007; Manitoba, 15% of positive tests reported in 2007 and 20% of positive tests reported between January 1999 to December 2007 among individuals who self reported ethnicity (2009).

In a recent study by Dr. Lindy Samson from the Canadian Pediatric AIDS Research Group on HIV, between July 1994 to December 2007 ACB women accounted for 56.5% of all of the cases of HIV infected women giving birth in Canada, and 61% of all infected infants were born to ACB women.

THE RESPONSE

While research is an important component of the response to HIV among ACB communities in Canada, research by itself is not a sustainable response. Research is likely to achieve its potential if it takes place within a supportive and enabling environment of institutional development, community engagement and advocacy and if linked to policy and programming.

In Ontario, the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) has been the main institutional driver for HIV prevention among ACB communities. ACCHO emerged in 2005 after a decade of community activism and advocacy initiated by a small group of concerned

community members. This early working group, which was known as the HIV Endemic Working Group (HEWG), consisted of service providers, policy makers, community members, and researchers who were troubled by the dearth of Canadian epidemiological evidence on the health of ACB communities. In 1999, the Working Group transformed itself into the HIV Endemic Task Force (HETF), and developed the *Strategy to Address Issues Related to HIV Faced by People in Ontario from Countries where HIV is Endemic* (also known as the “African and Caribbean Strategy”) over the next four years.

In 2003, HETF developed an expanded membership and terms of reference to become ACCHO, which is the lead organization for implementing the Strategy among ACB communities in Ontario. ACCHO is a provincial coalition of service-providers, researchers, community members and policy makers. The objectives of the Strategy are threefold: (1) to identify research needs, priorities and opportunities; (2) to facilitate community development in response to HIV/AIDS challenges faced by ACB communities; and (3) to coordinate the work of agencies, institutions and policy makers working with and for ACB communities regarding prevention, education, health promotion, care and support. Since 2005, ACCHO has continued to engage ACB communities in the response to HIV, build capacity among service providers, and support research to inform HIV prevention.

In Quebec, the Groupe d'action pour la prévention de la transmission du VIH et l'éradication du sida (GAP-VIES) is an AIDS organization serving more particularly the Haitian community and also Quebecers of African origin. Since 1986, GAP-VIES has been offering buddy programs, psychosocial support, pre- and post-test counselling, cultural mediation, women's programs, emergency financial help, help with medication, and a resource centre. In Nova Scotia, the provincial government receives HIV/AIDS policy advice from the Nova Scotia Advisory Commission which acts as a link between the government and Nova Scotia's Black community.

The Calgary Coalition on HIV and AIDS (CCHA) held a service provider consultation in 2005 and identified specific needs and challenges pertaining to serving the growing population of people coming from HIV-endemic countries. The report *Making Communities Stronger: Engaging African Communities in a Community Response to HIV/AIDS in Calgary* was later developed through a partnership between AIDS Calgary and the University of Calgary Faculty of Social Work in response to an environmental scan previously conducted by AIDS Calgary; the environmental scan served to assess the feasibility of engaging PHAs and those affected by HIV/AIDS in a dialogue about their supports and prevention needs. One of the key highlights from the *Making*

Communities Stronger report is the need to create culturally appropriate strategies for engaging African newcomer communities in the design and delivery of HIV/AIDS services.

While there are key emerging examples of community supported responses to HIV/AIDS across Canada, many of the provinces and territories still lack the type of community infrastructure similar to the ACB community in Ontario and to a lesser extent in Quebec. There is a need for continuous shared learning, exchange and coordination amongst agencies, researchers, and stakeholders working within ACB communities across the regions and provinces to strengthen the prevention response as recommended by the Federal Initiative to Address HIV in Canada.

Capacity building and community engagement

In 2004-2006 ACCHO developed and published the *HIV Prevention Guidelines for Service Providers Working with African and Caribbean Communities* in Canada. The Guidelines is a resource to build service providers' capacity to provide support for ACB communities in Canada.

ACCHO's Ontario-wide community engagement activities have included:

- *Keep it Alive*, a groundbreaking community-based HIV/AIDS awareness and prevention campaign implemented in 2006-2010. This province-wide campaign promoted HIV testing, condom use, and resisting stigma as an individual and community responsibility;
- The Ontario PHA Summit for ACB communities (2008) to promote greater and more meaningful involvement of PHAs in the Strategy. The Summit explored a range of issues related to GIPA/MIPA and PHA health and wellbeing. The Summit led to the development of the *Words into Deeds* project to more meaningfully engage PHAs in the response to HIV in ACB communities in Ontario. The Provincial Black PHA Advisory Body emerged from the *Words into Deeds* project to facilitate the engagement and involvement of Black PHAs in the response to HIV/AIDS in ACB communities in Ontario;
- The Ontario Black Gay Men's Summit (2010), which was an outcome of the MaBwana Black Men's Study of vulnerability to HIV among ACB gay and bisexual men in Toronto. The Summit discussions focused on developing shared understandings of health and wellbeing, social justice and community for ACB gay and bisexual men, trans men and queer (GBTQ) men from across Ontario. The Summit generated a number of possible community engagement initiatives for ACCHO.

In Quebec, the Montreal Public Health Department, GAP VIES and COQSIDA have been involved in a project to bring about knowledge transfer and exchange among researchers and decision makers who are responsible for improving the health of ethno cultural communities by: defining the terms of this partnership; determining the type of research data that will be most useful to decision makers; and systematically identifying the results of research and experience with sexually transmitted and blood borne diseases in ethno cultural communities and explaining and contextualizing these results in a comprehensible way for groups working with these communities.

Community-Based Research

Research should expand and improve the evidence base for HIV prevention. This includes promoting informed perspectives on the structural, systemic and interpersonal forces implicated in HIV and health. Moreover, research should also promote and facilitate community engagement. In Ontario, ACCHO has developed research to meet these requirements.

The African and Caribbean Stigma Study was implemented 2004-2006 as a partnership between researchers from ACCHO and the University of Toronto. This study was the first in Canada to explore the social, cultural, and structural dimensions of stigma affecting ACB communities. One of the outcomes of the study was the development of a framework to address the structural and systemic forces that sustain stigma and discrimination. The Stigma Study was followed in 2006-2009 by the MaBwana Black Men's Study of vulnerability to HIV among ACB gay and bisexual men. Similar to the Stigma Study, MaBwana was concerned with both interpersonal and systemic factors in relation to HIV and health. Contrary to how ACB communities are routinely understood in Canada, the findings from both studies demonstrated that ACB people are informed, knowledgeable agents who are interested in the health and wellbeing of their communities. These findings should prompt new, productive approaches to HIV prevention and health promotion that build on community assets and resilience.

Research activities in Ontario have also included two research conferences (in 2006 and 2009) that brought together service providers, community members, policy makers, research funding agencies and researchers from across Canada. These conferences: built stakeholder support for research, proactively engaged communities in research, and involved funding agencies as important stakeholders and partners in research development. ACCHO organized both conferences in order to collaboratively: (1) determine research needs, gaps, and set research priorities; (2) share knowledge and information on current and ongoing research; and (3) share

effective knowledge translation and exchange methods and strategies. At the 2009 conference, participants identified research priorities in basic science, epidemiology, clinical science, and social-behavioural science. The basic science priorities include further research on pathogenesis, prevention, and transmission. The priorities in epidemiology highlighted the lack of current data on HIV/AIDS trends among ACB communities across Canada. The clinical science priorities highlighted a need for greater focus on knowledge transfer and exchange (KTE) as well as population specific research on HIV infection and treatment. In terms of social-behavioural research, the following priorities were identified: people living with HIV/AIDS (PHAs) and aging, engagement of heterosexual men, second generation HIV positive youth, criminalization of HIV non-disclosure, capacity building, and the need for systemic and sectoral accountability.

The East African Health Study in Toronto (EAST), another pivotal community-based research study, surveyed the HIV and Health-Related Behaviours, Beliefs, Attitudes, and Knowledge of ACB communities in Toronto. EAST, a partnership between University of Toronto, Women's Health in Women's Hands, McGill University, Ontario Ministry of Health and Long-Term Care, and the HIV Social, Behavioural, and Epidemiological Studies Unit, is the only population based study that has been conducted among ACB communities so far in Canada.

GAPVIES believes that preventive interventions are more effective if based on knowledge of risk factors and that the benefits outweighed any possible risk of discrimination. In collaboration with Montreal Public Health Department, it has participated in several behavioral and surveillance studies.

In London, the Black African and Caribbean Canadian Health (BLACCH) Study, a partnership between the AIDS Committee of London, University of Western Ontario, ACCHO, and the London Cross Cultural Learner Centre is underway. The study is an interdisciplinary community-based study focused on understanding health and HIV in ACB communities in Middlesex County, Ontario. It is anticipated that the BLACCH study will provide much needed insight on the realities of urban-rural ACB communities.

The Global Ottawa AIDS Link (GOAL) project is a partnership involving researchers, community members, and health educators committed to facilitating the development of culturally appropriate HIV/AIDS support and services for ACB communities in Ottawa. GOAL activities have included an art-based HIV/AIDS prevention best practices workshop, bilingual HIV/AIDS epidemiological factsheets, the Ottawa Street Health team, and the creation of the guidelines for community-based research with ACB communities in Ottawa. The GOAL initiative also

started a twinning project between University of Ottawa, Somerset West Community Health Centre, and University of Rwanda to foster shared learning and best practices on HIV/AIDS reduction strategies.

In addition to research heavily influenced by ACCHO and GAPVIES, other research projects are being undertaken based on research partnerships established between academic institutions and community based organizations in several cities across Canada including Toronto, Windsor, Hamilton, Ottawa, Winnipeg, Calgary, Edmonton, Halifax and Montreal. These studies are exploring issues such as: Knowledge of, and attitude towards HIV/AIDS; Risk-taking behaviour – contributing factors and mitigating strategies; Community needs and priorities for HIV/AIDS programs and services; and Strategies for increasing access to programs and services (2009). Findings from these studies need to be disseminated and translated to inform policies, programs and further research to improve the response to HIV among ACB populations in Canada.

WHAT SHOULD WE DO NOW?

Race and culture, social exclusion as an outcome of racism, and stigma and discrimination, have often been ignored in health behavior theories. We need health behavior theories that are better able to inform interventions in racialized communities. There should also be a continued emphasis on community-based research that addresses community needs and priorities, helps to improve stakeholders’ understanding of ACB communities, and engages communities to build critical understanding of HIV and health. Research should also be ethical and respectful. These conditions will enable the design, implementation and evaluation of policies and programs that support social justice and improve the wellbeing of ACB communities in the long run. There is also an urgent need for intervention research, rather than the current exclusive focus on research to improve understanding. In addition, there should be greater attention to KTE and “research to action” strategies to build the knowledge base and inform policy and programs.

THE ROAD FORWARD: WHERE DO WE GO FROM HERE?

Traditional HIV prevention and health promotion approaches that over-emphasize community deficits and individual risk-taking behaviours may be harmful to the interests and wellbeing of

ACB communities in the long run. Health research on the lived realities and experiences of ACB communities in Canada requires an intersectional analysis that captures the complex, diverse, and transnational nature of these communities, and an understanding of community assets and resilience. We are proposing an ontological shift in health research, similar to what Kesby and colleagues have proposed for research with Africans in the UK. This is the approach that ACCHO has been taking in Ontario - examining intersecting identities and underlining the social determinants, interpersonal factors and structural/systemic forces - but it ought to be more widely subscribed.

Within the framework outlined above, researchers, service providers and other stakeholders must work together to (1) increase research capacity, (2) strengthen research partnerships, (3) continue supporting community-based research, (4) establish a Canadian ACB research network to help build research capacity and meaningfully engage communities as research stakeholders, (5) develop research to address the needs and priorities of ACB communities, (6) engage research funders (e.g., CIHR, OHTN, etc) to ensure that the needs and priorities of ACB communities are on their agenda, (7) strengthen the involvement of ACB PHAs in research development, (8) synthesize the existing research to (a) develop opportunities to build service providers' capacity to work with ACB communities, and (b) identify or develop research-based interventions, and (9) develop institutional responses at the national level and a national HIV/AIDS strategy for ACB communities across Canada.

The CIHR Social Research Centre in HIV Prevention

The CIHR Social Research Centre in HIV Prevention (the Centre) is a not-for-profit Canadian network of social researchers, community, public health practitioners and policy makers committed to advancing HIV prevention efforts through novel approaches to social science research, capacity building and knowledge transfer and exchange (KTE).

Created in June 2009 through the financial support of the Canadian Institutes of Health Research (CIHR), the Centre is hosted at the Dalla Lana School of Public Health, University of Toronto and is comprised of an inspired team of individuals spanning diverse professions, academic disciplines, and geographies across Canada.

The Centre provides leadership in developing integrated programs of prevention research, capacity building and knowledge translation and exchange aimed at improving services, increasing resilience, decreasing vulnerability to HIV, and ultimately achieving a reduction in HIV transmission.

Our working model is a public health approach which integrates multi-level analyses of vulnerability and risk, ensuring KTE across research, program and policy domains. The Centre is committed to strong multi-sectoral, multi-disciplinary collaborations, capacity building and KTE activities with policy, researchers and community partners. Guided by these commitments, the Centre:

- develops multi-site, theoretically and methodologically novel approaches to HIV prevention and intervention research
- supports promising trainees/students
- attracts new researchers to the field
- facilitates innovative yet accessible e-solutions to support collaborations that advance HIV prevention knowledge and action

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