The HIV Burden in the African Caribbean and Black Communities in Ottawa

Thesis submitted to the Faculty of Graduate and Postdoctoral Studies (FGPS) in partial fulfillment of the requirements for the M.Sc. degree in Epidemiology

Department of Epidemiology and Community Medicine
Faculty of Medicine
University of Ottawa, Ottawa, Canada

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ABSTRACT

Statement of problem: Ottawa Public Health has expressed the need for accurate and complete data/information on HIV in the Black community from Africa and the Caribbean (ACB) in Ottawa.

Method of investigation: A mixed methods approach was done. The first phase was a descriptive analysis of HIV diagnoses in the ACB population in Ottawa between 2005-2010. The second phase used qualitative interviews with people living with, and not living with HIV in ACB communities in Ottawa.

Results: HIV diagnosis rates were higher in ACB in comparison to the non-ACB population. The issues that emerged from interviews touched on HIV-related stigma, the exacerbating effect of HIV, essential gaps in current programs and HIV-related services for ACB communities.

Conclusion: The HIV diagnosis rates in the ACB communities in Ottawa provide reason for concern. OPH's approach to reducing HIV rates in ACB communities must attempt to incorporate understandings of the cultural context of HIV in the ACB communities for the betterment of HIV-prevention programming.

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LIST OF ABBREVIATIONS

ACB: African Caribbean and Black

ACCHO: African and Caribbean Council on HIV/AIDS in Ontario

AIDS: Acquired immunodeficiency syndrome

CHC: Community Health Centre

CIC: Citizenship and Immigration Canada

HEC: HIV-endemic country

HIV: Human immunodeficiency virus

HPPA: Health Promotion and Protection Act

HRSDC: Human Resources and Skills Development Canada

ICAD: Interagency Coalition on AIDS and Development

IDU: People who inject drugs

IME: International Medical Examination

iPHIS: Integrated Public Health Information System

IRPA: Immigration and Refugee Protection Act

MOHLTC: Ministry of Health and Long Term Care

MSM: Men who have sex with men

ODSP: Ontario Disability Support Program

OPH: Ottawa Public Health

PHA: People living with HIV/AIDS

PHAC: Public Health Agency of Canada

PHN: Public health nurse

SSA: Sub Saharan Africa

UNAIDS: Joint United Nations Programme on HIV/AIDS

WHO: World Health Organization

CHAPTER 1: Blacks and HIV/AIDS

INTRODUCTION

The trend of HIV/AIDS has been increasing steadily in specific subgroup populations in Canada. Among these subgroups we find people from HIV endemic countries. The larger part of these cases represents individuals from Africa and the Caribbean; moreover, the majority are of Black ethnicity. To understand the specific determinant factors that influence HIV acquisition and spread as well as the vulnerabilities to HIV in these subgroup populations, it is vital to be cognizant of what it means to be Black in Canada.

BACKGROUND

Blacks[1] in Canada

"Black" is a broad term used to include people of colour with an African heritage but where their birth country can span from Australia and New Guinea to West Indies, or North and South America (1). It is also part of the visible minority groupings classified by Employment Act as being "persons, other than Aboriginal peoples, who are non-Caucasian in race or non-white in colour" (2) Information on Black Canadians and other visible minority populations is federally mandated under employment equity legislation (3). Therefore is collected by the Canadian census based on self-reported data, as they have historically endured differential treatment due to their visible minority status (4).

Brief history of Black Canadians

In 1605, the first Black person was reported in Nova Scotia (5,6). The first shipload of African slaves reached the British North America in 1619 (i.e. British empires in North America), which began the era of Black slavery that prevailed for the next 200 years (5,6). Anti-slavery propositions were commenced in the 1790s

[1] Of note, Blacks herein will be referencing all Black Canadians that are first generation and more unless otherwise specified.

and finally came to pass when slavery was abolished by British parliament on August 28th 1833 and became effective on August 1 1834.

The migration of Black Loyalists, fugitive Black slaves from the Underground Railroad, refuges from the post-Civil War and others continued to come to Canada for another 100 years founding settlements in various parts of Canada (i.e. Nova Scotia, Ontario, Western Canada) and consequently forming the ancestors of Black Canadians today (5-8).

Immigration Trends of Blacks to Canada

Patterns of migration vary in cycles (9) and entry of migrants is dependent on the inception of immigration policies that determine the criteria of entry, which have varied greatly over the years. This is certainly the case for Black Canadians.

Black Canadians in 1881 comprised of 0.5% of the population corresponding to 21 400 recorded number of Blacks. In 1961, it was 32 100 representing 0.2% of the population (5). Although foreign-born Blacks came from various countries the majority migrated from the Caribbean and Africa (mostly Sub-Saharan Africa). Prior to 1961, the population of Blacks were mostly from the Caribbean, Central and South America (5).

A turnaround occurred after the 1961 census. This was most likely due to changes in immigration policies from 1964 to 1988 that became more permissive to other non-European countries with the objective of responding to labour market needs in Canada.

Between the 1960s and the 1990s there were several waves of migration from the Caribbean, in the late 1960s, the mid-1970s, the mid-1980s and the early 1990s (7). People from Jamaica comprised the majority of Blacks in Canada during this time, followed by people from Haiti from 1970-1980s. In the same time period, Black people from Barbados, the UK and the US arrived to Canada but in smaller numbers (5). Africans migrating to Canada became most prominent in the 1990s with an increase that continued well into the year 2000s. By 2001, people from Somalia, Ghana and Ethiopia were amongst the leading countries contributing to 20% of Black immigrants to Canada (5).

As of 2002, the Immigration and Refugee Protection Act (IRPA) came into effect in place of the Immigration Act of 1976 (10), setting out the legal framework to direct the economic, social and humanitarian objectives for Canada's immigration program (10). African countries have noticeably dominated the trends as a source of immigration increasing Black populations in Canada with the recent changes in immigration policies (7).

Generation Patterns

To determine the generation status of an individual you must question the place of birth of their parents (11). A person is considered first generation if they were born outside of Canada; second generation for those who were born in Canada and at least one of their parents is born outside of Canada; and third generation when both parents are born in Canada (11). When the generation status is analysed considering the visible minority status, it helps to reflect how immigration patterns formed the present face of Canadians.

In 2006 (Census), Blacks represented the third largest visible minority group in Canada with 783 800 or 15.5% of the total visible minority population. A little more than half of Blacks (52.5%) were first generations immigrants coming from Africa and the Caribbean. The countries most frequently cited as the place of birth were Jamaica, Haiti, Trinidad and Tobago, Ethiopia, Somalia, Ghana, Guyana, Nigeria, Barbados, and the Democratic Republic of Congo. Amongst all visible minorities there were 44.3% who were Canadian-born, therefore second generation immigrants. From a geographical standpoint, Ontario had 60.4% of Canada's total Black population where the largest number of Blacks was residing in Toronto. Just over half were first generation and from this group 55% were from three main countries: Jamaica, Trinidad and Tobago and Ghana. In Quebec, Blacks comprised the largest visible minority group in the province, mostly living in Montreal, and represented one fifth of Canada's Black population. Nova Scotia constituted the province where the majority of Blacks are Canadian born. Most were in Halifax where 9 in 10 Blacks were third generation or more. This relates to the immigration history of Black loyalists to this region in the late 1770s (5). Lastly the number of

Blacks in Ottawa-Gatineau was tied with Windsor and accounted for their largest visible minority group with 4 in 10 being born in Canada.

Sociodemographics of Blacks in Canada

Canada's Black population had a young age structure in 2006 with 28% of its population under the age of 15 years, especially when compared to non-visible minorities at 17% for the same age groups (12). This age structure was well reflected in Black women (52.1% of Black population) whose median age was 29.6 years and with 27% of them being 15 years of age and younger(3). If these women were of childbearing age and their age of arrival to Canada was young it could explain the younger age structure (3). Black women were also shown to have the largest share of lone parents compared to other visible minority groups (3).

In comparison to the non-visible minority workforce, the Black workforce was younger (15-24y: 17%, 25-44y: 41% and 15-24y: 20% 25-44y: 50% respectively) (12). Blacks are generally as educated as non-visible minority members but don't hold as many university-educated positions compared to other visible minorities (12). In addition, Canadian born Blacks do not fare as well if compared to its recent immigrant counterparts. Inadvertently, this bears an impact on their level of success in the workforce and their economical attainment. More than half of Blacks (58%) worked in clerical, semi-low skilled sales services and manual occupations, which require less than post-secondary education, training specific to the occupation, or training on the job (12). Likewise, Blacks were underrepresented as managers, or other types of professionals and their earnings compared to non-visible minorities differed by 23% with $40 200 versus $52 300 for those 15 years and more (12).

Black Community[2] and Faith-Based Organizations[3]

Historically faith-based organizations or churches have played an important role for people of African descent in North America (13).

[2] Black community here is used to reference the collective
[3] Faith-based organizations is defined as religious affiliated institutions

Both African American and African Canadians can relate to their experiences of slavery where faith-based organizations were an important focal point in their lives. In the midst of their struggles, African slaves found refuge in the church and felt safe to express their African identity (14). These organizations have been a gateway for the Black community in community mobilization, political advocacy and financial support (15). On the other hand, they have also served as a house of worship, a meeting place for social organizations and a place of community (16). Attendance or affiliation to faith-based organizations is consistently reported among African Americans (17). During the social exclusion experimented by African Canadians upon their settlement in Canada, the church also carried out a leadership role to address issues such as racisms and discrimination(13). At present, the church presence is still prominent and well noted for African Americans (18) but no such data is available in the Canadian context (13). However there are examples of anecdotal accounts of African Canadians attending various church-related activities in Toronto (13) and Montreal (19) such as church crusades, conferences, conventions and various other events, which have been used as ways to promote healthy lifestyles (Rhema Christian Ministries[4]).

Health of Blacks in Canada

Studies of health patterns within the Canadian and US population consistently show that Blacks have higher all-cause mortality rates, lower life expectancies, and worse mental health than Whites[5] or other racial groups (2,20-22). As for Blacks in Canada, studies are equivocal with few exceptions, as many of the research studies do not disaggregate conventional racial and ethnic categories to expose the potential disparities in health risk and health outcomes (2). Inadvertently, when bearing in mind the demographic and socioeconomic differences between Blacks and the Canadian mainstream population, there is no surprise to see these circumstances transpire into various health disparities among Black in Canada.

[4] Retrieved from http://www.rhemaonline.ca/index.asp
[5] Whites: Non-Aboriginal, Caucasian, white in colour

From the empirical evidence available, Veenstra 2011(23) showed that Blacks in Canada are twice as likely to be at risk for diabetes and three times likely to be at risk for hypertension compared to the white populations. Although the healthy immigrant effect did account for the difference of risk for diabetes, neither this health advantage nor other socioeconomic factors could fully explain the differences observed for the risk of hypertension. In Nova Scotia Black Women, Enang et al (2001) (24) identified the following health needs: diabetes, cardiovascular disease, HIV/AIDS and mental health. As this group of women represents a particular cohort of third generation immigrants in that region, these results might not be as representative for all types of immigrants. As for self-rated health, recent Black immigrants were 61% more likely to shift to poor health in comparison to other ethnic groups (25).

Contrasting evidence has also demonstrated that Blacks do not necessarily exhibit negative health outcomes when compared to other racialized groups. This is seen in Kobayashi team's work (2008) (26) were first generation Black immigrants in Canada report better health, functional health and are less likely to experience any activity restriction than multiple white ethnicities. However when lifestyle and socioeconomic factors are taken into account the health of Blacks and other ethnocultural groups were found to converge to that of non-visible minorities. Wu's (2005) (22) group also saw that the self-reported and functional health of Blacks was superior to its comparison group but there was not a clear pattern overall. To be considered here is the cultural influence of one's perception and understanding of their health problems. These perceptions might reflect the values and beliefs system of that culture and as a consequence impact how and if they report a health problem accurately (26). Therefore, if these perceptions are culturally specific, than the self-reported health might not coincide with the actual functional health status. Furthermore, other explanations at hand would include their level of understanding of health as well as previous experiences of racial discrimination (27).

HIV in Black People

Black people of Caribbean and African decent in Canada, diverse from a demographic, religious, cultural standpoint, are largely composed via the waves immigration from the last few decades. These populations are significantly affected by the HIV/AIDS epidemic. Although countries where HIV is endemic (See Appendix #1 for list of HIV endemic countries) constitute mostly Black people, the presence of HIV is not solely among the foreign born from Africa or the Caribbean but among African and Caribbean communities formed of 2nd, 3rd or more generations, that is Black Canadian-born with African or Caribbean ancestry (ACB[6]).

HIV prevalence and HIV rates are increasing faster among ACB subgroups of the population than any other population. For Canadian ACB populations, little evidence is available on the context in which HIV transmission occurs, factors that facilitate or reduce the transmission, and those that foster the ability to cope with HIV in those who are already infected (28). The assumption is that most infections have occurred prior to arrival in Canada but emerging evidence has shown an increasing proportion of becoming infected with HIV post-arrival (29). Depending on the experiences with their medical and social systems, immigrants and refugees infected with HIV from low or high-income countries will also be quite varied (30). In 2005, 95% of Black immigrants came from HIV endemic countries (HEC) (See Appendix #1 for list of HEC). It is imperative that we understand the context in which transmission occurs and acknowledge how best to undertake all preventive and curative measures that are evidence-based and culturally and equitably appropriate.

HIV Surveillance in Canada

HIV surveillance in Canada is part of the comprehensive approach of the Federal Initiative to Address HIV/AIDS[7]. It is the HIV/AIDS Surveillance Section of the Centre for Communicable Diseases and Infection Control at the Public Health Agency of Canada, who is responsible for the data collection and management,

[6] **ACB:** refers to first generation Black people from Africa or the Caribbean and Black people born in Canada with African and/or Caribbean ancestry, that is 2nd, 3rd or more generation immigrants; unless defined otherwise
[7] PHAC website: http://www.phac-aspc.gc.ca/aids-sida/fi-if/index-eng.php

analysis and report production related to HIV and AIDS in Canada. Estimates are calculated by using several sources of data including: HIV test reports, AIDS case reports, population-based surveys, targeted epidemiologic studies and census data(31).

The Surveillance and Epidemiology Division also conducts research and Surveillance activities in collaboration with other federal partners and research institutes[8].

Other contributing activities to the national surveillance databases are the Field Surveillance Program, the National Reportable Disease Program and the HIV Strain and Drug Resistance Surveillance Program[9].

As part of the federal governments commitment to addressing HIV/AIDS in Canada it contributes to prevention, support programs and in producing status reports in reference to 8 key priority populations: gay, bisexual, two spirit and other men who have sex with men, injection drug users, federal inmates, youth at risk, Aboriginal peoples, women and people from HIV endemic countries[10].

Specific to people from HIV endemic countries, the Public Health Agency of Canada (PHAC) has produced population-specific HIV/AIDS status reports pertaining to Black people and communities of African and Caribbean descent living in Canada (7,32). Additionally, an enhanced surveillance program referred to as E-Track is a behavioural and biological surveillance system designed to monitor trends in the prevalence of HIV and associated infections, behaviours and socio-demographic factors. The objective of this system is to increase the understanding of HIV transmission dynamics and inform the development of prevention programs for this specific population[11].

HIV-related Policy in Canada

The Canadian IRPA under section 38, outlines specific restrictions to Canada based on HIV status since 2002 (33). The objectives of medical restrictions on entry to Canada stated in the previous Immigration Act of 1976 are: 1) to control the

[8] PHAC website: http://www.phac-aspc.gc.ca/aids-sida/research/index-eng.php
[9] PHAC website: http://www.phac-aspc.gc.ca/aids-sida/about/surv-eng.php
[10] PHAC Federal Initiative to Address HIV/AIDS in Canada: Leading Together: Canada takes action on HIV/AIDS 2006; http://www.phac-aspc.gc.ca/aids-sida/fi-if/fa-if/index-eng.php;
[11] PHAC website: http://www.phac-aspc.gc.ca/aids-sida/pr/sec8-eng.php#con

spread of disease and 2) to limit cost of additional health care and other related public services (34). Citizenship and Immigration Canada (CIC) assess the eligibility of an individual based on the anticipated cost to the Canadian public purse (35).

Although HIV is not specifically mentioned in the IRPA as a criterion for exclusion and that HIV infection is not considered a public health threat (36), it is considered mandatory to be tested for HIV if >15y of age as part of the Immigration Medical Examination (IME) for Canadian permanent or temporary resident status. All prospective immigrants to Canada also undergo routine medical examination plus testing for syphilis if >15y of age, a chest X-ray if >11y of age for tuberculosis and a urinalysis if >5y of age within 12 months of arriving to Canada (34). Designated Medical Practitioners (DMP) conduct these IMEs under contract with CIC in either foreign or domestic medical offices and are responsible to provide a medical report to CIC on potential residents of Canada (35) Upon receipt of the medical report from the DMP, CIC makes the final decision on who may enter Canada (33). Those with symptoms for AIDS are automatically excluded before entry to Canada. However, restrictions based on HIV status do not apply to short-term visitors staying less than 6months (Canadian HIV Legal Network 2005[12]). Exemption is also granted to sponsored spouses, common-law partners, children of Canadian citizens or permanent residents, and refugees (33,37).

Medical inadmissibility is actually an acceptable practice outside of Canada, as other countries such as the United States, the United Kingdom and Australia uses this as a public health standard (33). In 2003, it is has been recorded that 60 countries also uphold this type of policy (9). Human rights concerns have been raised regarding this practice especially toward high-income countries as they are considered as denying available medical treatment for those who mostly need it (38). Furthermore, deportation on the grounds of people living with HIV bringing undue costs to the health care system has also been argued as unjustifiable (39). Zowall et al (1992) (40) attempted to conduct a comparative cost analysis (from an economical standpoint) to compare the economic burden of HIV to coronary heart disease with

[12] http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=95

the objective of evaluating HIV and other diseases that cause increase public health burden to Canadian society. Their analysis revealed that the economic impact of HIV was similar to that of coronary heart disease. With that, they emphasized the need to bear in mind other legal, ethical and social elements in the final analysis to bring about a policy that is equitable, feasible and reasoned. They indicated the added value of analyzing other infectious diseases not currently screened.

With 453 out of 4375 persons tested positive for HIV deemed inadmissible for entry into Canada, immigration alone cannot explain the high prevalence of HIV/AIDS in immigrant population (35). For those who are tested in Canada, surveillance data cannot identify whether HIV transmission occurred abroad or in Canada (31). Contribution of screening might need to be re-evaluated to assure it fits Canadian government and society's goals.

HIV Epidemiology

Global estimates

As of 2011, the number of people living with HIV was 34.0 million (31.4-35.9 million) compared to 28.6 million (26.7-30.9 million) in 2001, equivalent to a 17% increase (41). This translated to 0.8% of the adult worldwide population (15-49y) living with the HIV virus in 2011. The proportion of women was slightly below half of the grand total at 16.6 million (15.4-17.6 million) and there were 3.3 million children less than 15 years of age living with HIV[13]. Although the annual number of new HIV infections has shown a steady decline since the late 1990s, the number of new infections overall are still seen as high (42). In 2011, there were 2.5 million new infections, which represents more than one fifth fewer than the estimated number in 2001 (3.1 million).

Variability in HIV prevalence, different patterns of incident infections and various modes of transmission has led to increasing, stabilizing or decreasing rates of HIV infection in selected countries (figure 2.2 p.17) (42). There is evidence that there is an increase in HIV transmission in Eastern Europe and Central Asia in specific high-risk groups (i.e. IDU and MSM) (42). Other developed countries show

[13] WHO website: http://www.who.int/hiv/en/

stable annual rates of HIV infections including Western, Eastern and Central Europe, North America and Central Asia. Twenty-two countries of Sub Saharan Africa (SSA) are among 33 other countries demonstrating a decline in people newly infected with HIV by more than 25% between 2001-2009 (42). Despite its improvements, SSA continues to bear the highest burden of HIV globally (32). SSA accounts for 72% of all new HIV infections (1.8 million) and holds 69% of all people living with HIV worldwide (23.5 million) (41). On the other hand, the Caribbean may not contribute as much to the number of people living with HIV worldwide (230 000) but has 1.0% prevalence among adults, which is the highest in all regions outside SSA (41). Furthermore, an estimate of 1.7 million people died of AIDS-related illnesses worldwide in 2011, showing a decreasing trend since 2005 at 2.2 million. Among those, an estimated 1.2 million in SSA and 10 000 in the Caribbean people died in 2011.

National estimates

From 1985 to December 2009 the cumulative total of positive HIV test reports reported to PHAC was at 68,844 (43) and increased to 71 300 in 2011 (31). This amounts to an 11.4% increase. In 2009, the national rate for Canadian adults was 8.6 per 100 000 (43) and the estimated prevalence rate in Canada is 208.0 per 100 000 (31). HIV ethnicity reporting began in 1998, however Ontario and Quebec do not submit ethnic status information with HIV test reports. This data limitation is to be considered in all Canadian estimates. The categorization of HIV case reports with ethnic or race information in 2009 were the following: 44.2% White, 33.3% Aboriginal, 11.6% Black, 4.5% Asian, 4.1% Latin American, 1.1% South Asian/West Asian/Arab, and 1.1% other (43).

Overlapping are people who self-identify as Black and those born in HEC. HEC is defined as those where the prevalence of HIV among adults (15-49 years) is 1.0% or greater plus one of the following: 1) 50% or more of HIV cases are attributed to heterosexual transmission or 2) male to female ratio is of 2:1 or less among infections or 3) HIV prevalence greater than or equal to 2% among women receiving prenatal care (43). A listing of these countries has been described (see Appendix #1) containing 71 countries in total where 42 are in Africa (mostly SSA),

26 are in the Caribbean, Central/South America and 3 in Asia (32). According to 2006 Census, persons who were born in HEC comprised of 2.2% total Canadian pop (31,32). When second generation Canadians who have at least one parent who was born in a country on the HEC list are considered in addition to people born in HECs, the proportion was 2.7% (32). In 2006, the Caribbean and SSA countries labelled as an HEC and are major populations groups in Canada include: Jamaica, Guyana, Trinidad and Tobago, Haiti, South Africa, Kenya, Cambodia, Ethiopia, Somalia, and Tanzania (7). Ontario and Quebec have the largest proportions of individuals from HEC representing 3.8% and 1.8% of the provincial pop respectively (7). The five cities with the largest concentration of people from HEC include Toronto, Montreal, Vancouver, Ottawa and Calgary (7).

The distribution of new infections by exposure category[14] has changed since the beginning of the HIV epidemic in Canada (32,44). Among those who acquired HIV through heterosexual contact and were also from an HIV-endemic region represented 14.9% of prevalent HIV cases in 2011 (32). This has increased slightly from previous 2008 estimates at 9250 cases (14.0%) (32). In 2008, within the heterosexual endemic subcategory an estimated range of 370-690 HIV incident cases (32) was determined compared to 2011 estimates at 535 new infections ranging from 370 to 700, accounting for 16.9% of new infections in Canada (32). With the approximation that 2.2% of the Canadian population are from HEC (2006 Census), the estimated rate of new infections becomes 9.0 times higher among people from HEC than among other Canadians (31). In 2009, people who self-identify as Black represented 76.3% of persons attributed to the Heterosexual-endemic exposure subcategory (43). When gender was reported, females aged 15 years and older constituted 55.3% of positive HIV test reports for the period of 1998-2009 within the heterosexual-endemic exposure subcategory; the highest proportion of cases assigned to females than to males (32). Those with known exposure between 1998 and 2009, having heterosexual contact and are from HEC represented 38.8% of cases

[14] Exposure category refers to the most likely route by which a person became infected as defined by a hierarchy of risk; PHAC lists four categories as follows: 1) MSM 2) IDU 3) recipients of blood and blood products and 4) heterosexual contact – the last category is further divided in subcategories including persons who is heterosexual from an HIV-endemic country (HEC)

with 423 AIDS diagnoses. If stratified by ethnicity, nearly 90% self-identified as Black (32). Also in 2009, Black females within this group had higher proportions of diagnoses if less than 29 years of age (43).
All infants and children born to mothers infected with HIV are identified by the Canadian Perinatal HIV surveillance Program. It showed that of all 2009 reported cases Black women have the highest proportion of perinatally HIV-exposed infants compared to other ethnic groups in Canada (43).

As of January 2002, persons applying for permanent or temporary status are required to undergo an immigration medical examination (IME) and are tested for HIV if aged 15 years and older (or at any age if they present a known risk factor such as a blood transfusion) (35). IME HIV testing results are included in provincial/territorial reporting to PHAC. Between 2002-2006, 2567 applicants tested positive for HIV. Of these, 70% of applicants were from Africa or the Middle East and 22% from the Americas (including the Caribbean). In 2009, 574 applicants who underwent an IME tested positive for HIV, where 341 (59.4%) were born in Africa and the Middle East.

Ontario estimates

From November 1985 to December 2010, 31596 persons were diagnosed with HIV infection in Ontario. The breakdown by sex was 25656 males, 4750 females and 1190 unknown sex (45). During this period, male diagnoses have remained predominant while female diagnoses have increased noticeably from 2% in the mid-1980s to 25% in 2002 to 2008 (45). In 2009, Ontario accounted for the highest proportion of cases of all positive HIV tests reported to PHAC at 41.9% (30800 of 69844) (43).

According to the 2006 Census, 65% of all HIV endemic African and Caribbean populations in Canada reside in Ontario (46). Accordingly, the number and proportion of HIV diagnoses for individuals from HEC in Ontario increased steadily from less than 5% before 1990 to more than 20% since 2001. From 2001 and 2010 the number were relatively stable at an average of 23% (45). It also has been reported that the adjusted number and proportion of HIV diagnoses from 1985 to

2009 in Ontario was highest in females among persons from HEC at 42.6% (2050 of 4810) compared to males among persons from HEC at 7.5% (1947 of 25 990) (43). The age groups with the highest proportions of HIV diagnoses amongst persons from HEC from 1985 to 2009 were 20 to 49 years (46). When cases of HIV-infected mothers are analyzed, HIV-endemic maternal exposure category represents almost 2/3 of all cases in Ontario from 1984 to 2008 (60.7%) (46). HIV positive diagnoses stratified by ethnicity showed those identified as Black had the second highest proportion of HIV diagnoses in Ontario from January 2009-December 2011 after those who identified as White (24.7% vs. 54.6%) (47). Furthermore, from January 2009 to December 2011, 93.4% of reported HIV diagnoses among persons born in HEC with known ethnicity data were Black (47). In addition, the Laboratory Enhancement Program (LEP) at the HIV laboratory of Public Health Ontario also examined HIV positive diagnoses by ethnicity and exposure category[15] for both sexes from January 2009 to December 2011 showing Black persons with the highest proportion of HIV diagnoses amongst all ethnicities[16] for persons from HEC (47). In Ontario, an estimated 35% of HIV-infected persons as of December 2009 were unaware of their HIV status, by which the proportion varies by exposure category; about 46% of all infections among persons from HEC are unaware of their HIV status (45).

In 2011, 9210 cases of AIDS diagnoses were reported in Ontario (45). AIDS cases in Ontario represented more than half of cases reported to PHAC across all provinces in 2009 (46). The adjusted distribution of reported AIDS cases by exposure category from 1981 to 2010 demonstrates persons from HEC accounted for 8.2% of AIDS cases, third to MSM (68.4%) then Heterosexual (9.7%) exposure categories (45). From 1981 to 2008, of all reported AIDS cases (adjusted for unknown exposures) in Ontario, females from HEC represented over a third of AIDS cases (35.4%) while males from HEC represented 5.3% of AIDS cases (46). Age groups

[15] Exposure categories considered in Ontario analysis were the following: MSM, MSM-IDU, IDU, Mother-to-child transmission, Blood product recipient, Blood transfusion recipient, birth in an HIV-endemic area, Heterosexual transmission, High-risk heterosexual, Low-risk, Unknown

[16] Other ethnicity groups include: White, Aboriginal, East/Southeast Asian, South Asian, Middle East/North Africa, Latin American, Other, Unknown

from 25-49 years represented 85% of reported AIDS diagnoses from 1981 to 2008 (with known age at diagnoses) amongst persons from HEC (46). Again, AIDS cases among Blacks from 1990 to 2004 have been shown to be highest in persons from HEC compared to other exposure categories (46).

Ottawa estimates

The cumulative rate (using 2001 Census data) per 100 000 persons of HIV-positive diagnoses from 1985 to 2010 was second highest for Ottawa at 451.7 after Toronto at 789.2 per 100 000 (table 1.13) (45). For 2010, the rate of HIV diagnoses determined for the Ottawa health region was 17.3 per 100 000 (table 1.14) (45).

According to 2006 Census population estimates, there were 13 445 persons from HEC in the Caribbean, Bermuda, Central/South America and 17 630 persons from HEC in Africa residing in Ottawa-Gatineau (in Ontario-Quebec) (7). Ottawa had the second highest proportion of HIV diagnoses from 1985 to 2010 in its resident population representing persons from HEC after Toronto (Table 1.13a.) (45). HIV reported cases with known ethnicity from 1980-2004 showed 32.3% were self-identified as Black second to 60.7% self-identified as White (46).

When Black persons were considered in the analysis of HIV cases from 1985 to 2004, the persons from an HIV-endemic region category had the majority of Black persons HIV cases amongst selected exposure categories (i.e. MSM, MSM-IDU, IDU, Heterosexual) (46). If HIV-positive diagnoses are analysed by ethnicity and exposure category from January 2009 to December 2011, Black persons remained with the highest number and proportion of HIV-positive diagnoses when compared to other ethnicities[17]. In 2008, modelled prevalence and incident cases were determined for persons from HEC in the Ottawa region. The model estimates showed Ottawa had a prevalent population of 910 cases with HIV and 90 HIV incident cases for the same year (46).

As for reported AIDS cases, the incidence rate for the Ottawa health region from 1981 to 2010, was 91.1 per 100 000, second to Toronto's health region rate at

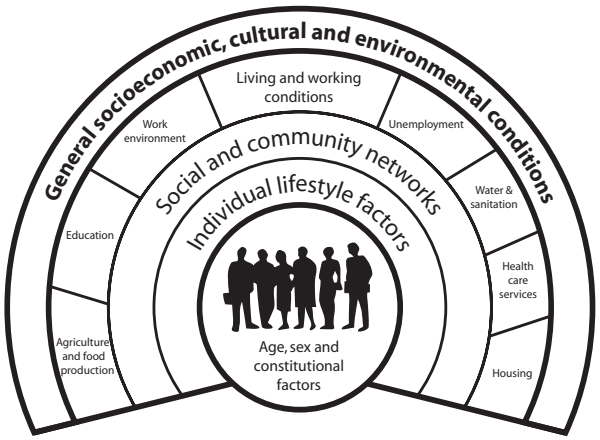
[17] Technical reports (2012): http://www.ohemu.utoronto.ca/tech%20reports.html

211.3 per 100 000 (table 2.15) (45). If considering persons from HEC for the Ottawa health region from 1981 to 2008, it had the second highest number of reported AIDS cases for the province of Ontario (46). For the same time period, 46.5% of all Ottawa reported AIDS cases for persons from HEC were female (46).

Vulnerabilities to HIV

Ecological models such as Dahlgren and Whitehead (1991) (48) socio-ecological model offers a useful way to approach the complex interrelating factors contributing to the vulnerabilities to the Canadian ACB population (Figure 1-1).

Figure 1-1: Dahlgren and Whitehead (1991) socio-ecological model



Individual factors

Biological factors

One in every 20 adults living with HIV is living in Sub-Saharan Africa corresponding to 69% per cent of all people living with HIV are living in this region[18]. Other than behavioural or social factors, biologically related factors have been speculated as an explanation of these geographical and racial differences in HIV prevalence. Kaul et al (2011) (49) have attempted to review the literature on such factors. Among their findings it stills remains unclear that the virus subtypes (i.e.

[18] WHO website (updated 2013) http://www.who.int/mediacentre/factsheets/fs360/en/index.html

HIV-1 group M is the most prevalent type worldwide and is subdivided in several subtypes) are distributed in a particular pattern in the world. Additionally, genetic resistance to HIV, which is bestowed for homozygous carriers of CCR5D32 prevalent in 10% of Europeans but much less common in non-Europeans, however more needs to be done on the genetic determinants. Genital co-infections such as gonorrhoea (GN), bacterial vaginosis (BV), and Herpes Simplex Virus (HSV) are understood to increase susceptibility to HIV infection due to immune alterations and by reducing mechanical and physical barrier of the virus (50).

Although STI rates in Canada are not categorized by race or ethnicity, gonorrhoea is considered to be on the rise[19]. High rates of STI infection have been found in Blacks in many parts of the world (51,52), which could be viewed as one of the contributing elements important for HIV prevalence in Black people.

Gender

HIV incidence in ACB women is increasing (32) and there is a mixture of individual and social-ecological factors that come into play. Male-to-female transmission of HIV is more efficient than female-to-male transmission (53) due to a larger number of target cells in the female genital tract compared with the male (49).

On the other hand, in African and Caribbean countries there are religious and culturally bound roles that appear to create divisions of labour or power (54), which then lead to socioeconomic dependency, impoverishment, and sexual vulnerability of women to HIV (55). This was acknowledged in African young adults from Windsor, Ontario who are living through the pressures of the "culturally entrenched gender inequalities" (56), since the African culture discourages if not prohibits discussing sex matters or negotiating sex (57). For Haitian women living in Quebec, avoiding speaking about their sexuality is a day-to-day reality but there is scarce data on their role in the decision's partner in using protective measures during intercourse (58).

[19] PHAC website: http://www.phac-aspc.gc.ca/sti-its-surv-epi/sum-som-eng.php

Socio-ecological factors: Lifestyle (personal health practices and coping skills)

Female Genital Mutilation (FGM)

Female genital mutilation is a documented practice still ongoing in many African countries and in a few countries in Asia and the Middle East. It is internationally recognized as a violation of human rights of girls and women (59). It crosses migration barriers as girls and women outside of their country of origin will return to have the procedure done (60). FGM refers to all procedures that remove external genitalia either partially or completely or cause injury for non-medical reasons (61). This practice is usually present in societies where gendered roles are unequal and harmful to women. The reasons for its practice are diverse (59). There are beliefs that it is necessary for girls rearing purposes or preparation for adulthood and marriage (62). It can be expected from men of the same culture for marriage (59). It can be seen as a way to preserve one's virginity or to restrain sexual desires in order to encourage fidelity (63). Christian, Jewish and Muslim religions have also been associated with this practice(59). The risk for HIV exists when the same instrument is used to perform FGM in groups of women and girls.

Vaginal cleansing and douching

Culturally mediated feminine hygiene practices, among African and Caribbean women involving excessive cleaning of the vaginal area. Various botanical agents, soaps or over-the-counter douching products can be used (James 2006, Kobetz 2009[20])(55). These practices have been associated with an increased risk of STIs, including HIV (55).

Alcohol and Drug abuse

Information on drug or alcohol abuse, dependency or addictions are not readily available on Black people, for instance the Canadian Alcohol and Drug Use Monitoring Survey (CADUMS) does not include data by ethnicity or race (64,65). However a consultation done by Health Canada (2001) (64) with recognized Black representatives affirmed that use of marijuana, hash, crack, cocaine and prescription

[20] https://apha.confex.com/apha/137am/webprogram/Paper200286.html

drugs put ACB community members more at risk f engaging in high risk situation, increasing their risk of HIV. In addition, the chewing of "Khat" or "miraa," tobacco-like leaves are an important problem in ACB communities. Recognizing that substance increases the risk of high-risk sexual behaviour it can also increase the risk of HIV infection in ACB populations using above-mentioned drugs on a regular basis. For instance, Adimora et al (2006) (66) found that Blacks in the US who acquired HIV infection through heterosexual transmission were more likely to report crack use and partnering sexually with others who also smoke crack.

Religion

Religion plays an important role in the African and Caribbean HIV/AIDS context (14,67). It has proven to be instrumental in the combat of HIV/AIDS (68) but has also propagated construed messages that have had its own impacts. Often the blame for the spread of HIV/AIDS has focused on the individual's lack of morality, liberal promiscuity or permissive behaviour (69). Other observations have indicated the effect of punitive preaching that compounds the feelings of guilt and even promoting more stigma without dealing with the root issue of HIV/AIDS(70). The promotion of restricted messaging focused on abstinence or that condoms encourage promiscuity therefore its usage is condemned, have been other accusations upon religious figures/leaders (67).

Constrained sexual activity within a polygamous relationship is however not prohibited by many religions. Polygyny is described as a gender-asymmetric partnership concurrency (71), which involves as simultaneous union of either a husband or wife to multiple spouses (72) but usually the women are monogamous (71). There here has been debate of the probability of it increasing transmission of HIV/AIDS but there is limited evidence describing this (71).

Social and Community Networks

Sexual Networks

The connection (direct or indirect) of individuals through sexual contact describes what are sexual networks (73). Sexual networks have been shown to play an important role in the transmission of HIV/AIDS (74).

Empirical evidence has shown the possibility of sexual dynamics to differ between Black versus White populations, for the reason that Black persons are more likely to choose other Black persons as sex partners, thus more racially segregated sexual networks(73).

The pattern in sexual networks that increases transmission of STIs and HIV are concurrent sexual relationships, that is overlapping sexual partnerships in time, permitting more spread than sequential relationships (74). Inadvertently, a higher presence of concurrent relationships and a higher prevalence of HIV within the same population would potentially lead to increase transmission of HIV. It has been shown in African Americans that concurrent relationships are an independent risk factor for acquiring HIV infection through heterosexual contact (66). Important risk factors subject to mediate higher concurrency in sexual relationships in African American women have been early sexual debut and being unmarried (75). As for men, associated factors to higher concurrency were being unmarried, early sexual debut, alcohol or drug intoxication during sexual intercourse, incarceration, having a non-monogamous female partner and history of sexual intercourse with a man (76). Van Veen et al (2011) (77) also studied concurrent partnerships among African and Caribbean migrants in the Netherlands and showed that men were more likely to have concurrent partnerships and women were less likely to use condoms with concurrent partners when compared to men. Although this type of data is not available in Canada it has been discussed that having multiple partners in African and Caribbean culture (via casual partners, "functional polygyny" or other) is not unconventional(55,58,72).

Another influential determinant of sexual networks is low sex ratios that have been found to be associated to concurrent partnerships. It is often found to be lower in Blacks due to various broad external factors (78). Men scarcity leads to greater opportunity to maintain simultaneous relationships with different women (73). Women in these relationships are at a disadvantage as the relationship is less secure. Inevitably they become more accepting of the conditions of the relationship and demand less of their partner (78). From Canada's standpoint, the estimated ratio of

Black men to women in 2006 is 0.92 versus 0.96 in white people (Statistics Canada 2006 census), indicative of a relatively lower sex ratio when ethnicities are compared.

Socioeconomic, Cultural and Environmental Conditions

Income, Education and Employment

The evidence is clear that socioeconomic inequities encompassing low income, unemployment and low education, result in poor health outcomes and premature death (79,80). This eventuality creates a social gradient of health that runs all across the social stratum of society and those at the lowest level carry the highest risk (81). Blacks history in Canada has involved living through much socioeconomic disparity in comparison to the mainstream dominant group (20). Given the supported association between relative poverty and risk of HIV infection (82), Blacks of African and Caribbean lineage residing in Canada are not averted from this risk.

Social Support

Immigrating to a new country entails losing the familiarity of ones home and personal support network (83). Once migrated to a new country the loss of a support network of family and friends in the country of origin can be particularly difficult (84). Social support provides emotional and practical resources (81) needed to withstand the processes of settlement through acculturation. People who get less social and emotional support from others are more likely to experience less well being which can impact behavioural patterns (81). Migration among other major life events has been shown to increase the risk of HIV infection (9,73,85). Vulnerabilities to HIV for migrants and as such for immigrants from African and Caribbean countries are widespread. Often there is a false reassurance where the perceived risk of HIV in Canada is underestimated which result in undermining the negotiation of safer sex or the application risk reduction behaviours (55). Recent immigrants sponsoring their family members may have been living apart for long periods of

time, which can lead to having concurrent relationships or sexual casual partnerships during these times of loneliness, putting them at risk (9). Long-term immigrants in developed countries often travel back to their countries of origin to visit family and friends, referred to as visiting friends relatives (VFRs) and have been shown to engage in more risky behaviour putting them at risk for acquiring STIs and HIV (86). In the case that migrants are in inadequate socioeconomic conditions or socially unstable, they are more inclined to forego preventive measures than to avoid HIV infection (9).

Social environment

Race has been defined and used in many ways (23). It varies historically and is subject to factors such as economic, political, social, and cultural practices (87). Primarily it refers to a categorization of identities imposed socially and organized according to phenotypes, skin colour, and other (88). It usually insinuates a dimension of inferiority (88). *Racialized identities* essentially would refer to assigning groups that socially have been determined as distinct (23).

Race is a social construct embedded in the description of *racism*, which entails an attitude that brings about directed actions to marginalize or oppress others (4). Racism has been shown to have repercussion on health and well being due to its limiting effects on educational, employment, and economic attainment opportunities among others (7,23). Unfortunately this is also true in Canada. The Ethnic Diversity Survey (2003) (89) described that one in five visible minorities report discrimination or unfair treatment 'sometimes' or 'often', with race or colour as the most common reason for perceived discrimination or unfair treatment. Additionally, among visible minorities, Blacks were more likely to report feeling that they had been discriminated against or treated unfairly by others because of their ethno-cultural characteristics. In relation to HIV, African and Caribbean people have been accused of the HIV epidemic and labeled stereotypes have superseded the reasoning of transmission dynamics for the epidemic to take place (53). These would be compounded to being marginalized by the acculturation process. This in turn can

lead to social exclusion, which has been described to accentuate the risk of HIV infection and redirecting people away from HIV-related support services (7).

Physical Environment

Racialized groups experience neighbourhood segregation where differences between neighbourhoods are reflected by the amount of resources, their location and acculturation of its members (20). Racialized communities are usually characterized of being more impoverished and hence concentrates issues related to its economic standing, such as social isolation, social problems, opportunities for economic success and overall health risks (20). This applies to many Black communities in Canada due to their socioeconomic disadvantage, as such being exposed to a greater of number of HIV risk-related circumstances (7). Residential segregation by race is also important in sexual networks, as people would tend to choose their sex partners in the same area where they inhabit (73).

Among visible minority federal offenders incarcerated in federal correctional facilities, Blacks were the 3rd largest groups, comprising 6% of the five offender groups (Caucasian >Aboriginal>Asian >Other) (90). Blacks were said to be overrepresented in the Canadian federal system(90). The prevalence of infectious diseases are known to be higher in federal offenders in comparison to the general population (91) and offenders are estimated to be 7 to 10 times more likely to be infected with HIV/AIDS [21]. The means by which this occurs in the federal institutions have involved unsafe tattooing practices[22] and sex in exchange for contraband cigarettes (verbal account from Correctional Services Canada). Other potential routes of HIV transmission among offenders can include injection drug use and rape (78). In addition, incarceration directly affects sexual networks either during imprisonment or when the offender returns to the community through the disruption of existing sexual partnerships (78). In essence, incarceration affects sex ratio by decreasing the "pool" Black men available to engage in a relationship and

[21]Canadian HIV/AIDS Legal Network (2006): http://www.aidslaw.ca/publications/interfaces/downloadDocumentFile.php?ref=638
[22]ibid

likely promotes concurrent sexual relationships by the inmate while in prison or the partner left behind engaging in new sexual relationships (78).

RATIONALE

Despite the efforts locally in Ottawa, there is a lack of evidence to inform prevention programs for HIV in African Caribbean and Black (ACB) communities in Canada. Although many efforts have been made through various programming, community based research and outreach initiatives, there are many issues which are not fully understood in this particular subgroup of the population. Much of the published research for this ethno-cultural group has been done in other countries such as the United States, where the determinants of health might not reflect the people of African and Caribbean descent who face the challenges of living with HIV in Canada. A better understanding of the specific factors which increase the risk of infection, and the issues faced by members of these communities living with HIV, would be useful to Ottawa Public Health in their HIV prevention activities.

OBJECTIVES

The overall aim of this project is to understand the burden of HIV-related disease in the African, Caribbean population of Black ethnicity in Ottawa and identify potential avenues to reduce the risk and/or mitigate the effects on the community. The specific objectives are:

1) To describe the epidemiology of HIV infection in the Ottawa ACB population including the pattern of exposures
2) To describe knowledge, attitudes, behaviours relating to HIV risk
3) To describe coping strategies, health seeking behaviours, and health care

This project used a mixed methods approach executed in two phases. The first phase, reported in Chapter 2, is a descriptive analysis of the epidemiology of HIV in the Ottawa ACB population. Phase one addresses objective 1 by describing the sociodemographic factors, risk factors and of reported diagnosis of HIV infection in the ACB population and non-ACB groups. Research questions addressed with this analysis included:

- What is the epidemiology of HIV infection in the ACB population in Ottawa?
- How do ACB and non-ACB populations compare regarding the pattern of reported HIV infection and risk factors for HIV infection?

The second phase, reported in Chapter 3, addresses objectives 2 and 3 and used qualitative interviews with people living with, and not living with HIV, to explore issues around knowledge, attitudes and behaviours related to HIV with consideration of the cultural context. Additionally, for those living with HIV, coping strategies, health seeking behaviours, and health care utilization were explored. The interviews were designed to address the following research questions:

- What are the core knowledge, attitudes around HIV-related risk behaviours, modes of transmission and risk reduction strategies?
- What are the coping strategies and resources available to HIV+ individuals from the ACB community in Ottawa?

- What are the health seeking behaviours and health care utilization of HIV/AIDS related health care services in the ACB community?

CHAPTER 2: Epidemiology of HIV in the African, Caribbean and Black Communities in Ottawa

INTRODUCTION

The phase of this study addresses objective 1 described above with the goal of examining a pattern of new HIV cases in the ACB population emerging in Ottawa, irrespective of whether they are true HIV incident cases arising in the population or cases who arrive in Ottawa through immigration. Comparisons of HIV diagnoses patterns are made with the non-ACB population to give a sense of how these groups are dissimilar or consistent. Even though they are living with HIV, their histories, reasons for testing and likely causative exposures may be different. This may have implications for how services are offered in a culturally sensitive way and may offer insight into prevention interventions.

METHODS

Study Design

A cross-sectional analysis was performed using a population-based database that contains all reported cases of HIV infection in Ontario. The analysis focused on the population resident in the catchment area for Ottawa Public Health (OPH) which is equivalent to the city of Ottawa municipality catchment area: from Cumberland in the east to Fitzroy Harbour in the west, and from the Ottawa River in the north to Osgoode in the south.

Case definition

Study participants included all nominal and non-nominal cases[23] diagnosed with an HIV infection, as defined by the Ministry of Health and Long Term Care (MOHLTC) (Box 1).

[23] **Nominal/non-nominal cases**: HIV tests can be ordered by a health care professional using the person's name (nominal) or using a code that will link the case back to the name (non-nominal)

Box 1: Ministry of Health and Long Term Care case definition (2009) [24]

Confirmed Case of Human Immunodeficiency Virus (HIV) Infection
Children < 18 months: • Detection of HIV nucleic acid (by deoxyribonucleic acid [DNA] polymerase chain reaction [PCR]) OR • p24 antigen (p24 Ag) in two separate samples collected one month and four months after delivery
Adults, Adolescents and Children >18 months: • Detection of HIV antibody with confirmation OR • Detection of HIV nucleic acid or p24 antigen
Laboratory Confirmation
Any of the following will constitute a confirmed case of HIV Children < 18 months (on 2 separate samples): • Positive for HIV nucleic acid • Positive for HIV p24 Ag (>1 months) • Positive HIV culture Adults, Adolescents and Children >18 months: • Positive for HIV-1, HIV-2 antibody with confirmation for HIV antibody (e.g. Western blot or immunofluorescent technique) • Positive for HIV nucleic acid • Positive for HIV p24 Ag • Positive HIV culture

The cases for this study were confirmed cases of HIV diagnosed between the January 01 2005 and December 31 2010, and had to be resident in the OPH catchment area at the time of diagnosis, even if the diagnosis was made out of province.

Data Sources

Integrated Public Health Information System (iPHIS)

The primary data source was iPHIS. According to the Health Protection and Promotion Act (HPPA), local health units including Ottawa Public Health (OPH) are mandated to collect information on HIV cases occurring within the regional boundaries and enter it into iPHIS[25]. Since 2005, iPHIS has been used across Ontario

[24] MOHLTC Infection Disease Protocol (2009) for AIDS: http://www.health.gov.on.ca/english/providers/program/pubhealth/oph_standards/ophs/progstds/idprotocol/appendixb/aids_cd.pdf

[25] http://www.apheo.ca/index.php?pid=187

for communicable disease management and reporting. It is a web-based application accessed by public health nurses (PHNs), epidemiologists and disease registrar officers, from all Ontario health units in relation to communicable disease cases.

OPH receives information on new HIV diagnoses for entry into iPHIS in the following ways.

Ontario Public Health laboratory

The Ontario Public Health Laboratory (OPHL) conducts all HIV testing in the province of Ontario. It receives all laboratory specimens from the Ottawa regional public health laboratory conducted in Ottawa hospitals, doctors' offices, Community Health Centres, the Ottawa Public Health Sexual Health Centre (SHC), as well as Anonymous Testing sites in the region[26]. All laboratory-confirmed positive results from the Ottawa area are then communicated to OPH.

Point of Care and the Prenatal HIV Testing Programs

HIV testing is also done as part of the Point of Care (POC) program and the Prenatal Testing Program. Since June 2007, point-of-care HIV testing has been available across Ontario at anonymous HIV test sites, public health sexual health clinics and community health centers in the province for no cost[27]. All clients with reactive test results are recommended to have confirmatory HIV testing[28]. At OPH, POC testing occurs through their SHC but clients who do not return for confirmatory testing would not be confirmed as an HIV case. The only POC testing results that are captured by Ottawa Public Health SHC are when a client's reactive results are confirmed with further confirmatory testing at the clinic. Other POC testing outside the SHC are not followed up at the clinic, giving only part of the cases truly identified by POC program in Ottawa.

The Ontario Prenatal HIV Testing program has been in place since 1998[29]. It is recommended that all physicians providing prenatal care offer HIV antibody

[26] Autonomous testing: Only positive cases who have accepted to follow through with treatment must release their personal identification and therefore are known to the health care system
[27] http://www.health.gov.on.ca/english/providers/pub/aids/reports/policies_procedures_quality_assurance.pdf
[28] http://www.health.gov.on.ca/english/providers/pub/aids/reports/policies_procedures_quality_assurance.pdf
[29] http://www.health.gov.on.ca/english/providers/pub/aids/reports/testing_times_ontario_prenatal_hiv_testing_programme_a.pdf

testing to all pregnant women and those planning pregnancies[30]. All positive results are reported to OPH for appropriate case management.

Other laboratories and CIC monthly notification program

Other sources of case information include laboratories not directly linked to OPHL, and monthly notification reports from Citizenship and Immigration Canada (CIC). The former can include testing done by Canadian Blood Services, life insurance companies, or from blood and tissue screening for organ donations. The latter has been a program since 2004. CIC has provided the Ottawa sexual health centre with a monthly notification report identifying HIV-positive individuals tested overseas who have entered Canada during the preceding months and who intend to reside in the province. This gives nominal information on HIV positive entrants in Ottawa as well as the date of birth, gender, telephone number, intended address with postal code in Canada, date of entry and immigration status category.

Out of province clients

On occasion, OPH will be notified of patients who have moved to Ottawa. As a standardized process, the out of province diagnosing health unit will inform OPH, as the new responsible health unit for the case. This permits the capture of the location of the source of disease at the same time ensuring case counts are accurate. The responsible and diagnosing health unit as well as the HIV case information is recorded into iPHIS.

When an HIV confirmed case is brought to the attention of OPH through one of these sources, a client chart is opened in iPHIS and is classified according to the MOHLTC case definitions.[31] The HIV case manager contacts the client and conducts an in-depth interview to collect demographic information, data on client risk factors, HIV testing history, and their health care provider. Data are recorded on two forms: HIV/AIDS STI Intake Form and the HIV Surveillance Form (See Appendix #2), with the data then entered into iPHIS.

[30] http://www.health.gov.on.ca/en/pro/programs/hivaids/prenatal/default.aspx
[31] http://www.health.gov.on.ca/english/providers/program/pubhealth/oph_standards/ophs/progstds/idprotocol/appendixb/aids_cd.pdf

Chart review

Ethnicity was not a data field in iPHIS during the time period of the study, so this information had to be captured through a patient chart review. All client charts, dated from January 01 2005 and December 31 2010, were stored at the SHU and reviewed by the principal investigator and Doaa Saddek, the Program and Project Management Officer at OPH. The ethnicity and country of birth of each client was identified on the HIV/AIDS STI Intake Form and the HIV Surveillance Form. This information was transferred to an excel spreadsheet that contained individual case information for the same time period of the study. The ethnicity data and data from the master file were merged to create the final dataset for analysis.

Geographic Population of Interest

The pattern of HIV infection was examined in three populations resident in Ottawa: (a) all residents, irrespective of country of birth or ethnic identification, (b) the ACB group, defined as all individuals whose country of birth was in Africa or the Caribbean, AND who identified as Black, and (c) the non-ACB group, defined as all individuals whose country of birth was neither in Africa nor the Caribbean, AND who did not identify as Black.

Of note, northern African countries were excluded to focus on Sub Saharan Africa (SSA), as northern Africa is not part of the PHAC listing of countries considered HIV endemic. As for the analysis, Black residents with an African or Caribbean ancestry but born in Canada were not examined as they only represented two HIV cases among all cases with Black race/ethnicity data. Moreover, cases whose country of birth was Africa or the Caribbean and who did not identify as Black were also not examined, since there were few cases that represented other ethnicities.

Denominator

Denominator data were derived from the 2006 Census. The Census Metropolitan Area (CMA) for Ottawa-Gatineau (Ontario part) aligns well with

borders of the OPH region. The definitions provided on place of birth[32], visible minority groups and immigrant status[33] were used to estimate the denominator populations for ACB-specific analyses. These groups of the population are summarized in Box 2 below.

In addition, 2006 Census microdata files were accessed through the University of Ottawa Geographic, Statistical and Government Information Centre (GSG)[34] for analyses that required specific 5-year age groups, country of birth, immigration status and visible minority categories.

Box 2: 2006 Census populations for the Ottawa-Gatineau region (Ontario part)

Populations	2006 Census
Ottawa CMA population	835470
African[35] and Caribbean (AC)	25210 Africa: 14460 Caribbean: 10750
○ Black African or Black Caribbean (ACB)	20245 African: 11680 Caribbean: 8565
○ Non-Black African or Non-Black Caribbean	3265
Other countries (excluding AC)	810260
○ Black	17770
○ Non-Black (non-ACB)	792490
All visible minority	162405
Not a visible minority[36]	673065
Black visible minority	39280
Other visible minorities[37]	123125

[32] http://www12.statcan.ca/census-recensement/2006/ref/rp-guides/immigration-eng.cfm
[33] http://www12.statcan.ca/census-recensement/2006/ref/rp-guides/visible_minority-minorites_visibles-eng.cfm
[34] 2006 census microdata provided a small sample of non-aggregated data, which contain samples of anonymous responses to the 2006 Census questionnaire. The 2006 Census public use microdata file (PUMF)[34] contains 844,476 records, representing 2.7% of the Canadian population. These records were drawn from a sample of one-fifth of the Canadian population. As the microdata file contains a record for each selected unit in the sample, weighting factors were also used to obtain population estimates.
[35] Africa represents countries from Sub-Saharan Africa; Northern Africa is not included
[36] Including White and Aboriginal population
[37] Excluding Black visible minority group

Data Abstraction and Management

All available client information on sociodemographics, HIV testing history and risk factors was extracted from iPHIS, supplemented by the ethnicity data abstracted from client charts (see Table 2-1).

Table 2-1: Summary of study measures

Sociodemographic Measures	
Study Measure	***Groups***
Age	<1, 1-4, 5-9, 10-14, ... 55-59, ≥60
Gender	Male, female
Ethnicity	Asian, Black, Latin American, North American Indian and First Nations, Metis, Inuit, South Asian, Arab and West Asian
Black/Non-Black	Black, Non-Black ethnicity
Country of birth	African country, Caribbean country, Canada, Other
ACB/non-ACB	People of African or Caribbean descent and Black (ACB), People not of African or Caribbean descent and not Black (non-ACB)
Reason for testing	Condom breakage, contact tracing, confirmation, entering study, immigration screening, insurance, prenatal screening, routine screening, symptoms, not applicable and not known
For immigrants only	
Time since immigration	< 5yrs, ≥5yrs
Risk Factors	
Study Measure	***Groups***
Sex-related risk factors:	• Men who have sex with men (MSM) • Having sex with a sex trade worker • Contact with HIV positive person, • Having a partner who is from an HIV endemic country
Injection-related risk factors:	• Receiving blood or blood products • Using illicit drugs, • Sharing needles and drug equipment • History of tattoos, piercing and acupuncture

For analyses focusing on the ACB population only, specific countries of birth in Africa or the Caribbean were used.

Exposure categories[38]

All new HIV diagnoses in iPHIS are assigned an exposure category among the categories listed in Table 2-1. This is done by the LAByrinth computer system of the HIV database. The system has an algorithm based on a mutually exclusive hierarchy. It assigns the most likely exposure to have caused the case's infection. If more than one exposure category is reported, the case's exposure category is classified according to the highest exposure category in the hierarchy. The only exception is if the cases reports to have sex with men and is an intravenous injection drug use, they are classified in a combined category. If risk factor information is not available, the computer will allocate a code as "no identified risk" or "NIR" or "unknown". The exposure categories of this system are listed in the Appendix (#3). The exposure categories used in this study and which reflects what is presently used at Ottawa Public Health is presented in Box 3.

Box 3: Exposure categories of study

Exposure category	Explanation
MSM	Men who report having sex with men
IDU	Case reports illicit drug use
MSM/IDU	Men report having sex with men + illicit drug use
Het- Partner	Case reports having sex with opposite sex partner that engages in high risk activity
HIV-Endemic	Cases that lived or visited countries where HIS is endemic
Het- NIR	Cases whose only reported risk factor is sex with opposite sex partner and not other information
Perinatal Transmission	Cases that were born to an HIV case
Occupational	Cases report an occupational exposure
Blood products or organs abroad	Cases reports receiving blood, blood products or transplant abroad

[38] http://www.ohemu.utoronto.ca/doc/technical%20reports/Endemic+tables+figs.pdf

Statistical Analysis

Frequency and Proportions

The sociodemographic and risk factor characteristics were described using frequencies and proportions. The distribution of proportions was presented for each characteristic.

Subgroup Analysis

Three subgroups were used to present sociodemographic and risk factor characteristics considering country of birth and ethno-cultural background during the study period. The first group included *all* diagnoses of HIV regardless of country of birth and race/ethnicity. The *non-ACB* group represented individuals with a diagnosis of HIV, born outside of Africa[39] and the Caribbean and who are not identified as Black. The *ACB* group included people from Africa and the Caribbean, identified as Black and diagnosed with an HIV infection.

Diagnosis rates

Age and Sex Standardized Detection Rates

The annual detection rates (or diagnosis rates) of HIV for the years 2005-2010 were calculated, as well as age- and sex-standardized annual detection rates per 100,000 from 2005 to 2010 for all three subgroups. The direct method was used, using 2006 Census population data in five-year age bands. A Bayesian calculation[40] [41] [42] was used to determine 95% confidence intervals.

Statistical software

The statistical analysis was performed using SPSS version 19.

[39] Northern Africa was excluded as it is not part of the PHAC listing of countries considered HIV endemic
[40] http://www.agenarisk.com/resources/probability_puzzles/bayes_confidence.shtml
[41] Roger Levy (2007) Bayesian parameter estimation; confidence intervals (Bayesian and frequentistic)
[42] Elberly (2003) Estimating Bayesian credible intervals

Ethical Considerations

In response to the ethical issues that might present when doing quantitative analysis, ethical principles of research (Belmont Report 1979)[43] were applied to try and reduce their occurrence as much as possible.

Confidentiality

A Non Disclosure Form for the Sexual Health Unit and an External Data Sharing Agreement form for the Epidemiology Unit at OPH were signed to gain access to HIV patient information and to ensure protection of identifiable data. Data collected from Sexual Health Unit charts, laboratory and information line databases, which had personal identifiers (such as name, date of birth, address, and postal code), were removed by the chart reviewer from the dataset to ensure anonymity of participants. The Sexual Health Unit practices for maintaining the security and integrity of charts were followed.

Respect for Persons and for Communities

To avoid public discrimination based on epidemiological results, it is important to be mindful that stigmatization is a major issue and to consider how it can prevent members of the ACB communities from taking on opportunities to use HIV prevention and diagnostic services. Presenting the outcomes of this study to HIV-service providers, and to the ACB communities can do this. The intent is to present to the ACB support group at HIV/AIDS committee of Ottawa (ACO), provide a summary of findings to OPH sexual health group and potentially strategize with other service providers ways to present the information to the ACB community. As such, the information can be used to ameliorate the provision of HIV-related services to these communities. This in turn can break the silence surrounding HIV, provide an environment that is supportive of prevention work, empower the ACB communities toward informed decision-making and improve the quality of life for ACB communities in Ottawa (James 2006).

[43] http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html

RESULTS

Diagnosis Rate

A total of 483 cases were identified for the time period in question, giving an average annual standardized diagnosis rate of 19 per 100,000 (95% CI: 17.3-20.7). The annual rates for the years 2005-2010 varied between 18 and 20.1 per 100,000 (Table 2-2). Data were missing on year of diagnosis for 139 cases. As shown in table 2-3, there were 342 male and 141 female cases (unknown: 98 male cases and 40 female cases), for an overall diagnosis rate (95% CI) of 13.3 (11.9-14.7) per 100 000 in males and 5.7 (4.7-6.7) per 100,000 in females.

Table 2-2 and table 2-3 also summarises the diagnosis rates by country of birth (AC/non-AC) and ethnicity groupings (Black/non-Black). A total of 106 cases (17%) had no information on country of birth and 129 cases (21%) had no information on ethnicity. For the ACB population, the overall diagnosis rate was 195.3 (95%CI: 159.3-231.3), with annual rates ranging from 141.8-278.6 per 100,000. For the non-ACB population, the overall diagnosis rate was 10.9 per 100,000 (95%CI: 9.5-11.6), with annual rates between 9.3 and 13.4 per 100,000.

The gender-specific diagnosis rates for the overall period, by country of birth and ethnicity are shown in Table 2-3. For the ACB population, the diagnosis rates (95% CI) per 100,000 were 95.9 (69.1-122.7) for males and 99.3 (75.2-123.2) for females. For the non-ACB population, the corresponding rates were 9.2 (7.9-10.5) and 1.75 (1.15-1.35).

Figure 2-1 summarises how the cases were distributed according to country of birth and ethnicity identification.

Figure 2-1. Summary of subgroups population by country of birth and ethnicity (Jan 1 2005 and Dec 31 2010)

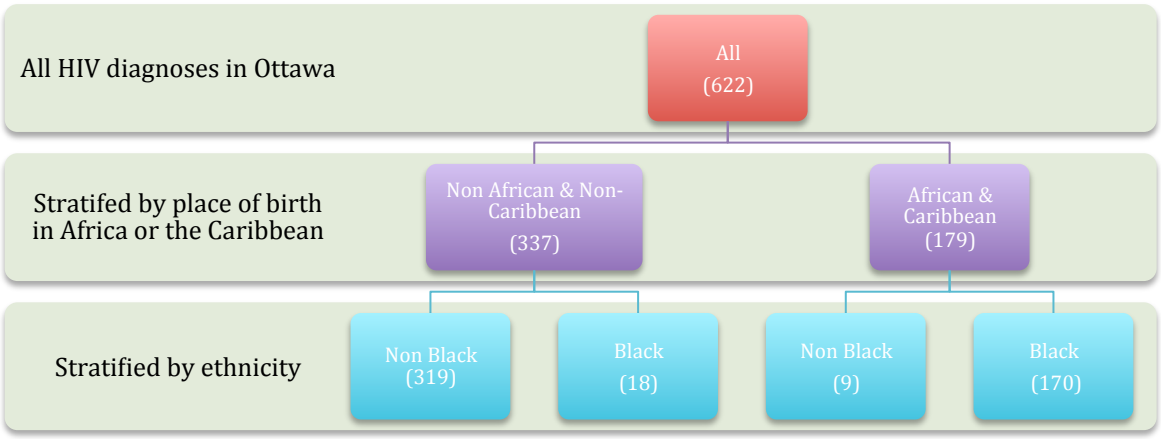


Table 2-2 Sex and age standardized* annual HIV diagnosis rates (per 100 000) in Ottawa† by country of birth and ethnicity from 2005 to 2010

	2005		2006		2007		2008		2009		2010		Average		
	Rate (No.)	95%CI	Rate (No.)	95%CI	Rate (No.)	95%CI	Rate (No.)	95%CI	Rate (No.)	95%CI	Rate (No.)	95%CI	Total No.‡	Rate	95%CI
All Cases	18.6 (76)	4.3	19.1 (78)	4.3	18.9 (81)	4.2	20.1 (87)	4.3	18 (79)	4.1	19.3 (82)	4.3	483	19	1.7
African§/ Caribbean	274.4 (28)	164.6	190.2 (31)	68.8	106.4 (16)	54	151.3 (26)	59.7	113.2 (19)	52.7	168.5 (21)	94.4	141	154.9	28.4
Black	278.6 (27)	110.1	227.4 (29)	87	141.8 (16)	74.2	196.8 (26)	79.2	147.2 (19)	70.7	179.8 (19)	100.8	136	195.3	36
Non Black	74.6 (1)	145.2	60.7 (2)	84	0	0	0	0	0	0	57.7 (2)	80.5	5	19.7	19.4
Other	9.9 (39)	3.2	9.9 (38)	3.2	14.2 (56)	3.8	12.3 (49)	3.6	12 (46)	3.6	11.7 (44)	3.5	272	11.7	1.4
Black	117.9 (2)	208	47.8 (2)	73.7	76.1 (3)	90.7	45.9 (2)	72.6	37.6 (1)	73.5	134 (5)	124.7	15	76.6	48.2
Non Black	9.5 (37)	3.1	9.3 (36	3.1	13.4 (53)	3.7	11.7 (47)	3.5	11.9 (45)	3.6	10.2 (39)	3.3	257	10.9	1.4

* Surveillance Unit Ottawa Public Health Excel worksheet for calculating direct standardization using population estimates for 2006 Census data for Ottawa-Gatineau (ON part) (in odesi)
†Cases newly diagnosed while living in Ottawa
‡Cases with known ethnic and gender data as well as year of encounter when diagnosis was made (row percent); missing data not included in cases are All cases: 139 (22.3%), Africa and Caribbean: 38 (21.2%), Black African and Caribbean: 34 (20%), non-Black African and Caribbean: 4(55.6%), Other Countries: 65 (19.3%), Black from other countries: 3 (16.7%), non-Black from other countries: 62 (19.5%)
§Sub-Saharan Africa (excluding North Africa)

Table 2-3 Age standardized* HIV diagnosis rate (per 100 000) in Ottawa† for males and females by country of birth and ethnicity from 2005 to 2010

Ethnicity	Male			Female		
	Total Cases‡	Rate	95% CI	Total Cases‡	Rate	95%CI
All	342	13.3	1.4	141	5.7	1.0
African§ and Caribbean	57	74.4	19.8	84	80.5	20.4
Black	54	95.9	26.8	82	99.3	24.1
Non-Black	3	14.8	16.9	2°	4.9	9.6
Other Countries	225	9.6	1.3	47	2.1	0.6
Black	8	59.1	46.3	7°	17.4	13.3
Non Black	217	9.2	1.3	40	1.75	0.6

* Surveillance Unit Ottawa Public Health Excel worksheet for calculating direct standardization using population estimates for 2006 Census data for Ottawa-Gatineau (ON part) (in odesi)
†Cases newly diagnosed while living in Ottawa
‡With known ethnic and gender group data as well as year of encounter when diagnosis was made (row percent); missing data not included in cases - Total: 138 (98male, 40 female; 22.3%), Africa and Caribbean: 38 (12male, 26 female; 21.2%), 34(10male, 24 female; 20%), non-Black African and Caribbean: 4 (2male, 2 female; 55.6%), Other countries: 65 (58male, 7 female; 19.3%), Black from other countries: 3 (2male, 1female; 16.7%), non-Black from other countries: 62 (56male, 6 female; 19.5%)
§Sub-Saharan Africa (excluding North Africa)

Sociodemographic factors

Overall

Table 2-4 summarises the overall sociodemographic characteristics of the cases. Excluding cases with missing data (N=112, 18%), the mean age at diagnosis was 38.1 years, with most cases in the 25-49 years age category. For those where place of birth was reported (N=516, 83%), the majority (251,48.6%) were Canadian-born, followed by Burundi (25, 7%), Congo (20, 3.9%), Ethiopia (24, 4.8%), Haiti (23, 4.8%), and Rwanda (18, 3.5%) [Data per country of birth not shown]. For Non Canadian-born, where time since immigration data were available (183, 49.3%), 125 (68.3%) reported arrival less than 5 years previously. Of the 494 (79,4%) who indicated a reason for HIV testing, 189 (38.1%) cases reported routine screening and 127 (25.6%) immigration screening.

ACB Populations

A total of 170 cases fulfilled the definitions for ACB (Table 2-5), of whom 106 (62.4%) were female. Excluding the 34 (20%) cases where age was unknown, 113

(66.5%) fell into the age group 25-49 years with a mean age of 37.7 years. The majority (140, 82.4%) indicated Africa as their place of birth. Of the 130 cases where the data were reported, the time since immigration for 90 (69.2%) was less than five years. Of the 158 who stated a specific reason for HIV testing, 93 (59%) indicated immigration screening.

Non-ACB Populations

A total of 319 cases fulfilled the definition for Non-ACB (Table 2-6). Excluding the 112 cases for whom age was unknown, 193 (75.1%) fell into the age group 25-49 years, with a mean age of 25.7 years. The majority (249, 78.1%) indicated Canada as their country of birth. For those born outside Canada, time since immigration was unknown for 31 (44.3%). Of the 39 where the data were reported, the time since immigration for 26 (66.7%) was less than five years. Of the 237 who indicated a reason for HIV testing, 162 (68.3%) reported immigration, prenatal, or routine screening.

Table 2-4 Selected characteristics of HIV cases diagnosed in Ottawa for 2005-2010

Characteristics:	Total Cases	% of Total
Total	622	100
Age (years)		
1-4	1	0.2
5-9	1	0.2
10-14	0	0.0
15-19	12	2.5
20-24	22	4.5
25-29	64	13.2
30-34	83	17.1
35-39	80	16.5
40-44	90	18.6
45-49	90	13.2
50-54	37	7.6
55-59	16	3.3
> 60	14	2.9
Unknown	112	18
Mean: 38.1		
Gender		
Male	440	70.9
Female	181	29.1
Unknown	1	0.2
Country of Birth		
African Country	143	27.7
Caribbean country	36	7.0
Canada	251	48.6
Other	86	16.6
Unknown	106	17
Time since Immigration		
Less than 5 years	125	68.3
5 years and more	58	31.7
Unknown	188	50.7
Reason for HIV testing		
Condom Breakage	1	0.2
Contact Tracing	28	5.6
Confirmation	2	0.4
Entering Study	1	0.2
Immigration Screening	127	25.6
Insurance	8	1.6
Prenatal Screening	8	1.6
Routine Screening	189	38.1
Symptoms	68	13.7
Not Applicable	14	2.8
Not known	48	9.7
Unknown	128	20.6

* Unknown category represents missing data for each characteristic including Age, Gender, Country of Birth, Time since immigration, Reason for testing

Table 2-5 Selected characteristics of HIV cases diagnosed in Ottawa from 2005-2010 in African, Caribbean and Black communities in Ottawa

Characteristics*:	Total ACB	% of ACB Cases
Total	170	100
Age (years)		
1-4	0	0.0
5-9	1	0.7
10-14	0	0.0
15-19	5	3.7
20-24	4	2.9
25-29	15	11.0
30-34	28	20.6
35-39	28	20.6
40-44	24	17.6
45-49	18	13.2
50-54	8	5.9
55-59	3	2.2
> 60	2	1.5
Unknown	34	20
Mean 37.7		
Gender		
Male	64	37.6
Female	106	62.4
Country of Birth		
African Country	140	82.4
Caribbean country	30	17.6
Canada	N/A	N/A
Other	N/A	N/A
Time since Immigration		
Less than 5 years	90	69.2
5 years and more	40	30.8
Unknown	40	23.5
Reason for HIV testing		
Condom Breakage	0	0.0
Contact Tracing	5	3.2
Confirmation	0	0.0
Entering Study	0	0.0
Immigration Screening	93	58.8
Insurance	2	1.3
Prenatal Screening	5	3.2
Routine Screening	27	17.1
Symptoms	13	8.2
Not Applicable	6	3.8
Not known	7	4.4
Unknown	12	7.1

*Unknown category represents missing data for each characteristic including Age, Time since immigration and Reason for testing

Table 2-6 Selected characteristics of HIV cases diagnosed in Ottawa from 2005-2010 in persons not from Africa, the Caribbean and of other ethnicities in Ottawa

Characteristics*:	Total Non-ACB	% Non-ACB cases
Total	319	100
Age (years)		
1-4	0	0
5-9	0	0
10-14	0	0
15-19	6	2.3
20-24	16	6.2
25-29	32	12.5
30-34	34	13.2
35-39	38	14.8
40-44	54	21.0
45-49	35	13.6
50-54	21	8.2
55-59	11	4.3
> 60	10	3.9
Unknown	112	18
Mean: 25.7		
Gender		
Male	273	85.6
Female	46	14.4
Unknown	1	0.2
Country of Birth		
African Country	0	0
Caribbean country	0	0
Canada	249	78.1
Other	70	21.9
Time since Immigration		
Less than 5 years	26	66.7
5 years and more	13	33.3
Unknown	82	30.9
Reason for HIV testing		
Condom Breakage	1	0.4
Contact Tracing	18	6.4
Confirmation	1	0.4
Entering Study	1	0.4
Immigration Screening	22	7.9
Insurance	5	1.8
Prenatal Screening	2	0.7
Routine Screening	138	49.3
Symptoms	51	18.2
Not Applicable	8	2.9
Not known	32	11.4
Unknown	128	20.5

*Unknown category represents missing data for each characteristic including Age, Gender, Time since immigration and Reason for testing

Reported Risk Factors

Multiple risk factors could be reported per case. In total, 59 (9.5%) cases had no information on risk factors. Among all cases (Table 2-7), not using a condom was the most frequently reported category (249, 44.2%), followed by MSM (225, 57.1%) and sexual partner from an HIV-endemic country (151, 26.8%). In all, sex-related risk factors were reported more frequently than blood -related.

In the ACB population, the most frequently reported category was a sexual partner from an HIV-endemic country (117, 73.6%), followed by not using a condom (50, 31.4%). Sex-related risk factors were more frequently reported than blood/injection-related risk factors. For the non-ACB population, data on risk factors was available for 87.1% of cases. The most frequently reported risk factors were MSM (170, 66.1%), not using a condom (176, 58.5%), sharing needles (60, 19.9%) and having an HIV positive sexual contact (59, 19.6%). Higher rates of sex-related than blood/injection-related risk factors were reported.

Exposure Categories

Table 2-8 summarises the exposure categories assigned to cases by the LAByrinth algorithm. Overall, the MSM, IDU, and MSM-IDU categories were allocated to 290 (52%) of cases. For the ACB population, the most common exposure categorisation was having lived in or visited an HIV-endemic country (142, 89.3%), whereas for the non-ACB, MSM, IDU and MSM-IDU categories accounted for 226 (78.3%).

Table 2-7 Frequencies of selected risk factors among persons diagnosed with HIV in Ottawa from 2005-2010

Risk factor*:	Total Cases	% of Total	Non-ACB Cases	% Non-ACB Cases	ACB Cases	% ACB Cases
Total†	622	100	319	100	170	100
Sex-related						
MSM	225	57.1	170	66.1	5	8.6
Sex with sex trade worker	20	3.6	13	4.3	1	0.6
Contact is HIV positive	91	16.2	59	19.6	14	8.8
Partner is from country where HIV is endemic	151	26.8	18	6.0	117	73.6
No condom use	249	44.2	176	58.5	50	31.4
Blood-related						
Received blood or blood products	29	5.2	14	4.7	14	8.8
Injection drug use	44	7.8	35	11.6	0	0
Shared needles and drug equipment	66	11.7	60	19.9	1	0.6
Tattoos/acupuncture /piercing	43	7.6	35	11.6	7	4.4

*Known risk factor data used (Row percent). The no. (%) of missing case information from risk factor data was: 59 (9.5%) for total cases, 18 (5.6%) for non-ACB cases and 11 (6.5%) ACB cases; More than one risk factor can be identified for a case

†Missing data not included in total: 106 (17%) missing from total number of cases with known country of birth PLUS 18 non-ACB cases from Black category and 9 ACB cases from non-Black category which are not applicable to these categories

Table 2-8 Frequencies* of HIV diagnoses according to country of birth, ethnic background by exposure category† in Ottawa for 2005-2010

	MSM		IDU		MSM-IDU		Het-Partner		HIV-Endemic		HET-NIR		Perinatal		Occupational		Received blood / organ abroad	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
All n=622	210	38.4	65	11.9	15	2.7	29	5.3	176	32.2	42	7.7	6	1.1	1	0.2	3	0.5
A/C n=179	5	3.0	0	0.0	1	0.6	6	3.6	146	88.5	2	1.2	4	2.4	0	0.0	1	0.6
Black n=159	4	2.5	0	0.0	1	0.6	6	2.5	142	89.3	1	0.6	4	3.5	0	0.0	1	0.6
Non-Black n=6	1	16.7	0	0.0	0	0.0	0	0.0	4	66.7	1	16.7	0	0	0	0.0	0	0.0
Other Country n=306	164	53.6	56	18.3	12	3.9	21	6.9	20	6.5	29	9.5	1	0.3	1	0.3	2	0.7
Black n=17	6	35.3	0	0.0	0	0.0	0	0.0	9	52.9	1	5.9	1	5.9	0	0.0	0	0.0
Non-Black n=289	158	54.7	56	19.4	12	4.2	21	7.3	11	3.8	28	9.7	0	0	1	0.3	2	0.7

*Proportions with known data (row percent); Information unknown for 75 (12.1%) of reported cases (missing data not included in frequencies)

†Exposure category based risk factor most likely responsible for infection

CHAPTER 3: Knowledge, Attitudes and Behaviours of HIV in ACB Communities in Ottawa

INTRODUCTION

The methods and results of qualitative interviews are described here exploring various issues around knowledge, attitudes and behaviours related to HIV and the experience, coping strategies, health seeking behaviours, and health care utilization of individuals in the ACB community both living with or living without HIV. This chapter addresses objectives 2 and 3 indicated in the background section.

METHODS

Study Design: philosophical Orientation and Paradigm

The nature and process of inquiry on HIV in ACB communities has ontological, epistemological, and methodological understandings (92). In this context, the ontological assumption is that multiple realities are at play when considering the complexities of living with HIV as a Black individual. The epistemological assumption and methodological assumptions are that these realities would be described as accurately as possible through the interchange that occurred between the participant and the researcher to reflect (represent) best what was expressed by participants (92).

Social constructivism (also referred to as naturalistic inquiry or qualitative description) was selected as the paradigm to guide the process of enquiry (93). Social constructivism is particularly suitable to attempt to understand the world in which participants live and work (94), and my reliance on each participant's notion, interpretation, and meaning of his or her experiences (95). Additionally, the principal investigator (PI) attempts to resolve a specific theoretical view of the target phenomenon (i.e. ACB experience), rather the purpose was to try to elucidate a pattern of meaning (94).

This qualitative phase of this study was set in Ottawa.

Study Participants

Study participants interviewed for this study had to fulfill the following eligibility requirements:

- Man and woman over 18 years of age
- Self-identified as Black
- Born in Africa, the Caribbean or Canada (with African/Caribbean ancestry)
- Living with HIV or not living with HIV (either unknown/untested or negative for HIV)
- Resident in Ottawa

Potential eligible participants were identified through collaboration with service providers who were themselves members of the Black community, and/or who worked on HIV initiatives and/or worked patients living with HIV, at Ottawa Public Health, AIDS committee of Ottawa and the Infectious Disease clinic at The Ottawa Hospital General Campus. As current epidemiology supports the increase of HIV/AIDS cases in people from HIV endemic countries, and affecting a great majority of Black individuals, study participants had to have African or Caribbean ancestry to be considered for the qualitative portion of this study. For feasibility purposes and relevance to Ottawa Public Health programing, residents were selected from the Ottawa area.

Recruitment of Participants

Purposive sampling was used, in the form of typical sampling and referral sampling (94,95). For the former, participants were recruited from venues that would typically involve ACB communities. For the latter, key participants were invited to refer other potential participants whom they thought could contribute to the study. Individuals who contacted the PI (Dominique Elien Massenat) directly to participate in the study were invited to a face-to-face interview. Participants at the HIV clinic in module G at the Ottawa General Hospital interested to participate in the study were provided details of the study on-site. A scheduled time and date was then organized for a future interview with the PI.

General ACB population not living with HIV

The population in this qualitative arm were Black Ottawa residents of African or Caribbean descent, older than 18 years of age representing the general population not living with HIV. Although their HIV status was not laboratory confirmed, participants voluntarily provided this information if they responded to the participant questionnaire. Recruitment of community members in the ACB populations for participation in similar studies has been used before (97,100, 141). Recruitment activities involved a wide distribution of posters and an information letter. These were posted at various venues with the permission of respective owners or organizers including ethnocultural community centers, HIV/AIDS organization, universities and cultural festivals. Media outlets addressing the African and Caribbean communities in Ottawa were also used to announce the study, such as the website BlackOttawa411 and the monthly edition newspaper, the Spectrum. Additionally, an information letter was addressed to members of ACB communities via a Black community blog, known as Black Ottawa Dialogue, created by the president of Black History Ottawa, Mr. Godwin Ifedi. The members enlisted on this blog are Black community members interested in being informed of Black community activities/events and promotes discussion on issues relating to the Black populations. Mr. Ifedi sent the e-mail correspondence, so that no privacy violation of potential participants would be made. Lastly, the listserv by the name of "African studies @ Carleton Digest", displaying African and Caribbean related activities and events in Ottawa, also showcased the poster to their followers.

ACB Population living with HIV

As for individuals living with HIV, they would be informed of the study through the HIV clinic at the Ottawa Hospital in Module G. Dr. Raymond Corrin and Dr. Bill Cameron agreed for the study to be presented to their patients during their HIV clinic hours. Infectious Disease (ID) nurses working at the clinic briefly presented the study to patients. All the ID nurses were briefed of the study by the principal investigator (PI). The PI was on site to provide details to interested participants and to arrange an appointment for a separate encounter. The

coordinator of the Infectious Disease clinic at Module G, Joanne Thibert (RN), provided assistance to arrange an appropriate setting for these encounters.
All patients were approached for their participation in the study without any coercion. They were always given the choice to receive further information by the PI. It was also clearly stated that their involvement or their refusal of participating in the study would not in any way affect the health services they received.
In table 3-1 you will find summarized the various venues and outlets utilized for recruitment.

Table 3-1 Summary of recruitment venues

Venues	Strategy
Media/Publication	
Spectrum (newspaper)	Poster
Black Dialogue Ottawa (blog)	Poster /Information letter
Black Ottawa 411 (website)	Poster
African Studies @ Carleton Digest (List serve)	Poster
Ethno-cultural Community and Service Centers	
Ottawa Community Immigrant Services	Poster Information Letter
Immigrant Women Services Ottawa	Poster Information letter
Community Health and Service Centres	
Carlington Community and Health Services (CHC)	Poster
Centretown CHC	Poster
Pinecrest-Queensway Health and Community Services	Poster
Sandy Hill CHC	Poster
Somerset West CHC	Poster
South East Ottawa Community Services	Poster
South Nepean Satellite Community Health Centre	Poster
Vanier Community Services Centre	Poster
HIV/AIDS groups	
AIDS Committee of Ottawa (ACO)	Poster
Health care related facilities	
Sexual Health Clinic	Poster
University of Ottawa Health Services (Dr. Kilby and Dr. Loemba)	Poster
Dr. M. Mclaren's clinic	Poster
Infectious Disease clinic at Ottawa General Hospital (OGH)	Poster and Information Letter

Venues	Strategy
Leisure/Activities	
Haitian Festival of Ottawa 2011 Jamaican Festival of Ottawa 2011	Poster and Information Letter
Youth/Students	
University of Ottawa Health Promotion Centre	Poster
Carleton University (billboard)	Poster

Interviews with participants took place in various locations to try and increase easier accessibility for them. They were at the following sites:

- Sandy Hill Community Health Centre 221 Nelson street
- Somerset West Community Health Centre 55 Eccles street
- Centretown Community Health Centre 420 Cooper street
- Vanier Community Service Centre, 290 Dupuis street
- Sexual Health Centre 179 Clarence street
- AIDS Committee of Ottawa, 251 Bank street
- Infectious Disease clinic in Module G, Ottawa General Hospital

Data Collection

Those who consented to participate engaged in a 60-minute semi-structured interview with the PI, using a semi-structured interview guide. Several topics were covered during the interviews with participants living with HIV and those not living with HIV. They are presented in Table 3-2. These topics were selected by conducting an environmental scan of Canadian studies and reports pertaining to the ACB population and HIV as well as information provided by informants familiar with this area of research. The topics were either inspired from theses sources or deemed lacking in the literature, which would be relevant to the ACB population in the Ottawa context. For instance, knowledge attitudes, risk behaviours, and health care utilization were described in the East African Health Study in Toronto attempting to capture the gaps in HIV research by interviewing participants from Ethiopia, Tanzania, Uganda, Kenya and Somalia (96). Furthermore, the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) focused on HIV-related stigma by exploring the experiences and responses of People from African and Caribbean Communities in Toronto (97). All the topics described in Table 3-2 were explored with participants and further topics were probed if presented through the qualitative interviews.

The interviews were conducted in French or English, according to the participant's language preference. All necessary documentation (i.e. consent forms etc.) was translated by a translation company on the French Language Services from the City of Ottawa list of suppliers and proofread by one of the City of Ottawa's translators. All interviews were audio-recorded and hand-written notes were taken with the consent of participants.

The interviewer debriefed with participants at the end of interviews, and answered questions if raised.

Table 3-2 Topic areas covered in semi-structured interviews with participants

Participants not living with HIV	Participants living with HIV
• Knowledge of HIV • Attitudes/Perceptions/Behaviours of HIV • Perception of individuals of the ACB community living with HIV • Risk factors for the spread of HIV in the ACB community • Ways to prevent the spread of HIV in the ACB community • Ways to assist individuals of the ACB community living with HIV	• Life experience with HIV • Reaction to HIV diagnosis • Perception of HIV • Support and coping strategies while living with HIV • Health care utilization • Utilization/Accessibility to HIV-related services • Availability of support for individuals from ACB community living with HIV

Sample Size

With qualitative research, the necessary sample size is difficult to estimate before the data collection begins. However, some researchers suggest that data saturation can often be achieved by analyzing 6-10 or up to twelve interviews depending on the criterion used to make the final decision (98,99). Hence, the target number of interviews for this study was 10-12 for those not living with HIV and 10-12 living with HIV, therefore a total of 20-24 qualitative interviews. This permitted to obtain a good variety of experiences from the ACB communities in Ottawa within a feasible timeframe and for maximum use of available resources. Even if specific target numbers of participants were set, recruitment was influenced when

interviews revealed no new themes. This occurs when it is demonstrated that the data collected reached the extent that would no longer provide further knowledge on what is being studied (95). The quality of information obtained per sampling unit helps establish when to stop sampling as opposed to the final number (98).

Analysis

The interviews were transcribed verbatim for analysis by the principal investigator and a third party transcription company. The analysis was based on elements of the Data Analysis Spiral model elaborated by Creswell (2007) (94). The organization of all the transcriptions in specific password protected computer files allowed for data management. Analysis of transcriptions began by reading and identifying segments of the data that relate to the research questions posed in this study and reducing the data into meaningful segments. Open coding was done by assigning codes to pieces of data. These units of data were organized according to an organizing scheme and formed the database upon which to base the analysis. This was followed by analysis coding where each unit is compared to another unit of information with the intent of finding recurring regularities in the data. The units were then classified in comprehensive classes of categories into broader themes. Interpretation and reflection on the meaning of the units of data is followed by provisionally scheming the categories to sort the evidence within those categories. The categories became abstractions derived from the data. These categories had to meet several criteria, such as being responsive to the research question; comprehensive to include all the relevant information from the data; mutually exclusive incorporating only units of data once; reflective of what is in the data; in agreement conceptually by having all categories characterized similarly (95).

Validation, Consistency and Transferability

Qualitative validation and reliability in this study was accomplished by peer examination. Members of the thesis committee, with diverse content knowledge (public health, HIV/AIDS clinical management, HIV research and visible minority research), commented on the findings. Transferability was sought by assuring maximum variation (e.g. age, education, immigrations status, etc.) in the sample

captured, permitting a broad range of application to the readers or users of this research (95).

Ethical Considerations

In response to the ethical issues that might present when doing qualitative research, ethical principles of research (Belmont Report 1979)[44] were applied to try to mitigate any harmful effects and reduce their occurrence as much as possible.

Respect for Persons/Beneficence/Justice

The level of physical and emotional harm/discomfort expected was low due to the nature of the study. However, the potential risks of participating in the study were also declared openly to the participants. Interviews were conducted in a safe and welcoming environment for participants to feel comfortable to express their thoughts. It was encouraged that all participants alert the PI if they did not feel comfortable. All concerns were taken seriously and followed up immediately. All possible measures were undertaken to assure no harm was caused. Risks to participants may encompass feeling vulnerable of sharing personal and sensitive information about them. They also could have had emotional responses related to their past experiences on this topic. For these reasons, participants were reminded that they do not have to answer questions if they didn't feel comfortable to do so.

Respect for Communities

Issues relating to the acceptance of HIV prevention, education and testing in the ACB communities are not to be ignored. It was important to be aware and mindful that stigmatization is an important issue and how it may prevent members of the ACB communities to take part in this study. It was also vital not to participate in perpetuating HIV-related stigma by challenging the misconceptions around HIV and providing accurate information on HIV and its risks when applicable. As indicated above, relevant stakeholders such as HIV-service providers and ACB community members would be informed and empowered knowing the research findings, in order to enhance service provision in the ACB community.

[44] http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html

Confidentiality

Anonymity of participants and confidentiality of the data was kept throughout the study according to the requirements stated in the Personal Health Information Protection Act[45].

Using a unique numeric code ensured the privacy of each participant. The PI assigned a unique research identifier to extracted data, to keep track of files and to be able to trace information back to the source chart if needed. This unique identifying code was assigned for appropriate storage, tracking and security purposes. No records bearing the participant's name ever left the Ottawa hospital. Additionally, with the use of the unique numeric code, the participants were unidentifiable on the transcripts and other related research documents.

All computerized databases identified subjects by numeric codes only, and were password protected. Collected data from participants, transcripts and audio files were stored on password-protected files. All electronic documents were transferred and secured by using encrypted USB keys.

All audio recordings given to a professional transcription company and all final transcripts sent to the principal investigator were stored on password-protected files and secured by using encrypted USB keys. The transcription company signed a data sharing agreement.

To ensure anonymity of the participants during the receipt of their honorarium, they were asked to provide their initials to confirm their participation and the PI signed as a witness. All passwords were kept confidential in the office of the PI in charge of regulatory documentation. Once the study completed, study documents will be stored at the hospital in a locked room for 2 years. The boxes will be transferred to a long-term storage facility (Securit) for 13 years. The transfer of the study information will be documented. At the end of the 15year storage period, documents will be shredded to ensure patient confidentiality. All electronic data and documentation will also be deleted at the end of the 15year storage period, and its destruction will be documented.

[45] PHIPA (2004) : http://www.ipc.on.ca/images/resources/hguide-e.pdf

Informed Consent

Prior to the start of the interview, the PI provided a consent form and used a non-persuasive manner to obtain consent. The PI read through the consent form with the potential participant to ensure understanding of what the study entails and what is expected of participants. The PI described the purpose and scope of the project, the type of questions to be asked, how the results would be handled and the steps to ensure participants' anonymity. The PI highlighted at several steps during the consent process that the participant has complete liberty to participate or not in the study without impact on any services they may receive from Ottawa Public Health/The Ottawa Hospital or other health care-related services (further detail provided in section on Ethical Considerations). At the end of each encounter, participants voluntarily completed an anonymous socio-demographic questionnaire. Each participant received an honorarium of $20 for research participation. Questions were addressed throughout the consent process.

RESULTS

Participant Characteristics

Of the overall sample of 24 participants interviewed, only 22 were used for qualitative analysis, representing 10 participants not living with HIV and 12 participants with a positive HIV status. Due to technical difficulties there were two interviews of participants from the general ACB population could not be included in the analysis (went from 12 participants to 10 participants). Participant sociodemographics were available for 23 of the participants initially recruited unless the participant decided not to provide that information. The patient characteristics are displayed in Table 3-3.

Table 3-3 Summary characteristics of all participants taking part in the semi-structured interviews

	Participants living with HIV (n)	**Participants not living with HIV (n)**	**Total Participants (n)**
Gender			
Male	4	4	8
Female	7	8	15
Total	11	12	23
Age range			
18-25	0	5	5
25-29	0	1	1
30-34	0	0	0
35-39	1	2	3
40-44	3	0	3
45-49	4	3	7
50-54	2	0	2
55-59	1	0	1
>60	0	0	0
Total	11	11	22
Highest level of education			
High school or equivalency	5	3	8
College or trade	2	0	2
University	4	6	10
Masters	0	2	2
Doctorate	0	1	1
Total	11	12	23
Ethnicity			
African	8	7	15
Caribbean	2	3	5
Other (Mixed)	1	2	3
Total	11	12	23
Immigration Status			
Canadian citizen	5	9	14
Permanent resident	5	3	8
Refugee claimant	1	0	1
Total	11	12	23
Time since immigration			
Less than 5 years	4	2	6
Between 5-10 years	1	2	3
More than 10 years	5	5	9
Not applicable	1	3	5
Total	11	12	23
Employment status			
Working	6	6	12
Unemployed	2	3	5
Student	3	3	6
Total	11	12	23
Personal income			
No income	1	1	2
Less than $ 39 999		6	12

	Participants living with HIV (n)	Participants not living with HIV (n)	Total Participants (n)
	6		
$40 000 to 59 999	2	1	3
More than $60 000	0	3	3
Not mentioned	2	1	3
Total	11	12	23
Marital status and living arrangement			
Married and living together + living as married	3	1	4
Married and living apart	2	0	2
Not married	1	10	11
Widowed	5	1	5
Total	11	11	23
Religion			
Christian	7	7	14
Muslim	3	3	6
Non believer	0	0	0
Other	1	1	2
Total	11	11	23
History of HIV test			
Yes	11	8	11
No	0	3	3
Total	11	11	22
HIV status			
HIV+	11	0	11
HIV-	0	9	9
Unsure	0	2	2
Decline to answer	0	0	0
Total	11	11	22

Note: One HIV positive participant did not complete the questionnaire and one HIV negative participant did not provide all answers to the questionnaire.

Of all participants, almost two-thirds were female for both the general ACB population group and HIV positive groups. They represented various age ranges with people between the ages of 45-49 years being most prevalent. For HIV positive participants they were all above the age of 35 years. There were more participants of African descent in comparison to participants originally from the Caribbean in the total group. The majority had Canadian rights and privileges since almost all of participants had their Canadian citizenship or permanent residency status. In all participants, 5 were Canadian born and the rest foreign born. Among foreign-born participants 6 were recent immigrants (time since immigration below 5 years), 3

were relatively recent immigrants (time since immigration between 5-10 years), and 9 were long-term immigrants (time since immigration more than 10 years). In addition, most HIV positive participants were foreign born and more than 1/3 had immigrated to Canada in the last 5 years. As for participants not living with HIV, the majority were either Canadian-born or had been in Canada for more than 10 years. From a socioeconomic standpoint, more than half had individual earnings less than $39, 999. On the whole, more than half of participants had a university degree or more, noticeably most of these participants were general ACB population group. As for marital status and living arrangements, the group not living with HIV were mostly not married. However, among the HIV-positive group participants had varied living circumstances. Amongst these, almost 2/3 were either widowed or married and living apart. All participants had religious affiliation or beliefs (Christianity, Muslim or other) with a good portion being Christian. For the ACB participants not living with HIV, almost 3/4 of them indicated to have had previous HIV testing and 2 out of 11 participants were unsure of their HIV status.

Interviews with participants from the general ACB population not living with HIV

A total of 10 interviews from ACB community members not living with HIV were used for analysis with the intent of construing their perceptions of HIV, their attitudes vis-à-vis HIV and people living with HIV/AIDS (PHA) from the ACB community and their impressions on ways to address HIV within the ACB community. From these interviews, several issues put forward gave perspective on the cultural context where HIV stands in the ACB community in Ottawa. These viewpoints were captured in several themes and subthemes listed as follows:

1. HIV in Canada is different from back home
    a. Common knowledge of HIV
    b. New outlook on HIV
2. HIV-related stigma still exists in ACB communities
    a. Old school mentality in ACB communities
    b. Isolating effect of HIV
3. Understanding sex in ACB communities

a. Sex talk
b. Relationship dynamics in ACB communities

4. Root problems of HIV in ACB communities
    a. Racism and discrimination
    b. Homophobia and the Down Low
5. Deficiencies in prevention programs and HIV-related services for PHAs from the ACB community
    a. Targeted needs for subgroups in ACB community
    b. Need for open communication
    c. Importance of cultural interface between health services/supports and ACB individuals living with HIV
    d. Psychosocial support for PHA members of the ACB community

HIV in Canada is different from "back home"

Most, if not all participants were able to comment on the basic knowledge of HIV by speaking to its etiology, mode of transmission, certain risk factors of infection, progression of disease and disease prognosis. Here are some of the comments that depicts this well:

> *"I know it's a human immune virus… It's you know something you can have without having any symptoms really, and there are a variety of ways you can contract it that aren't always sexual". (ACBN06)*

> *"…sharing needles with someone who has the virus, unsafe sex once again, and also… I don't know if it's true but my understanding is it's very easy to get the virus if… Like same sex, same, you know, like male-to-male sex or something like that. And also if there is a wound, a cut, through blood, contact with blood…" (ABN10)*

> *"It's an incurable disease…" (ACBN05)*

> *"…so far there is no treatment or there is no vaccine to prevent it, but there are different kinds of drugs that can help them to prolong their lives." (ACBN11)*

As for preventive measures to protect oneself from HIV infection, most participants were likely to repeat usual cited messages relating to risky behaviours to avoid.

> *"Ways to prevent it, don't do drugs (laughs), or don't share needles, don't have unprotected sex and, I don't know, use a condom (laughs)". (ACBN08*)

There was a general sense of comfort on what one should know at least enough to converse on relevant elemental information on HIV/AIDS. Many also presented a positive outlook on HIV disease by comparing it to any other chronic disease that requires clinical management, where anyone can be affected. The fate of PHAs didn't seem more compromised than other chronic conditions as long as they receive the appropriate treatment, support and care. This is well spoken to by participant ACBN11:

> *"So the thing is I'm just encouraging a lot that it's nothing to have HIV, just like it's having some kind of disease that everybody can have it". (ACBN11)*

The treatment and care of HIV between Canada and Africa was brought up which showed the encouragement of accessible care for HIV in Canada, which is not necessarily the case in certain countries in Africa. For this reason, the prognosis of an HIV diagnosis was often contrasted between countries.

> *"I know in the country in Africa that I have seen, it is like when you know you are infected with HIV/AIDS, everyone knows that it is the end, it is your end, so there is no hope but arriving here we show you that it is more, you can live, there is hope". (ACBN05)*

> *"…it's a condition and here in Canada we say that it is a chronic manageable condition, but in most of the African countries they see it as a death". (ACBN03)*

In all, the views of HIV in Canada in comparison to their home country (either Africa or the Caribbean) were generally consistent.

HIV-related stigma still exists in the ACB community

The positive outlook on HIV was readily contrasted with further insight from all participants. The impression remains that there is still a large amount of unawareness within the ACB community, which leads to fear of HIV and judgment of PHAs in the ACB community. This was referred to and well encapsulated in the slang expression "old school mentality". This expression usually implies adherence of traditional policies and practices[46] or making reference to an earlier era, anything that is considered old fashioned[47]. Many thought that the less information you had on HIV the more you would rely on your own personal experience and ingrained impressions of what HIV is. Many are familiar with HIV because of what they've seen in their own country of birth (in Africa or the Caribbean) or what information was accessible to them while in Canada; often many myths still prevail in people's understanding of HIV.

> *"…but I would say most black people look at it as a very, very dangerous disease and they don't want anything to do with anybody with HIV". (ACBN10)*

> *"…a lot of people are still not understanding what the disease is about, how you can catch it, how you cannot catch it, so that may lead to fears of that person". (ACBN12)*

[46] Definition from Merriam-Webster dictionary
[47] Definition from Wikipedia

> *I know there are people that think we can catch HIV in ways like that are stupid quote unquote. I know there are people who are propagating false beliefs like people, people of authority, like I heard one teacher once in high school say that we can catch it from toilets… there are still myths. (ACBN13)*

In this group, almost all participants had never had any interaction with anyone infected with HIV, for which they were aware of at least. If they did, it involved participants who've migrated from an African country. A qualitative study of African and Caribbean communities in Toronto revealed that many of their participants did not feel that they knew the context of HIV for their communities in the Canadian context, either because the information was not readily available or that the media coverage on HIV/AIDS focused solely about the situation in Africa (100). One participant made the point, that although second generation immigrants or first generation immigrants who have immigrated at a young age might be more open and not have the "back home" experience with HIV, they can be greatly influenced by their elders.

> *"Well the young people I think are different probably and they are a bit more open than the older generation I find, but even them may be suffering because if they're connected to their elders it will still be I think an issue for them. So morality issues, fear of catching the disease, not knowing really what it is because if a person has HIV they can still be fine and then there's confusion also". (ACBN12)*

Usually immigrant social circles often involve their family members that become a great importance for childcare and social support (101); the idea of having an influence on the children's upbringing could relate to this fact. Others participants argued that the amount of information available to ACB communities would not change how people would react to HIV.

> *"Regardless of how much scientific data comes out about you can't get it through saliva you can't get it through all sorts of ordinary stuff, like touch. Uhmm… people are still worried they'll treat you differently and may not be obvious but they will treat you differently and that's probably the disincentive". (ACBN02)*

This worry stems from the fear of broken confidentiality in the ACB community. It is understood that any personal or identifiable information is widely discussed among members of the ACB community and this information can actually be relayed "back home". It is usually not of bad intent but out of cultural norm or habit. The interconnectedness within the community and their country of origin is a reality for many.

> *"…when you are from my country you are most likely to know people back home… Very tricky again in our community because of the things that I've said, everybody knows everybody else and people talk." (ACBN03)*

> *"In fact a lot of people say, if it's just Canada I don't care if everybody knows about my HIV status, but I don't want my mum to know, I don't want people back home to know, because they say that it will devastate them". (ACBN03)*

> *"I have negative thoughts with regards to that, because in Africa it has always been the case. When something happened, its normal that the whole neighbourhood would be aware…it is still the same, it has not changed completely, it is still the case". (ACBN05)*

Theses statements depict the stigma related to having an HIV diagnosis when part of the ACB community. Among participants it is well recognized the impacts one would have to face if diagnosed with HIV. Many spoke of the chastising, and

isolating effect of having HIV, making them unable to want to disclose to their loved ones and thus suffer the consequences of bearing the effects of the disease on their own.

> *"Man if I was HIV I wouldn't share (laughs). Because I'm sorry, again in the black community they can be very ignorant… So it just, there's lots of stigma and I wouldn't tell nobody". (ACBN04)*

> *"But what's particular to the black community or people of African decent maybe still I think HIV/AIDS is not something that people want to discuss or be open about, like they would be maybe Diabetes… I find anyway in the black community not an issue that can easily be discussed" (ACBN12)*

Results from the East African Health Study in Toronto (2008) (96), surveyed people from five East African communities to examine HIV/AIDS issues and concerns in the context of general health issues and behaviour. One of those issues was HIV-related stigma, which demonstrated that those who knew someone with HIV or had better knowledge on HIV had a decreased stigma score than those who didn't. Another study looking at the perception of African women in Philadelphia also identified their horror of disclosing their positive HIV status due to the undue effects of rejection, and complete isolation by the community (102). The fear of disclosing ones HIV status could be for the various reasons that have been shared by participants on their impressions of PHAs in the ACB community. Among these were impressions PHAs were promiscuous; unattractive, unwanted or undesirable; or excluded from the marriage pool. There was also blame of the individual bearing the disease saying, "People living with HIV should be ashamed" (ACBN04). There is a sense of embarrassment by being associated with the HIV diagnosis, which relates to the mode of transmission, hence a reason for others to be able to cast judgment of how someone acquired HIV.

"A lot of people don't think it's a problem, I think that's my view, other people consider anything that have to do with sexuality and sex very private, so they would not discuss it, since HIV is transmitted generally through sex or sexual activities" (ACBN12)

"it seems like a very embarrassing thing to die of. It's not like you've died of malaria or cancer, it seen as a disease of a moral failing or what is the word…some sort of moral flaw. So it's not seen as a disease you get through no fault of your own". (ACBN02)

Another point alluded to in the latter quote is a religious connotation that pertains to how people of African and Caribbean origin are highly religious (14,67). HIV has often been attributed to a sort of curse or bearing of a sin. Therefore an individual's religious beliefs might influence their understating and interpretation of the disease or how they approach care if infected with HIV. For instance, Gardezi et al (2008) (100) also showed that depending on a person's religious beliefs, people of the ACB community might think the disease can't attain them or that it is not present in people of a certain religion, hence leading to less use of preventive measures when engaging in high risk sexual behaviour and increasing their risk of acquiring HIV.

Regardless of the impressions stated, stigma is clearly an important issue that is present in the ACB community regarding HIV status. Participants either expressed it for themselves or it was the fear of others who might impose these feelings of stigma toward them. Many participants voiced having HIV as an additional weight to other issues would be too much for any member of the ACB community. The group qualifies this as a significant and pressing concern. The participant expresses this here.

" …here like we're trying to be accepted so it also becomes like we don't want to be too closely attached with something that's so stigmatized, because we're a marginalized community". (ACBN06)

Understanding sexual dynamics in ACB communities

When sex matters were discussed with participants it brought a lot of strong emotion from extreme concern to feelings of disappointment on what seemed to be outstanding barriers to openly speak about it. Many commented on the scarcity of information for ACB community members or the lack of knowledge on sex-related issues that were deemed important to avoid high-risk situations to acquire HIV.

> *"What I think that is that people are afraid to talk about it, they don't want to admit that it (HIV) is a reality in the community and they don't wont to admit that they themselves (ACB community) are also sexually active". (ACBN13)*

> *And the youth, the other thing that I can see is the youth, they will be high risk in many ways, African and Caribbean youth…To be honest I worked with many groups of that communities, sex and discussing about sexual activities is not open in their homes, even the most cultivated, I don't know, urban people are still not comfortable (ACBN12)*

> *"I was surprised how many of, you know, my friends, my peers, and then the youth I work with had no information about sex or sexuality… and I feel in a context where you're not talking about sex period, you're almost more vulnerable to HIV/AIDS because you just don't really know information, you're not going to be safe" (ACBN06)*

Noticeably in the last two quotes, ACB youth have been identified as most vulnerable due to their lack of sex information.

Another factor raised, was that social class or educational background did not seem to make a difference in the level of knowledge on sex-related topics, but cultural ways directed how sex was interpreted and discussed. This is expressed in the quote below:

"Many communities have different ways of thinking about sex and sexuality. Again, black communities and sex and sexuality, again is a challenge by itself, so this is just one more added layer". (ACBN12)

This acknowledges that privacy on personal matters were considered by our participants as paramount and depending on the ethnocultural background, it guided how sex was discussed, expressed and experimented by ACB members of the community. This was shown in a qualitative study of Somali women who shared their high need of privacy and respect for issues that pertain to sexual practices and gynaecologic concerns (103).

Black immigrants from the Caribbean, tend to inhabit the same neighbourhoods, and intermix socially (104). This tends to be the same for Black immigrants of African origin (103). As highlighted by the following quote, it is then not surprising how this brings to form relationship dynamics as well.

"… we tend to date the same people, we tend to hang out with the same people. A lot of people will not go out of their community to marry or to even date, so because of that then there's a likelihood. We don't have a bigger group to choose from, it is the same". (ACBN03)

Accordingly, to understand the interconnections that are made within the ACB community it is important to understand what cultural behaviours lead to these connections and how that may affect their vulnerability to HIV infection.

"there's a tendency I find black men will go with a variety of women, but black women sort of feel for whatever reason that they got to stay with black men (laughs), so there's also a sense that like there's a scarcity". (ACBN06)

"…there's this whole men will be men attitude that is just terrible. To do with infidelity and that kind of stuff it's sort of like, oh that's just what they do, which I totally don't agree with". (ACBN08)

There are several issues that are presented in these quotes. First, the known (and relatively accepted fact by participants) that ACB men tend to maintain multiple sexual relationships at a time. This is noted in a couple of studies examining high-risk sexual behaviours in African American men. In these studies, Black men were more likely to engage in multiple sexual relationships than Whites (76,105). Black women on the other hand have been reported to have less multiple partners than Black men (105), however concurrency in sexual relationships was highest for Black women if compared to other ethnicities (75). It was also indicated by Adrien et al (2010) (58) that men of Haitian origin could regularly have at least one casual partner. Therefore, it is not only eminent among participants but also reported in several studies. Of note, polygyny is still a common practice in various African countries and is practiced depending on many cultural, religious and other factors; although prohibited in Canada it could be partly attributable to this practice. Secondly, women seem to "accept" Blacks' men behaviour willingly or not. As mentioned above, for various psychosocial, socioeconomic reasons they might feel there only option is to stay in relationships where their male partners are also engaged in sexual encounters with other partners. Thirdly, women were said to be at a disadvantage since men are considered scarce in the ACB communities, considering ACB women would normally have relationships with ACB men. This is not only an impression but also a reality in Ottawa (ON region), as the sex ratio for Black men and women is estimated at 0.86 in comparison to non-visible minorities in Ottawa at 0.94[48].

[48] 2006 Ottawa Census Profile

Interviews with participants with HIV positive status

A total of 12 interviews from ACB community members infected with HIV were used for analysis in the attempt of understand and acknowledge the resources and coping strategies for ACB living with HIV as well as the seeking behaviour and use of HIV-related services, either health or non-health based. PHAs from the ACB community elaborated on various contextual issues, which influenced their personal experience and guided their approach to living with HIV. The themes and subthemes elaborated from the analysis were put forward as follows:

1. Attributable source of HIV infection
    a. Belief of HIV infection
    b. Unclear how HIV acquired
2. Debasement of PHAs from the ACB community
    a. Being set apart from ACB communities when diagnosed with HIV
    b. Struggles for ACB community members when living with HIV
3. Support systems for ACB living with HIV
    a. All types of support are essential for ACB to cope with HIV
    b. Positive mindset leads to a changed outlook on HIV for ACB
4. Service use by ACB living with HIV
    a. ACB living with HIV value health care services available to them
    b. Non health-related services are in greater need for ACB individuals living with HIV
5. Gaps in present activities in Ottawa for ACB living with HIV
    a. Good but not enough
6. Community divide between broad/inclusive services for PHAs versus culture specific services for ACB
    a. Desire for broader community services for ACB living with HIV
    b. Desire culturally specific services/support for ACB living with HIV

Attributable source of HIV infection

When participants were asked to discuss their impressions of how they acquired HIV there was a divide in the answers from clear assumptions of the source to complete dismay in understanding how it could have happened.

For those with a presumption, they mostly involved circumstances of infidelity by their partners or victimization by being raped.

> *" I was raped during the war…" (ACBP05)*
>
> *"Yeah, a guy raped me" (ACBP11)*
>
> *"I think it was my husband…because I was never promiscuous" (ACBP03)*

The first quote brings up the situation of warfare and armed conflict that usually results in widespread social disruption and putting vulnerable populations at risk of human right abuses and sexual violence (107). The last quote pertains to the issue of concurrent sexual relationships that is shown to occur in African and Caribbean culture (55).

On the other hand, other participants would state no history of risk factors that they are aware of that could have be put them at risk for HIV infection. Participants described the constant rumination of "how" or "why" this happened as unfavourable. The lack of conclusive answer would bring them to blame anything or anyone for their diagnosis.

> *"I don't understand where I found this, how I got this; I tried to go back in my memory and I don't know. I can't say otherwise I will risk blaming anybody" (ACBP02)*

For participants who were not aware of the source of their HIV came to discover their positive HIV status while immigrating to Canada (35).

Debasement of PHAs from the ACB community

All participants spoke of the devastation of being diagnosed with HIV. Often the initial reaction was that they were going to die within a short period of time and characterized having the disease as "death". This period in their lives while living with HIV is depicted in the quite below.

> *"It was like death, like I was looking at death in my face, to tell you the truth… I did believe I was going to die, that's what I thought, I was going to die" (ACBP12)*

This characterization of HIV/AIDS was accompanied by feelings of hopelessness by most participants. Life prospects seemed out of reach and daily living seemed harder to bear.

> *" With HIV, there is no life for me" (ACBP01)*

> *"I was discouraged with life. I didn't know what to do…It is not easy to live life with HIV, taking the medication day after day…" (ACBP09)*

> *"I had stopped saving, stopped thinking of studying or going back, but I thought of erasing this form my mind et I erased enjoying life, why get dressed, why put on make-up…all these things were futile to me…" (ACBP04)*

For some, these expressions of despair spiralled into a negative state of mind that became even detrimental to their mental wellbeing.

> *"I didn't feel like living…" (ACBP04)*

One of the major claims brought by most participants was the fear of the ACB community of knowing their HIV status. This fear stemmed from either

acknowledging the community's culture toward gossiping or relating to other people's experience when they were diagnosed. Here we have the anticipation of being found out by other members of the ACB community and the affect it would have on them.

> *"They will start talking about me, and that will kill me, they will try maybe to separate me from them" (ACBP07)*

Participants also described the type of labels they foresee would be projected from the ACB community if their diagnosis with HIV would be known.

> *" You become invisible and harmful (to them). You are no longer considered, they see you like if you are going to infect them". (ACBP02)*

> *" It is monstrous…It is a degrading disease…People have a tendency to say maybe she was promiscuous and she is a prostitute …the labels are degrading". (ACBP03)*

> *" …it's like a campaign of dirtying people living with HIV" (ACBP04)*

There was concern conveyed by participants for their loved ones and the level of understanding of their situation. They preferred not to venture in those prospects and keep the information to themselves.

> *"Nor my mother. Nobody of my family knows that I have HIV…I want to keep it that way." (ACBP01)*

> *"They (children) know that it is bad, it is a disease, a disease of prostitutes, of vagabonds, we are marginalized" (ACBP04)*

"For my kids, I know one day they will know, I will be the one to tell them." (ACBP08)

The last quote brings up the question as to when is the best time to address this information with one's children. The greatest concern provided by participants was focused on the children's reaction, which could parallel the reaction of the ACB community. The following quote expresses the possible reason why that would be the case.

"People from here (Blacks of African and Caribbean descent born in Canada), they don't have much information on HIV, I know there is not a lot". (ACBP06)

The participant's impression relates to the exposure she has had of HIV and the higher prevalence HIV/AIDS in her country of origin. A great majority of Black immigrants to Canada do come from countries where HIV is endemic (32) hence would grant individuals from these countries greater exposure to the spectrum of issues that can be associated with HIV more than the younger Black generation of Canadians without the same experience as their parents.

Some of the participants' fears unfortunately came to reality and were subjected to feel ashamed, rejected, deserted, and repelled by others. The following quote speaks to examples of what they experienced.

"He put my name in the street like dirt to all his friends…this friend told everyone in the Black Haitian community in Ottawa" (ACBP01)

" I heard the gossip behind my back, it's like the person has no value…they lose their value, their beauty, all their dignity" (ACBP03)

For these stated reasons, many participants felt the need to live in secrecy and avoid any chance of their HIV status to be known. The control of their personal

information becomes high priority for them to feel comfortable to take part of the ACB community, if they did at all.

> *" We have to protect ourselves from a social point of view and from others…there are risks that come back to you like consequences of stigmatization, your image, so its better for it (HIV status) to stay with you and the doctors…that are informed more than others." (ACBP06)*

> *"When that time I found out I decided to close the door to anybody, I didn't tell no-one because I knew people, friends, when they know about this they will start looking at me in a different angle…" (ACBP07)*

> *"I couldn't tell them that we have HIV, and with the feeling that we are going to have a child with HIV also played a big role…The fear of community, like people can run into… Unfortunately maybe the paper could be, your prescription could be, go under the table or wherever, someone can run into anything." (ACBP12)*

Participants also detailed their perceptions of the life experiences with living with an HIV diagnosis. Times of struggle, pressure and discouragement represented much of what was shared. The struggles pertained to the limitations caused by living with HIV.

> *"The impact that I have inside is I know what I have. That's the only… And I'm not free… I have limit how far should I go" (ACBP12)*

> *"I understood that I was limited in doing certain things, it discouraged me a lot because I realized that I could not flourish…that means I am obligated to do what I don't like because I limited by this disease". (ACBP03)*

One aspect that was embedded in most participants' experiences was the added load an HIV diagnosis to that of being Black. The toll seemed to make living with HIV even more unbearable compared to other non-visible minorities.

> *"But the truth is that when you go out there just being black alone, there's lots of things you go through, lots of things" (ACBP12)*

Here the participant expresses that there is already much to tolerate and endure when you are a Black person in a Canada that having to deal with HIV is just another added difficulty. Similarly, research in Uganda showed that Black people with HIV/AIDS felt the burden of being identified as Black and being infected by HIV (108). Of mention, was the divide with the acculturation process impressed by participants, with the desire to integrate in the host country but also wanting to retain their own cultural values.

> *"There is generally an integration process but specifically regarding positive cultural values of our country that has to stay, because there are more generations that have to inherit them" (ACBP06)*

The self-induced pressure of wanting to succeed in the newly adopted host country intensifies these struggles expressed by participants.

> *"You say to yourself, 'I am going to make myself a new life. What I used to live will not be' ". (ACBP02)*

> *"You come out of a refugee camp, from a country in warfare, with great economic difficulty, you come here (to Canada) for you. There is none of that here (in Canada), everything is clean, and therefore you don't think that HIV exists here" (ACBP04)*

The prospects of a new life seemed promising for participants but then tarnished with the HIV diagnosis. The last quote asserts the unexpectedness of even "finding" HIV in Canada. As mentioned previously, this has been highlighted in the literature as a false sense of security by newcomers from HIV endemic countries who migrate thinking they leaving a country with high prevalence of HIV to another with lower prevalence diminishes any risk of being exposed.

Other cultural pressures revealed by participants are to have education and to find employment. This was a cultural expectation found in the following quotes:

> *" For us (Blacks of African and Caribbean descent) it is employment that determines who you are" (ACBP04)*

> *" We as Haitians we love to work to have our own income, for help I did not as for help" (ACBP08)*

In these quotes educational attainment and employment are considered key to the identity of ACB individuals. The last quote also gives a sense of pride to have to ask for help for financial assistance and addresses the will of acquiring means by one's efforts. As for most participants employment was not readily available and their diagnosis did come as a factor of them either getting employment or staying employed.

> *"I did three years without a job, so it was really hard on me" (ACBP02)*

> *"Frustrations from not being able to work in field of experience with obtained education or diplomas" (ACBN04)*

Handa et al (2003) (82), showed for PHAs of African and Caribbean descent that often their fear of disclosing their HIV status limited their employment opportunities or when employed the disease course at times compromised their ability to fulfill their work obligations. Medication side effects have also been a cited as a factor of affecting job performance (109). In either case, these situations could

lead people to live in low-income situations or even in poverty which has also been shown to accentuate disease progression from HIV to AIDS (7).

The latter quote reiterates the frustration and discouragement of many internationally educated professionals who face many barriers to find employment in their chosen career in Canada. Standard practice of many regulated professions is overseen by governing agencies in each province. Although professional associations routinely recruit internationally trained professionals they often do not recognize their degrees and work experiences; as such they must be re-certified and re-trained through these same professional associations (110). Therefore the frustration comes from the inability to practice in their field of expertise.

Among participants some had the opportunity to work while others would receive income support from the Ontario Disability Support Program (ODSP). For those who did have a job, they expressed how hard they worked to barely get by to have their basic necessities.

> *"I had to work 7days a week, for my kids in Haiti, they have no dad, I am the one sending money to them in Haiti" (ACBP07)*

> *"I'm still in school, I have a part-time job, I have a lot of responsibility. I have to pay my bills, my apartment, everything, I have to look after these kids too at the same time and I have to finish my school. Because I'm taking a loan that I don't know even if… If I graduate I don't know if I'm going to find a job… So I'm thinking about all these things, finances and others… How do I even ask…?" (ACBP12)*

For those receiving income from ODSP they were grateful of the support but realize that the amount provided would not be sustainable on a long-term basis.

> *"For the time being I have what I need, until I find work… I get to find myself a bit… it is not 100% what I want but still can get something to*

eat and have some money to purchase soap, or for example personal garments" (ACBP09)

" What they (ODSP) tell me is that what they give is enough for your rent. They can't give more than that. So I had to look for work, I needed to eat. I needed to be resourceful…to find something to eat…traveling was hard, what can you do you can't ask for more… They say 'This is what we give everybody'…" (ACBP02)

The next series of quotes refer to the economic challenges faced by many participants. The inability to find adequate employment and hence acquire sufficient income was a great concern.

"Many want to return studying or find work because work helps remove the stress, the financial stress, and moral stress" (ACBP04)

People here (ACB support group) are isolated and lack work. 99% don't have work. Often enough they have their diplomas but they really want orientation on where they can get more sessions, the kind of information and sessions on knowing where to go" (ACBP10)

"So but again, having HIV then you have financial problems, and you have a family, and there is no programs in place that can really empower you to do something. Like especially learning… it doesn't matter how old you are you should learn some trade, something to help you… Those things can help, and especially the black community here, for immigrants, it can help" (ACBP12)

"I always think of working, that is my biggest preoccupation" (ACBP09)

Support systems for ACB living with HIV

All participants admitted to needing support to cope with their HIV diagnosis and during the course of their disease. They acknowledge and communicated how essential it was to be surrounded and to avoid isolation.

> *"It became too hard for me to handle" (ACBP04)*

> *"I needed to talk to someone…" (ACBP12)*

Several participants sought the support of family members but with mix results. For those who had a positive experience they can't imagine having gone through without their families' support.

> *"The first thing that made me accept my disease was my family…they showed me love". (ACBP05)*

Furthermore female participants with children frequently explained the encouragement their children gave them for wanting to survive to take care of them and respond to their needs.

> *"It's by looking at the long term consequences because I have a child that was still in school, so I said to myself, 'okay I need to live for her'" (ACBP05)*

> *"Sometimes I find it exhausting, there are moments I tell myself 'no I am not taking the medication', but something inside me says 'No, No take the medication or you will die. You will leave your children and they are too young'". (ACBP09)*

For those with a negative outcome were in the end rejected by their family and led to seek help from other sources.

"No I told them, they just didn't want to hear it so I didn't tell them anything more, that's about it" (ACBP11)

What made it harder for these participants is the lack of social networks.

"I have no family here" (ACBP01)

"All my family (is) still in Africa" (ACBP12)

"It has been 8 years since I have been with them (children)" (ACBP08)

It has been described that immigrants rely heavily on their social networks, especially for settlement purposes. Usually they are comprised of family members and very close friends (89). It takes some time in the country for this network to expand(83). All in all, participants agreed that family presence was considered crucial.

The majority of participants stated their faith in religion/God practised in various ways but essentially relating to its importance in coping with their disease.

"I am a believer and I believe there is a God, I believe there is a destiny." (ACBP05)

"If it wasn't for God that was with me I wouldn't be here today". (ACBP04)

"I put everything in God's hands". (ACBP08)

"I continue to pray to God". (ACBP09)

In reference to the Toronto study mentioned above, PHAs of African and Caribbean descent also explain how religion has served them as a means to cope and a source of comfort in dealing with respect to their disease (82)

Other types of support described by participants were health care personnel they encountered through their journey in HIV-related services. Many brought up the added benefit of having professionals in the field provide them with the additional information support to better understand how to best manage their disease.

> *" My local doctor… he called me to his office and he told me the problem that is bad news. But at the same time he gave me hope, he told me I'll have good news too" (ACBP07)*
>
> *"I spoke a lot with the social worker" (ACBP09)*
>
> *"He (the doctor) supported me, and it is him that gave me strength to accept, and to have a presentable face" (ACBP09)*

Another opportunity to achieve support indicated by some participants was the participation at the current support group for ACB living with HIV at the AIDS Committee of Ottawa (ACO). It is pioneered by a person living with HIV from the ACB community and has been ongoing for several years. Participants who have engaged this group saw it as a way to share with others living similar experiences.

> *"Often I come to the group. We come, we share, we discuss, prepare food together, we eat and we have a good time. Besides that I stay at home" (ACBP09)*
>
> *"If you meet people like you, there is something that changes in you. You can't handle it on your own. You need to share with others. You need to*

share with other, help others…it helps people accept their situation" (ACBP05)

"I saw other people who gave me council. They told me 'there are others who have been living with HIV for 5 years, others 10 years, it depends of the person'. By listening to this it gave me hope" (ACBP09)

The same way participants expressed the importance of avoiding isolation, the same way this support group seemed to provide the appropriate venue for some to combat their feelings of loneliness and provide a social network for them to rely on.

One aspect articulated by a few participants was the necessity to change mind frames to be able to transition from the shock of the diagnosis, to its acceptance and moving on with one's life. For that to happen many of the supports systems mentioned above by participants have assisted them with that progression. Until that happened, they found it difficult to lead a "normal" life.

"It is daily battle, this disease, you have to fight it. If you do not eat well, if you don't do any sports, if you don't have an active life, the disease will take over you and your mind" (ACBP10)

"So after I understood how you get infected everything changed, plus the quality of medication here that you get helps… I mean gives you that confidence that… You are not thinking that negative about the condition; it's not a disease anymore, it's just a condition that somebody can have" (ACBP12)

"Until today I'm surviving and strong because I don't put in my head at all" (ACBP07)

"Well I'm not angry anymore, I was angry at first, but it's just like anything else I guess; it's there" (ACBP11)

In all these cases, time was an important element that brought positive change, as long as they did what was necessary to cater to their needs and found the encouragement required to move on.

Service use by ACB living with HIV

Many of the services used by participants in relation to their HIV care pertained to their family physician, the HIV clinic at the Ottawa General Hospital (OGH) and the health and non-health professionals by which their HIV specialist referred them to.

> *" I see the psychiatrist, my family physician and I have a social worker" (ACBP01)*

The perception of services was mostly positive. Participants seemed satisfied and even grateful for the services provided. These impressions were most applicable to HIV-related services given at the HIV clinic in the infectious disease hospital department.

> *"It is very efficient, I cannot complain" (ACBP02)*

> *"They (hospital services) took care of me. They provided me with advice. For me they are like family. They helped me a lot" (ACBP08)*

Accessibility to front-line health care providers or HIV hospital-related services were also favourable by most.

> *"Me personally I did not encounter any barriers" (ACBP02)*

> *"I received all that I needed" (ACBP05)*

> *"There are clinics happening but I see other people that can go to the clinics…they do everything so there is discretion" (ACBP03)*

The last quote pertained to the importance accorded by participants of having HIV-related medical services offered in confidentiality. As alluded to previously, participants highly regarded their privacy especially to avoid HIV-related stigma.

A clear consensus among participants was a lack of information on various issues that they face as immigrants in addition to living with HIV. Their impressions was that the information might be present but that they didn't feel that it was readily accessible to them.

> *"It may exist (information) but I don't know it. It may happen that organizations that do help with financial issues and ways of transportation but I may not know". (ACBP02)*

> *" The community (ACB community) does not have enough information" (ACBP03)*

> *" I don't believe there is a lack of services, but of information" (ACBP04)*

As most PHAs in this study represented immigrants from African or Caribbean countries, many of the information requested pertained to immigrant settlement services critical for appropriate integration on the long term. HIV-related services for specific subgroups of ACB community members were also mentioned.

> *"Especially for newcomers, the services, they complain a lot is especially regarding housing, reception received, once they have arrived in the country they are left to themselves… Besides ACO, to my knowledge there is no other assistance…that is at all levels, level of immigration, health services, housing, and at all levels" (ACBP10)*

"Someone who's like myself (a street person) that could actually be here for when you come here, and not these people that they put in charge that has no idea what they're talking about" (ACBP11)

"On the side of women, especially with immigrants, they need a lot, a lot of help. Like counselling, I mean about relationships. But as people who are coming in the country, we don't know how the system works. We don't know what this so-called freedom and human rights… I think counselling and talking to families will be a big thing, and having projects, especially in place for women" (ACBP12)

"Impossible to do prevention work without involving men" (ACBP04)

The first two quotes look at the services that would serve immigrants PHAs and homeless PHAs. The issues faced by immigrant reflect their journey as they accommodate to the dominant Canadian culture, therefore PHA who've recently migrated to Canada can attest to this transition period. This was described in more detail in the background section. Also addressed previously was the relationship between living with HIV and poverty. HIV infection can lead to poverty depending on the course of disease, the adverse effects caused of the medication enabling to work and the money required to pay for treatment (109). The last quotes target services relating to prevention in women and men. It is noteworthy that the suggested preventive approaches would involve dealing with the dynamics in sexual relationships and addressing issues in both genders.

Financial assistance services have been raised previously but here participants address the issue of having a comprehensive service that would permit PHAs to pursue their education without having to receive social assistance.

"But the question is, I don't want to go on Welfare, I don't want that, I want to work, I want to use my head. I don't want it to make me feel like

I need somebody to stand there and help me, I don't need that, that's what makes me totally angry with the system" (ACBP12)

"The medications are so expensive…when you work and have a salary but at a certain amount they tell you to pay for everything because you are working" (ACBP03)

"When you are on ODSP or welfare, they pay your medication but if you have a student loan they no longer pay for the medication" (ACBP03)

For residents in Ottawa to receive financial support there are two social assistance programs available in Ontario[49]: Ontario Disability Support program (ODSP) and Ontario Works (OW). PHAs can be eligible to receive financial support through the income support stream of ODSP as long as they fulfill the required criteria regarding health status and financial situation. If you receive income from other sources (e.g. child sponsorship support, work) it will be deducted from the income support provided. As every case is dealt with according to their specific situation, outcomes may vary for each PHA. PHAs could also apply for OW to receive employment assistance or income assistance but the eligibility criteria is less applicable to those living with a disease such as HIV/AIDS. The impressions communicated here indicate that the coverage of living expenses and related expenses to living with HIV might not be completely covered by these services and aren't sufficient to become completely independent of these services.

In follow-up to the above-mentioned topics, most participants also put across the need for better integration of services. Having navigated through many services and organizations, participants often perceived there was a lack of communication between these entities or a missing link that could potentially help complement the work they do.

[49] http://www.mcss.gov.on.ca/en/mcss/programs/social/

"I have children, I can't leave my children to come (to community services). If you want me to come you must accommodate me. Where am I going to put my children?" (ACBP04)

" Many of the information sessions, conferences are in English meaning that francophone are always lacking information" (ACBP04)

"I arrive at a service, I present myself, and the person does not speak French. I have difficulties. I am blocked" (ACBP08)

" I have the impression that Health Canada, I don't know who subsidizes all these community centres, but there is no follow-up. There needs to be the hospitals, the community centres…must work together". (ACBP10)

Of note, immigrants of French speaking countries of Africa and the Caribbean have voiced their concerns of not having any specific resources or services that cater to their linguistic needs. In addition, the social planning council of Ottawa (2010) (111) indicated that 61% of immigrants living in Ottawa of French-speaking countries were from Africa and the Caribbean (mostly from Sub-Saharan Africa). In this sample of PHAs, three-quarters (9 out of 12) of participants were French-speaking.

Gaps in present activities in Ottawa for ACB living with HIV

The current activities that are provided at AIDS Committee of Ottawa (ACO) specifically targeted at the ACB community have been well appreciated by most participants. Communal activities and group discussions have helped many participants, particularly in creating a venue for members of the ACB community living with HIV to reunite. However some have signalled there are substantial needs of the community, which are still not being met. Besides ACO no other avenues would carry these type of services specifically directed for members of the ACB community.

"We can find interest coming here (ACB support group) but for me I don't want to come to seat. Even if I am sick, I am young, I want to find work, I can continue my studies… but not all my colleagues I see here want the same goals". (ACBP03)

"Not specifically for people with HIV, but introduce things that people can just join and do together… But if you make it specific for people with HIV it has stigma behind it…Like you cannot only even talk about the black community because now you see people mixing black and white, so it can be just a general…" (ACBP12)

"Because you don't have someone to talk to, let's go there, eat the food and laugh and go on or maybe let's go to the park and eat a BBQ; I don't think that is a program. We are mature people, we don't need that. We need something that is creative, that it can help you build your own life, build a community, teach other people". (ACBP12)

The desire expressed in these quotes and communicated by a few participants is to have more formalized programming that can link them to the information there are seeking, that will help advance members of the ACB community in reaching their individual goals and that will make them ACB living with HIV feel part of the ACB community as a whole. A qualitative study conducted with the inclusion of service providers in HIV/AIDS from Ottawa discussed this similar topic and admitted to the need for expanded services but that budgetary cuts and the lack of funding opportunities for ethno-specific programs and activities creates a road-block for HIV/AIDS organizations (82).

Community divide between broad/inclusive services for PHAs versus culture specific services for ACB

When approaches to services addressing ACB community needs were discussed there was some differences in perceptions of how best to tackle it.

> *We are not a huge community…white, black… and we don't need that. We can just be one person. And with one voice the government hears too…" (ACBP12)*

> *"They (Other ethnicities) have their activities and we have ours, but I don't see activities that bring us together" (ACBP03)*

> *"The white community has more information on this disease and benefits in comparison to the ACB community" (ACBP03)*

Essentially you found a part of participants that appreciated the particularities of ACB culture and values, but from a programmatic approach appreciated the critically mass required to demand for services and the wish to be connected to the services and programs that other groups may be benefiting from. The previously mentioned Ottawa focus groups of HIV/AIDS service providers did claim that fund allocation were given to risk groups considered high priority, therefore other risk groups would not collect a similar amount.

Most participants did express the lack or representativeness in the field of HIV/AIDS-relates services and programs. The general sentiment was that having familiarity and an element of trust in the person providing support was seen as beneficial if not required. This was introduced earlier when addressing health care providers who provide care to PHAs (112).

> *"Have more people of their race (laughs) to talk to, because there is none… Yeah, it would be nice. It would be a good thing…I don't know many black people who are HIV actually…I really never sat down with a black person to really discuss the issues" (ACBP11)*

In addition, it was felt that people couldn't fully understand what you are going through and provides adequate services and support if they weren't of the same community (ACB)

> *"People won't go to a place that has nothing, where there is nothing in common" (ACB04)*

What was seen as encouraging to PHAs in this group was to have positive examples and relevant success stories that spoke to them. This could serve as a case in point or even a standard for all PHAs of the ACB community to follow or emulate in order to reach better health outcomes and life-related achievements.

> *" I don't see people that live, that can go work, that are in good condition, that are taking care of themselves, that can progress especially us as immigrants" (ACBP03)*

> *"The services actually I would advocate for is try improve like people's lives through motivation like learning; go learn some more, don't stop thinking that life is gone, number two" (ACBP12)*

Lastly, there was also the belief that in order to address the issues of ACB living with HIV/AIDS the solutions needed to come from them. A bottom-up approach that takes into account PHAs from the ACB community realities, impressions on plausible solutions as well as their involvement in the final decision-making.

> *"We need to give the power to the people, the community (ACB), because no one knows best then the people" (ACBP04)*

Chapter 4: Discussion

Summary of findings

The present study was a first attempt to gain further understanding on the current situation of HIV/AIDS in people of African and Caribbean descent in the Ottawa area. First, this was examined by conducting a descriptive analysis. Patterns of risk factors, exposure categories, and diagnosis rates were described in people of African and Caribbean descent of Black ethnicity (ACB) and people of other ethnicities (non-Black) originating from different countries other than Africa and the Caribbean (non-African non-Caribbean, non-ACB). Second, this was explored by carrying out qualitative interviews with members from ACB communities. Knowledge, attitudes and behaviours around HIV were examined with individuals with a negative or unknown HIV status. Coping strategies, health seeking behaviours, and health care utilization were inquired with individuals that had a positive HIV status. By doing so, each stage of this study contributed to provide a more elaborate picture of certain sexual attitudes and behaviours complimented by the specific cultural values of the ACB group.

The major quantitative findings of this study show that in the Ottawa region from 2005-2010, the diagnosis rates of HIV diagnosis are highest in people of Black ethnicity and from Africa and the Caribbean (ACB) compared to other ethnicities and originating from other regions than Africa and the Caribbean (non-ACB). Furthermore, gender-specific HIV rates were higher among Black females from Africa and the Caribbean than non-ACB. HIV diagnosis rates were also highest for Blacks from Africa in comparison to Blacks from the Caribbean. Among immigrants to Canada, the five countries representing the highest proportion of HIV detection rates included: Burundi, Congo, Ethiopia, Haiti, and Rwanda. The Heterosexual-endemic exposure category was highest among ACB individuals with a positive HIV diagnosis, and it is even more likely to be found in the ACB group compared to non-ACB group. The risk factors most reported in the ACB group were having a sexual partner from an HIV-endemic country and not using a condom during sexual intercourse. Immigrant screening was the most common listed reason for receiving

an HIV test that led to an HIV diagnosis for the ACB group and more likely reason compared to the non-ACB group. Interestingly, when looking at the most likely mode of transmission of HIV, ACB reported MSM as an exposure less than non-ACB but having a partner from an HIV endemic country was more reported.

It would have been preferable to estimate the incidence and prevalence rates of HIV in the ACB population, but there were numerous challenges with determining these estimates with the available data. Not being able to confirm when the members of the ACB group had their previous HIV negative test result made it difficult to determine when they actually become a new case. The additional difficulty was the ascertainment of cases where the ACB group screening process was mostly compulsory whereas non ACB group testing was mostly personally driven. This introduced a systematic bias between both groups and hence made it harder to quantitatively describe these groups using prevalence or incidence. As described in the next section, the negative connotation associated with HIV in the ACB group also has been shown to deter the group from HIV prevention measures such HIV testing. Hence, leading to an underestimate of the true number of HIV cases detected in this group and indicative of the need for better outreach-related activities to increase HIV testing.

Nonetheless, these quantitative findings do corroborate with Ottawa estimated proportions and modelled incidence rates of HIV diagnoses in Black persons from HIV-endemic countries demonstrated by Remis et al (45). National and provincial also parallel the information presented as an eminent concern in ACB populations, the increasing trend of HIV/AIDS in Black ACB women, and continued need to address HIV vulnerabilities specific to the ACB in Canada (7,32,45).

In this study, the Black men and women of African and Caribbean descent, either living with HIV or not, identified a number of social and structural factors that can impact HIV prevention efforts and inform current HIV-related services and programs for PHAs provided in Ottawa. The major crosscutting topics that emerged among the groups of participants included:

- HIV-related stigma and discrimination is a major issue in the ACB community

- Exacerbating effect of HIV on ACB population living in Canada
- Requisites for programs and HIV-related services addressed to people of Black ethnicity born in Africa or the Caribbean

HIV-related stigma and discrimination is a major issue in the ACB community

Both groups of participants acknowledged the strong presence and debilitating effect of HIV-related stigma and discrimination lived by ACB community members. Stigma has been described as "a multi-dimensional concept of which the essence focuses on deviance from an accepted standard or convention" (97). Stigmatization is a process reinforced by a particular cultural setting, power relations (113), and fuels on social inequalities already present (114). These cultural viewpoints may be rooted from perceptions of the media, cultural beliefs or institutions; regardless of their origin these perception don't solely depend on ignorant attitudes or lack of clear information. As such, individuals "labelled" with a stigmatizing feature are unfortunately subjected to the judgment of others, which can lead the individuals to internalizing negative responses of others (self-stigmatization) and/or being directly marginalized by others. HIV/AIDS definitely poses this stigmatizing nature and it is accentuated in people from high HIV prevalent countries (as those represented in this study) due to their experience with the disease. Various negative connotations have been associated with HIV. As such stigmatization often leads to discrimination. This is where a distinction is made on someone being treated unfairly and unjustly on the basis of belonging or being perceived to belong to a particular group (108). Participants of the general ACB group spoke of living with the preeminent impression of others that Blacks are intrinsically associated with HIV/AIDS (in relation to its speculated source), Blacks as sexualized people, and Blacks "bringing in" the problem of HIV/AIDS to Canada; that is regardless of their efforts to set themselves aside from those images. A qualitative study of African and Caribbean communities in Toronto (2003) (82) also revealed that many of their participants living with HIV felt they were consistently fighting widespread stereotypes without an appropriate assessment of the real

issues. Additionally, since they attribute great importance of self-image and community acceptance, many HIV positive participants felt the need to self-isolate themselves and avoid any possibility of disclosing their HIV status. Similar sentiments were expressed by the above focus group of African and Caribbean PHAs in the Toronto qualitative study (2003) (82).

As a matter of fact, PHAs of this study experienced discrimination since they were seen by some of their own brothers and sisters as undesirable members of the ACB community or even society. PHAs of the ACB community in this group felt set apart from the ACB community with the constant fear of being part of community gossip and experiencing rejection from the ACB community. As such, many live in secrecy for the most part by keeping their HIV status from their families, children, friends, and colleagues due to the damning effect of their HIV diagnosis. This was also provoked by the unbearable thought of their family members becoming aware of their HIV status, which would automatically assume the worse and cause them to worry for their wellbeing since they are bearing this alone in a foreign country. This is important to note, as research studies conducted in the US and the UK indicated that accessing care can be affected by stigma and act as a barriers for people living with HIV of African descent(102). Again in the qualitative study done in Toronto for PHAs of African and Caribbean descent, they indicated that stigma did add complexity to accessing services by PHAs (82). Anderson and colleagues (2004) (115) described in a qualitative study of African women in London, who preferred to avoid any contact with community services due to fear of their personal information being passed on. UNAIDS (2007) (116) further added that due to HIV-related stigma, people were less likely to come for HIV testing, disclose their HIV status to others, adopt HIV preventive behaviour, or access treatment, care and support. They believed the outcome of disclosing would be too great and they take the chance of losing everything. PHAs in the group of participants accorded a great importance in the level of confidentiality in services provided to them. They valued immensely this practice and often indicated the dissatisfaction of not having similar services back in their home country. It was evident that without the implementation of privacy and confidentiality regulations they would not participate in these services.

Of importance and well described by both groups of participants, is the preeminent unfavourable perception of men who have sex with men (MSM) of the ACB community and the related discriminative actions based on sexual identity. This could partly be based on Black men sexuality being perceived as hypermasculine, hyperheterosexual and aggressive(117). Therefore Black MSM would not fit this image of Black sexuality, as such not considered "Black" and for that reason be ostracised from the ACB community. The social injustices suffered by Blacks who self-identify as homosexual are described by Adams-skinner et al. (2010) (118) in the context of West-Indian MSM (MSM from the Caribbean). They indicate that the pre-migration experience of stigma and negativity against MSM in their own country of origin often forces them to migrate to countries more accepting of MSM. Accordingly, ACB community members are not stigmatized or discriminated against solely based on their HIV status but it often goes in accordance with what it connotes (negative images, origin, etc.) (108); Reinforcing social stereotypes and inequalities as well as leading to the depriving ACB community members of accessing much needed services and programs.

Exacerbating effect of HIV on ACB population living in Canada

With this said, both PHAs and those not living with HIV expressed that ACB community members are in a position where they have to withstand the struggles of being an immigrant in a new country, compounded with an HIV diagnosis that makes the acculturation experience seem even less achievable.

Challenges portrayed by participants depicted substandard living due to unemployment, low income, linguistic barriers, and inaccessibility to certain HIV-related support services. Therefore, the layered labels of being Black, foreign born and having an HIV diagnosis was considered by all a triple burden to carry. It was generally viewed by both groups of participants that the root problems from which stem these issues are institutional, systemic and cultural racism and discrimination. The participant's sentiment was that if racism was well embedded in society, that they would naturally experience differential outcomes from other ethnic counterparts, let it be employment, education or access to services. Socio-economic

inequality along racial lines has long been recorded by various surveys and reports in Canada(12,20,119). Conventional explanations usually base these disparities on recent immigration, lack of Canadian experience and differences in education attainment (20).

Counterarguments to the explanations emphasize the importance of racially motivated policies that have led to racial stratification of Canada's economy and a great proportion of racialized groups in a restricted range of job opportunities accompanied by low wages, skill levels and/or career prospects (4,20). Regrettably, systemic forms of racism are well recognized in Canadian society (88,120,121) and thus limit opportunities around education, employment, housing and civic participation (7,20).

Given what has been described, adding a diagnosis of HIV/AIDS is viewed as causing more undue stress and further marginalization.

Requisites for programs and HIV-related services addressed to people of Black ethnicity born in Africa or the Caribbean

When it came to health care services, participants used them diligently. PHAs in this group especially were extremely grateful of the services. They also expressed their satisfaction with all health care professionals and the appreciation of their knowledge and expertise. However, HIV-related services that are non-health were considered lacking and disconnected from other HIV-related services and programs. These pertained mainly to deficient information on the immigration process, employment and financial support, and in the French language. This led to the conclusion that ethno-specific services are not sufficiently offered and available to respond to the current needs. As much as the current support group for African and Caribbean members of Ottawa living with HIV is appreciated for its activities at the AIDS Committee of Ottawa, the lack of funding, resources, program planning and political support have been identified as the culprits for insufficient progress for the ACB community regarding HIV/AIDS in Ottawa.

Regardless of the overwhelming difficulties, PHAs in this study showed a great amount of resilience and resourcefulness. This group found it essential to rely

on their surrounding support systems to bear the burden of having HIV/AIDS. With time, PHAS avoided isolation at all cost and utilized family members, children and health care personnel as a source of encouragement. In addition, they saw the importance of changing their way of thinking in order to move forward and not let their HIV diagnosis pull them down. Adopting a positive and more productive mindset was identified as a key transition to start accepting the disease. Reliance on various religious faiths was also prevalent and described as a source of strength and great meaning to most. ACB community members not living with HIV anticipated the need to having these various supports that were culturally appropriate and stressed how important they need to be acknowledged in services and programs offered to PHAs from the ACB community.

Contribution to Ottawa Public Health Programming

This mixed methods study highlights various needs that can be factored in public health programming at OPH as well as local initiatives working to reduce HIV transmission in the Ottawa community among high-risk groups and bring awareness to the issues among Blacks of African and Caribbean descent relating to HIV/AIDS. The striking issues emerged from the analysis merits to be considered when collecting ethno-specific data or offering targeted programs. These activities were reviewed bearing in mind the findings of this study for how data is collected on this subgroup of the population, what indicators might be missing to better understand the data, how we can best collaborate with other stakeholders in the community and how to ameliorate present HIV-related programs and services.

Data collection on ethnic specific groups and HIV

In Canada, many authors have remarked on the lack of Canadian data regarding health in various racial and ethnic groups (26,122,123). If it is collected it's been criticized to confound the concepts of race and cultural identity (88). The issue is when racial groups are used when it is ethnic and cultural groups patterns that ought to be examined (87,124). Race identification relates to physical or biological traits features such as skin colour, without taking into account the sociocultural similarities within groups (125). In the context of HIV in ACB

populations, the use of race to define racial groups to provide understanding on risk factors for a communicable disease such as HIV does not allow to make any assumptions on behaviours, attitudes or even decision-making processes involved in sexual practices for people of African or Caribbean descent(1,126). This is also the case for visible minority groups as they include a wide range of heterogeneous groups (88). It therefore muddles classifications such as race, ethnicity and nationality (88). On the other hand, ethnicity could be considered more appropriate. It has been defined as a self-chosen category that reflects ancestry, culture, religion, language and geographic location relevant to a particular time (87,88). If specific ethnic groups are applied they refer to the sociocultural influences with the context of their nationality rather than on physical characteristics (1). It also encapsulates behavioural, cultural, and environmental factors that increase the risk of disease (124). Using ethnicity provides an alternative that is removed from the historical discredit of slavery, and other historical events focused on phenotypical differences. Currently, race/ethnicity data is not collected province-wide therefore is not entered into iPHIS (see section on Data sources p.36). OPH is part of several health units in Ontario to collect independently this information (personal communication). Race/ethnicity data are recorded on two forms: HIV/AIDS STI Intake Form and the HIV Surveillance form present in every client chart (See Appendix #2). At the time of this study, for any analysis to be done using these variables, information must be taken from client charts and client-specific race/ethnicity then added into individual-level data. Considering the above information there are some issues highlighted here with some suggested solutions.

Table 4-1 Issues with data collection on ethnic groups at Ottawa Public Health

Issues	Suggested solution
• The ethnicity variable on the HIV/AIDS STI Intake form and the HIV Surveillance form is actually defined and grouped according to visible minority definition of Statistics Canada[50]	• Study and review concepts of race and ethnicity and prioritize issues in relation to public health surveillance, programs, and research (125,127)
• Data collected are based on observer-derived measures	• Ethnic group attribution should rely on the self-identification with various and relevant options (124,127)
• Racial/Ethnic groupings are too broad, which masks the heterogeneity in each group regarding history, culture, language, etc.	• Analyze subgroups within the ethnic groups to improve it's specificity (87,124,125,127)
• Data is restricted to only visible minority categories i.e. Black	• For more precision and applicability, suitable prefix to describe ethnic groups for the ACB populations are African or Caribbean + country in question for more specific subpopulation (e.g. African Kenyan, African American) (124)

Challenges anticipated in colleting ethnicity data can touch on issues regarding feasibility of data collection (e.g. cost-related, lack of incentive to collect data, etc.), and the validity or generalizability of the data (e.g. cultural differences within an ethnic group; unawareness of their own ancestry; mixed ethnicity, etc.). Acknowledging these difficulties, the attempt to collect epidemiologic data on risk factors and HIV by race and ethnicity is worthwhile if it means better formulating prevention programs targeted at specific groups.

[50] Visible Minority and Population Group Reference Guide: http://www12.statcan.gc.ca/nhs-enm/2011/ref/guides/99-010-x/99-010-x2011009-eng.pdf ; Ethnic Origin Reference Guide: http://www12.statcan.gc.ca/nhs-enm/2011/ref/guides/99-010-x/99-010-x2011006-eng.pdf

Provided ethnicity is used to analyze data concerning HIV in the ACB population, it is important to consider other indicators that will bring other dimensions and more specificity to the data collected. Many variables have been discussed in the literature. Those relevant to the ACB population that are not currently used at OPH or lack completeness are discussed herein (Table 4-2). Acculturation is a construct that is measured using various proxy factors in order to investigate the process of integration of a newcomer. The underlying assumption is the longer one resides in a new country, the more exposure there is to the dominant culture and the more they can adapt to the sociocultural environment. These proxies can include: age at arrival, length of stay since immigration, and citizenship status. Age at arrival is considered an important proxy as the younger the children arrive to Canada and are raised in its social system, the more culturally and behaviourally similar they might be to the Canadian born(128). Length of stay since immigration considering year of arrival, are factors that can give light to the effect of different arrival periods to Canada(129). Citizenship status can be an indicator on the level on integration to the various challenges of accessing services expected for different immigrant categories in Canada(25,130,131). Birthplace is an important indicator to be considered as is helps to capture the differences found in broad ethnic group categories relating to cultural attitudes to health behaviour and even health care use(125,129). Lastly, adding generational status is a great way to capture the differences present between second or third generation parents or grandparents, acknowledging the divergence of culture, and migration history (124).

Table 4-2. Some additional useful indicators when collecting data on ethnicity

• Age at arrival • Length of stay since immigration • Citizenship status • Birthplace • Generation status

Additional risk factors that could be considered with ACB clients have been raised during the analysis of qualitative results. They referred to experiences of rape

and concurrent sexual partnerships. Every experience of rape described by participants in this study, made reference to abuses or sexual violence that have occurred against women migrating from war-torn countries. As Canada maintains its humanitarian objectives, it will continue to welcome women refugees from countries where high HIV rates exist and for which mass displacements and conflicts is a daily reality(9). Casual partnering and "functional polygyny" have been described previously in the background section and shown to be important risk factors in ACB populations for acquiring HIV(55,66,75). That said, when referring to clients about the history of multiple sexual partners, the context and overlapping of sexual partnerships in time are aspects to be considered.

HIV health promotion and disease prevention in ACB populations

Empower communities

In order to engage ACB populations and be successful in empowering theses communities, it is best to focus on outreach activities. In this study and in the literature it is clear that reaching out to these communities requires establishing a trusting relationship to base any HIV prevention effort(132).

As such, the involvement of community leaders to raise awareness on ACB/HIV related issues and emphasized the inclusion of faith-based organizations (FBO). FBOs are known to influence knowledge, attitudes and beliefs about health and have conducted many HIV prevention activities (16,133). As the implication of FBO is slowly getting traction in the Canadian setting (e.g. Rhema Christian Ministries[51]), it would be beneficial to explore the experience of US FBOs as well as refer to frameworks that have already been developed(68)).

Members of the African, Caribbean and Black communities could be described as group oriented, as well as dependent on family support and friends as their social support network. They also consider their involvement in relationships as part of their identity(1). For this reason, communal activities are well appreciated by these groups and could be an interesting option for HIV/AIDS preventive activities.

[51] Retrieved from http://www.rhemaonline.ca/index.asp

Where the entire ACB community can benefit from outreach activities, participants urged for targeting youth, women and men of the community. More targeted approaches is also viewed as invaluable in other sources(134) to effective prevention actions such as health education. Vulnerabilities identified for youth in ACB communities were age-appropriate education on HIV-specific sex and relationship topics. Omorodion et al. (2007) (56) conducted an explanatory study of the sexual behaviours of African youth aged 18-25years, which also uncovered their level of discomfort in talking about sex to their health care providers or their parents. They preferred to have these conversations with their peers or siblings of the same age to avoid any judgment or reprisal. The issue of pop culture and gender norms were also described by participants and indicated by ICAD/ACCHO (2010) (135) as important topics to be included when tailoring health promotion activities. ACB men and women were claimed to have scarce discussions especially regarding sex-related issues and addressing relationship dynamics. Reasons for insufficient discussions were related to various views on sexuality varying by learned values, cultural backgrounds, and influences of religion. Again, these are important topics that ought to be included in opportunities for learning designed to improve health information on HIV(76,105).

Healthy Environments

To change community perceptions about HIV/AIDS in the ACB community significant effort must be put on addressing the stigma and discrimination present in these communities(133). With that, barriers to promoting HIV preventive services can be more easily alleviated and PHAs in the ACB community can feel more welcomed and integrated in the community. As alluded to previously, community leaders and representatives can play a major role in leading the way to normalizing HIV like any other disease. Having PHAs from the ACB community as community spokespersons is also viewed as beneficial to help normalize HIV/AIDS within the ACB community(136). Meaningful involvement of PHAs could provide that leadership needed in advocacy-related initiatives that pertain to the context of ACB community members.

Collaboration

Facilitating and strengthening collaborative efforts between various services can only be beneficial to ACB community members and is aligned with the desired outcome of decreasing HIV infection in this community. Public health can expand their reach of preventive services by building partnerships with settlement services, social services, and HIV-service providers. Recent Black immigrants of African and Caribbean descent as well as second generation and more ACB community members can often experience substandard living at least until they get established(130). However certain Blacks studies have shown, they never reach the same standard of living as the dominant population group(20). Certain immigrants don't necessarily achieve intended lifestyle goals but will forgo their expectations for the appreciation of the freedom and human rights they experience in Canada(130). As discussed previously, situations that may put ACB community members more vulnerable to HIV include: inaccessibility to sexual health services, precarious immigration status, unemployment and poverty(137) (See section on Vulnerabilities to HIV). Public health can be a key participant in creating essential networks linking the above-mentioned agencies/services, which in turn would allow improving the capacity of the community/service sector and help to facilitate the goal of increased awareness of ACB community members to the risk, protective and resilient factors to sexual health.

Enhancement of service delivery

The literature has shown that the appropriate provision of services to ACB populations depended on factors such as the health care provider's understanding of their culture (103,112). This can be accomplished by increasing cultural sensitivity or awareness among service providers, educators, and other professionals. Additionally, programs, services and supports offered to the ACB community can integrate the epidemiology of the disease among ACB communities along with information on cross-cultural relations, cultural differences, the health beliefs and behaviours around HIV(138,139). Participants also valued increasing the representativeness of Black people of African and Caribbean descent as front-line

workers and/or health care professionals. In that, they expressed that their cultural intricacies regarding HIV would be better understood.

Limitations of study

Due to limitations in the data of this study, the results must be interpreted with caution. The findings may not be representative of the true ACB population diagnosis rates of HIV in Ottawa for a number of reasons. The date of the diagnosis does not necessarily reflect the time of HIV infection. There may have been a delay of many years between the diagnosis and the infection. Furthermore, the magnitude of HIV infections in ACB populations might also be understated due to various patterns of HIV testing behaviour; hence those untested and undiagnosed cannot be accounted for. Likewise, anonymous HIV test results and POC testing results performed outside the SHC are not included in the HIV database, which again can lead to underestimated diagnosis rates of HIV in the ACB community. It also should be noted that cases that are diagnosed outside of Ottawa but are now residing in Ottawa are indeed prevalent cases but would be counted as incident cases. These would involve cases coming from out of province as well as from out of country. Additionally, for appropriate comparative analysis of the ACB group and the non ACB group, comparative statistical tests such as a Chi-square testing should have been used to establish if the distribution of variables being compared are independent of each other. Information on risk factors depended on self-reporting, however because of the negative connotations around HIV in this community, it is subject to social desirability bias and as a result underreporting of certain risk factors. This in turn can explain the results of the subgroup analysis for certain risk factors and exposure categories where there were small numbers and wide confidence intervals. In this study missing data was also an important issue. Incomplete data entry on data collection forms and unavailable information were major causes of missing data on ethnicity and country of birth. With 21% of ethnicity data and 17% of country of birth data unavailable for analysis, the results would undoubtedly be affected and must be considered in its interpretation. An additional limitation was basing the denominator on 2006 Census data to calculate

estimates for 2005 to 2010. As we are dealing with an unfixed population, the incident estimates are most likely underestimated as the Ottawa population has increased[52], and projections of the diversity in Ontario's CMAs is also expected to continue to increase(140).

In spite of some challenges, this study does provide an initial look at the HIV diagnosis rates in the Black African and Caribbean community members residing in Ottawa. It also gives an opening to understand the cultural context of HIV in the ACB communities. Further elaboration could be possible on topics such as public health messaging for the ACB and advocacy regarding issues pertaining to the their vulnerabilities to HIV infection. The resulting study findings do give an opportunity for OPH to reflect on its approach of targeted HIV prevention programming in a way that encourages exploration of other strategic avenues for the ACB population, further collaboration with ACB communities and more research on questions that remain unanswered to better address HIV/AIDS in the ACB community in Ottawa.

[52] 2011 Ottawa Census Profile

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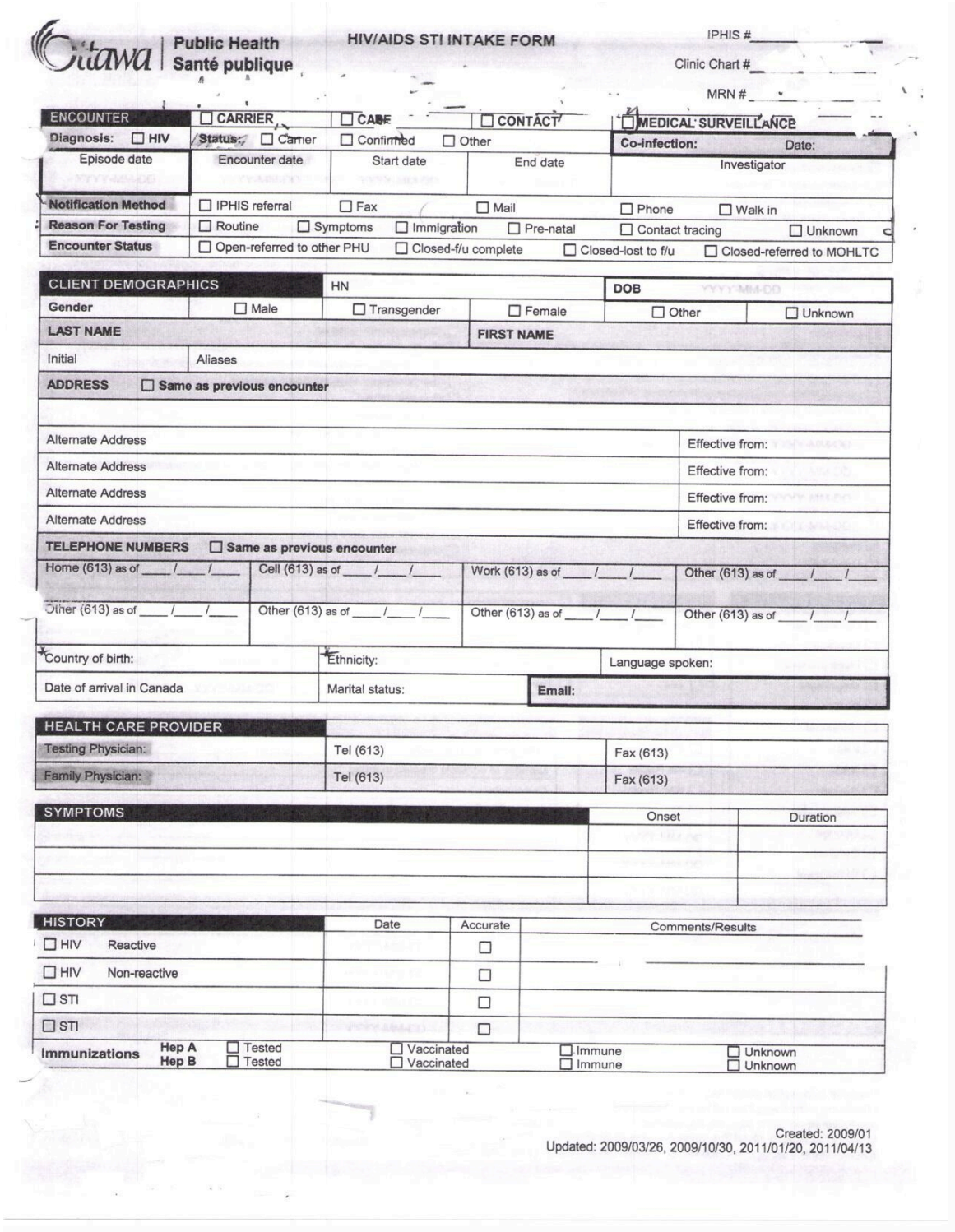
APPENDIX 1: List of HIV Endemic Countries

Africa	**Caribbean, Bermuda and Central/South America**	**Asia**
Angola Benin Botswana Burkina Faso Burundi Cameroon Cape Verde Central African Republic Chad Democratic Republic of Congo (formerly Zaïre) Djibouti Equatorial Guinea Eritrea Ethiopia Gabon Gambia Ghana Guinea Guinea-Bissau Ivory Coast Kenya Lesotho Liberia Malawi Mali Mozambique Namibia Niger Nigeria Republic of the Congo Rwanda Senegal Sierra Leone Somalia South Africa Sudan Swaziland Tanzania Togo Uganda Zambia Zimbabwe	Anguilla Antigua and Barbuda Bahamas Barbados Bermuda British Virgin Islands Cayman Islands Dominica Dominican Republic French Guiana Grenada Guadeloupe Guyana Haiti Honduras Jamaica Martinique Montserrat Netherland Antilles St. Lucia St. Kitts and Nevis St. Vincent and the Grenadines Suriname Trinidad and Tobago Turks and Caicos Islands U.S. Virgin Islands	Cambodia Myanmar/Burma Thailand

Source: PHAC 2012(32)

APPENDIX 2: HIV/AIDS STI Intake Form and HIV Surveillance Form



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HIV/AIDS STI INTAKE FORM

IPHIS #_____

Clinic Chart #_____

MRN #_____

ENCOUNTER	☐ CARRIER	☐ CASE	☐ CONTACT	☐ MEDICAL SURVEILLANCE
Diagnosis: ☐ HIV	Status: ☐ Carrier ☐ Confirmed ☐ Other			Co-infection: Date:
Episode date	Encounter date	Start date	End date	Investigator
Notification Method	☐ IPHIS referral	☐ Fax	☐ Mail	☐ Phone ☐ Walk in
Reason For Testing	☐ Routine ☐ Symptoms	☐ Immigration	☐ Pre-natal	☐ Contact tracing ☐ Unknown
Encounter Status	☐ Open-referred to other PHU	☐ Closed-f/u complete	☐ Closed-lost to f/u	☐ Closed-referred to MOHLTC

CLIENT DEMOGRAPHICS	HN		DOB	
Gender	☐ Male	☐ Transgender	☐ Female	☐ Other ☐ Unknown
LAST NAME		FIRST NAME		
Initial	Aliases			
ADDRESS ☐ Same as previous encounter				
Alternate Address				Effective from:
Alternate Address				Effective from:
Alternate Address				Effective from:
Alternate Address				Effective from:
TELEPHONE NUMBERS ☐ Same as previous encounter				
Home (613) as of ____/____/____	Cell (613) as of ____/____/____	Work (613) as of ____/____/____	Other (613) as of ____/____/____	
Other (613) as of ____/____/____	Other (613) as of ____/____/____	Other (613) as of ____/____/____	Other (613) as of ____/____/____	
Country of birth:	Ethnicity:		Language spoken:	
Date of arrival in Canada	Marital status:		Email:	

HEALTH CARE PROVIDER		
Testing Physician:	Tel (613)	Fax (613)
Family Physician:	Tel (613)	Fax (613)

SYMPTOMS	Onset	Duration

HISTORY	Date	Accurate	Comments/Results
☐ HIV Reactive		☐	
☐ HIV Non-reactive		☐	
☐ STI		☐	
☐ STI		☐	

Immunizations					
	Hep A	☐ Tested	☐ Vaccinated	☐ Immune	☐ Unknown
	Hep B	☐ Tested	☐ Vaccinated	☐ Immune	☐ Unknown

Created: 2009/01

Updated: 2009/03/26, 2009/10/30, 2011/01/20, 2011/04/13

HIV SURVEILLANCE FORM

Ottawa | Public Health / Santé publique

Please complete form and return to:
Ottawa Public Health C/O Michèle Gauthier RN, PHN
179 Clarence St Ottawa ON K1N 5P7
Tel: 613-580-6744 ext.22528
Fax: 613-580-2831

Reference Number: _____

Client Information

Last Name: _____ Health Number: _____ DOB: _____

First name: _____ Country of Birth: _____

Gender: _____ Marital Status: _____ Date of arrival in Canada: _____

Address: _____ Address Effective From: _____

Tel: _____ Language spoken with client: ❑ English ❑ French ❑ other _____

Stage of Infection

❑ HIV ❑ AIDS Specify AIDS defining illness and date of onset: _____

Symptoms: _____ Duration: _____

_____ Duration: _____

HIV Testing History

Reason for current HIV test: _____

Previous Reactive Result: ❑ NO ❑ YES Date: _____ City: _____

Previous Non-Reactive Result: ❑ NO ❑ YES Date: _____ City: _____

Client Risk Factor(s) (please ✓ all applicable risks)

Exposure Setting
- ❑ Accidental
- ❑ Bath house
- ❑ Homeless
- ❑ Country where hetero HIV transmission predominates
- ❑ Non medical non occupational exposure (piercing/tattoos)
- ❑ Occupational exposure to body fluids
- ❑ Travel outside province (specify):

Medical Risk Factors
- ❑ Genital ulcers
- ❑ Infant born to case or carrier
- ❑ Received blood/blood products
- ❑ Received organ, tissue, donor insemination
- ❑ Pregnant

Other (specify):

Behavioural Social Factors
- ❑ Condom breakage
- ❑ Judgment impaired by alcohol/drugs
- ❑ Met partner through internet
- ❑ Multiple sex partners in last 6 months
- ❑ No condom used
- ❑ New partner in last 2 months
- ❑ Partner bisexual
- ❑ Partner from country where hetero HIV predominates (specify):
- ❑ Partner is HIV +
- ❑ Partner is homosexual
- ❑ Partner with multiple sex partners
- ❑ Partner received blood/blood products
- ❑ Partner shares needles/drug equipment
- ❑ Partner from outside of province (specify):
- ❑ Sex for drugs
- ❑ Shared needles/drug equipment
- ❑ Shared sex toys
- ❑ Sex trade worker
- ❑ Sex with opposite sex
- ❑ Sex with same sex
- ❑ Sex with sex trade worker

Recipient / Donation History ❑ NO ❑ YES

Recipient of: ❑ blood/blood product ❑ organ ❑ tissue ❑ semen ❑ ova

Donation of (since January 1978): ❑ blood ❑ organ ❑ tissue ❑ semen ❑ ova ❑ breast milk

Date: YYYY-MM-DD City and/or Hospital: _____ Name of Attending Physician: _____

Canadian Blood Services to be Notified by: ❑ Physician ❑ Public Health ❑ N/A

Updated: 2010-01-27; 2010-02-03, 2010-02-26

Ottawa Public Health / Santé publique Ottawa
179 Clarence Street / 179, rue Clarence
Ottawa, Ontario K1N 5P7

613-580-6744 | TTY / ATS : 613-580-9656
toll free / sans frais : 1-866-426-8885
ottawa.ca/health | ottawa.ca/sante

APPENDIX 3: LAByrinth computer system exposure categories

Exposure according to LAByrinth	*Explanation*
MSM	Men who report having sex with same sex or who are bisexual
IDU	Case reports illicit drug use
MSM/IDU	Men who report having sex with same sex (or bisexual) + report using illicit drugs
Clotting factor	Clotting factor recipient
Blood and blood product	Blood product recipient
HIV-endemic	Case reports coming from country where HIV is endemic
Transfusion	Transfusion recipient
Occupational	Cases reports an occupational exposure (i.e. needle-stick injury)
Perinatal	Perinatal transmission
Low risk heterosexual	Case reports a heterosexual partner with no infectious disease risk
High risk heterosexual	Case reports a heterosexual partner with infectious disease risk
No identified risk	No identified risk
Unknown	Unknown exposure

Source: http://www.ohemu.utoronto.ca/tech%20reports.html