

Barriers, Access, Resources, and Knowledge (B.A.R.K.): An Analysis of HIV  
Testing vis Women's Voices in Ottawa

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## ABSTRACT

Women within African, Caribbean, and Black (ACB) communities are experiencing a higher burden of the HIV epidemic than other groups of women in Canada and a low uptake of HIV testing and counseling. As HIV testing is a well recognized HIV prevention strategy, increasing HIV testing within those most affected by HIV in Canada is a high priority. Therefore, this study gathers and describes the perceptions, experiences, and knowledge of HIV and HIV testing and counseling among women within ACB communities in Ottawa. These perceptions and experiences provide rich context to current barriers to HIV testing and counseling access among these groups of women; context that is utilized to ground recommendations to improve experiences of HIV testing and counseling and to increase the uptake of HIV testing and counseling among ACB women. In essence, this study provides recommendations *by* ACB women *for* ACB Women.

## **PART ONE: INTRODUCTION**

## CHAPTER ONE: SOCIAL EPIDEMIOLOGY OF HIV IN CANADA

*“Epidemiology is the study of the distribution and determinants of health-related states or events in specified populations, and the application of this study to the control of health problems”*-Center for Disease Control- Centers for Disease Control<sup>1</sup> (*emphasis mine*)

### Epidemiology, Social Epidemiology and HIV

As stated above, a common definition of epidemiology<sup>1</sup> is two-fold: 1) "study of the distribution and determinants of health-related states or events in specified populations" and 2) "application of this study to the control of health problems."<sup>1</sup> This definition illustrates the breadth of the undertaking of epidemiology- it is a discipline that attempts to both define the parameters of a health state or disease and then help to reduce the burden of that disease/health state within the populace. When creating parameters of surveillance, epidemiology provides the underlying structures that define the "specified populations"<sup>1</sup> through meaningful categorization of data that are then used to structure response, or prevention efforts, towards the "control of health problems"<sup>1</sup>. Therefore, as categories directly affect response, or "control of health problems", it is important that critical reflection of the creation or construction of these categories be maintained.

In perhaps no other disease is the need for critical reflection on disease parameters and corresponding prevention efforts more necessary than in the study of the Human Immunodeficiency Virus (HIV). Early investigation into the virus focused on individual characteristics and behaviors in determining HIV risk and in doing so reduced the epidemic into "biological individualism" where there existed little understanding of the ways in which social, or structural factors impacted individual behaviors. Instead, focus was placed on the individual behaviors themselves (such as sharing needles and participating in condom-less sex and/or having multiple partners). These behaviors were then labeled "risk behaviors".<sup>2</sup> Few analyses were dedicated to contextual social factors and if social factors were included, they were most often adjusted for as potential confounders or proxies for unavailable individual-level data.<sup>2</sup> While this approach continues to be widely used and is perhaps the most well known model for many epidemiological investigations, in the case of HIV or other non-uniform infectious disease

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<sup>1</sup> This definition is also used by the World Health Organization (WHO): "Epidemiology is the study of the distribution and determinants of health-related states or events (including disease), and the application of this study to the control of diseases and other health problems."<sup>102</sup>

patterns that emerge as a result of the dependent nature of disease transmission, or where the outcome in one person is dependent on the outcomes or experiences of others, an approach focusing on the individual is not ideal.<sup>2</sup>

One approach towards disease investigation that not only takes social factors into account, but also maintains society as its focal point is social epidemiology. This particular branch of epidemiological investigation does not have a clear, definitive methodology. However, it defines itself as: “the study of the distribution of health outcomes and their social determinants. It builds on the classic epidemiological triangle of host, agent, and environment to focus explicitly on the role of social determinants in infectious disease transmission and progression.”<sup>2</sup> In other words, instead of foregrounding the individual factors as the loci of investigation, social epidemiology privileges societal factors as its focus.

While social epidemiology privileges societal factors in analyses and attempts to examine interactions of socially created structural systems in producing and maintaining risk environments, it does not currently include the socially created structure of epidemiological investigation itself and its possible effects on prevention efforts for transmission and progression of diseases within its focus of analysis. For example, epidemiology groups data in different ways for different reasons (ideally in a way that is meaningful to populations to which they serve), and is therefore not exempt from social influence. Further, the discipline of epidemiology is socio-historically located and as such, could be interacting with other social structures and factors to impact disease response and categorization- especially concerning diseases reliant on social structures for transmission, such as HIV. Therefore, although there is now much research on the contribution of social structure to environments of risk, risk behaviors, and prevention efforts, there is less discourse on the effect of epidemiology as a social structure and its effects on prevention efforts. Therefore, while this study grounds itself within social epidemiology, it maintains a critical lens of epidemiology as situated within social and power structures and how these social and power structures may be affecting prevention discourse of HIV.

### **HIV Surveillance in Canada**

Federal epidemiological surveillance of the HIV epidemic within Canada categorizes the epidemic by exposure categories. The current system of surveillance assigns one exposure category to each case of diagnosed HIV based on a hierarchy of risk factors; if more than one risk factor is reported, the case of HIV in question is classified according to the highest risk

category. These risk factors are identified by the health care provider that undertook the test and as such, are dependent upon the questions asked by the health care provider as well as the information the diagnosed individual chooses to disclose at the time of the test.<sup>3</sup> Currently these hierarchical categories in Canada are: men who have sex with men (MSM); men who have sex with men and who participate in injection drug use (MSM-IDU)<sup>ii</sup>; people who participate in injection drug use (IDU); heterosexual non-endemic; heterosexual endemic; and others (see Table 1).<sup>3</sup> The surveillance reports for the most recent estimates of new HIV infections (for 2014) in Canada further grouped surveillance data by sex (male and female) and ethnicity/origin, which was defined as either aboriginal or non-aboriginal.<sup>3</sup>

**Table 1:** HIV exposure categories used for HIV case surveillance.<sup>3</sup>

<b>Exposure category classification</b>	<b>Type of exposure</b>
Men who have had sex with men (MSM)	During male-to-male sex
Injection drug use (IDU)	During use of injection drugs
MSM-IDU	During either male-to-male sex and/or the use of injection drugs - used in instances where both exposures were reported for one person
Heterosexual/endemic	Exposure during heterosexual sex and born in a country where HIV is endemic*
Heterosexual/non-endemic	Exposure during heterosexual sex and born in Canada or in a country not on the HIV-endemic list
Other	Exposure attributed to receipt of transfusion of blood or clotting factor, perinatal exposure, or occupational exposure

Adapted from PHAC, 2015.

<sup>ii</sup> This is the only category in which two exposure categories are applied to one diagnosis, as the risks of each of these categories are conserved to be more or less equivalent.<sup>3</sup>

These exposure categories are created and applied to monitor the HIV epidemic in Canada as well as to inform prevention efforts.<sup>3</sup> Further, as transmission is largely dependent upon the current socio-historical context and social structures<sup>2</sup>, these categories are mutable. To this effect, the most recent surveillance report issued by the Public Health Agency of Canada (PHAC) explicitly states the uncertainty of the current exposure categories when it comments that the current exposure hierarchy would benefit from a review and that PHAC will be working with provincial and territorial experts to conduct this review of terms.<sup>3</sup> In other words, the surveillance data are grouped to describe the epidemic, yes; but they are also grouped to be meaningful for prevention efforts.

As surveillance data are subject to reporting delays, under-reporting, and changing patterns in HIV testing behaviors, data only describe the diagnosed portion of the epidemic within Canada, not prevalence or incidence<sup>3</sup>. Therefore, statistical modeling and other sources of information are currently used to estimate the state of the epidemic within Canada. Analysis of the HIV epidemic through application of exposure category reveals that the majority of estimated new infections by the end of 2014 occurred within the MSM exposure category (54%), followed by heterosexual non-endemic (19%), heterosexual endemic (14%), IDU (10%), MSM-IDU (3%) and finally other (less than a point estimate of 20 people)<sup>3</sup>. The epidemic is currently largely male, with 77% of all estimated new infections being among men and 23% of all estimated new infections in 2014 being among women<sup>3</sup>.

Prevalence estimates tell much of the same story (see Table 3), with close to the majority (49%) of those estimated to be living with HIV by the end of 2014 being exposed through the MSM category, followed by 16% exposed through heterosexual contact non-endemic, 15% through IDU, 15% through heterosexual contact endemic, and 0.8% through other means. Also, women continue to account for a smaller portion of the epidemic than men, with 22% of those estimated to be currently living with HIV being of female sex and 78% being of male sex.<sup>3</sup>

As the confidence intervals of absolute numbers of estimated new infections for 2014 and 2011 overlap<sup>iii</sup> (63,400-87,600 in 2014 compared to 57,600-80,000 in 2011),<sup>3</sup> there is no statistically demonstrable evidence of a reduction in estimated incidence. Similarly, a

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<sup>iii</sup> It should be noted that the method of prediction for the number of undiagnosed people relied upon updated data from earlier years with revised methods to adjust for under-reporting, reporting delay and duplicates, which was then applied retrospectively to the 2011 data, resulting in similar proportions of undiagnosed for both 2011 and 2014 (approximately 21%), thereby making any comparisons between the proportions impossible.<sup>3</sup>

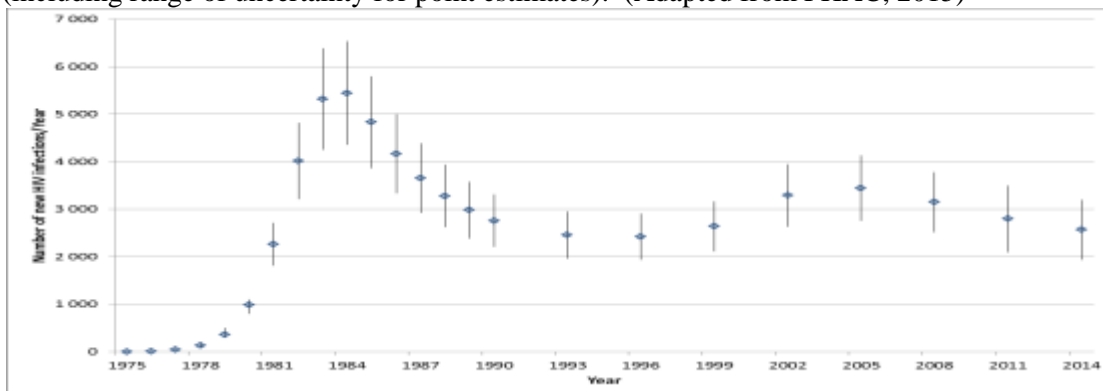
comparison of absolute numbers of estimated new infections for the years 2011 and 2014 among the category of women provided no statistically demonstrable evidence of a reduction in estimated incidence (13,800-20,000 in 2014 compared to 12,500-18,000 in 2011); the same is true of the exposure category heterosexual endemic (9,300-13,400 in 2014 compared to 8,400-12,000 in 2011).<sup>3,4,5</sup>

### Generalized Population Incidence and Prevalence of HIV in Canada

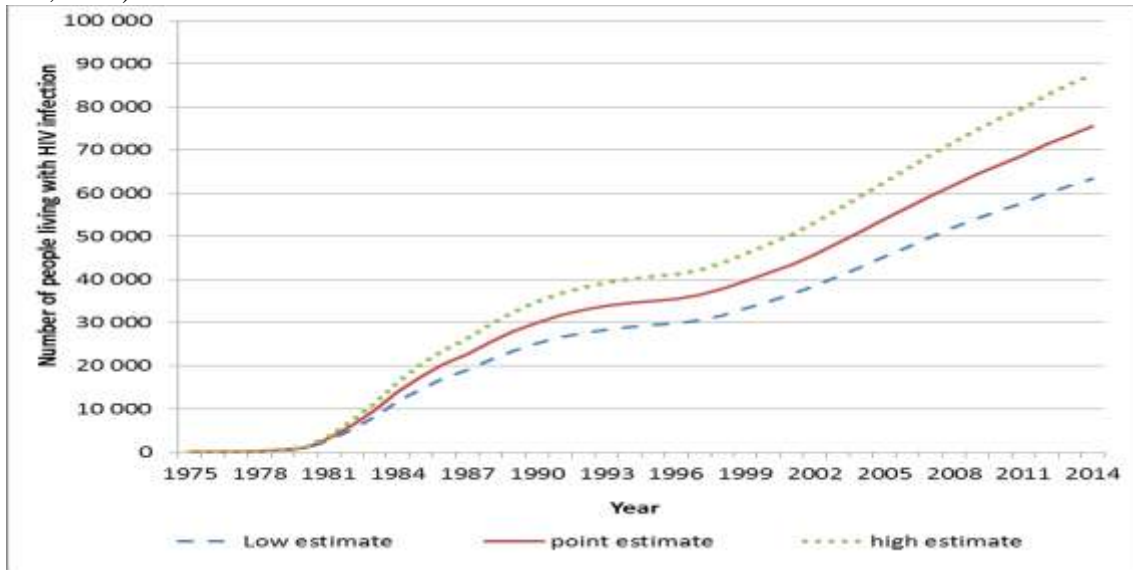
Based on most recent data, 2,570 new HIV infections were estimated to have occurred in 2014 (range between 1,940 and 3,200) with an incident rate of 7.2 per 100,000 Canadians (range between 5.5 and 9.0 per 100,000 population).<sup>3</sup> The prevalence (those currently living with the HIV) at the end of 2014 was estimated to be 75,500 people (range between 63,400 and 87,600), resulting in an estimated prevalence rate of 212 per 100,000 population (range between 178 and 246 per 100,000 people)<sup>3</sup>. Further, it is estimated that almost a quarter of those living with the disease are unaware that they have acquired the infection and remain undiagnosed and unlinked to care. The Public Health Agency of Canada (PHAC) estimates the total number of people undiagnosed to be around 16,020 with a range between 13,000 and 19,000 people and accounting for 21% of people living in Canada with HIV by the end of 2014<sup>3</sup>.

An examination of these rates over time seems to demonstrate a decline in estimated incidence (see Figure 1) with a rise in estimated prevalence (see Figure 2)<sup>3</sup>. However, when the range of uncertainty as well as number of point estimates are taken into account (see Figure 1), there does not appear to be enough data to demonstrate a statistically significant decline in HIV incidence in Canada since 2005, thereby making a declaration of declining incidence rates within the past ten years problematic.

**Figure 1:** HIV incidence: Estimated number of new HIV infections in Canada for selected years (including range of uncertainty for point estimates). (Adapted from PHAC, 2015)



**Figure 2:** HIV Prevalence: Estimated number of people living with HIV in Canada by year. (Adapted from PHAC, 2015)



However, there is a definitive trend towards increasing prevalence (see Figure 2). This increase is attributed to the availability of new HIV treatments reducing HIV mortality- as the incidence of infection has not depreciated significantly, and those who experience HIV now have access to better medications and are therefore living longer lives, the total number of people living with HIV in Canada has been increasing every year (see Figure 2).<sup>3</sup> Therefore, although mortality rates have declined, morbidity rates have risen and continue to grow in Canada resulting in a steady increase of Canadians living with the disease.

These rates demonstrate that Canada is not classified as an HIV endemic country by the World Health Organization and the UNAIDS's three category ranking system of HIV epidemics worldwide. However, these observations are only one part of the story of HIV in Canada. If one only takes the general incidence and prevalence rates of Canada into account and compares them to worldwide categorizations of the epidemic, one walks away with the impression that Canada is a "low level" epidemic or the lowest category of the World Health Organization and UNAIDS's three category ranking system of HIV epidemics worldwide. The rating system developed by these organizations defines "low level" as epidemics in which HIV prevalence does not exceed 5% within any population in the country, "concentrated" as epidemics in which a low level (<5%) of HIV prevalence exists within the general population but a consistent

prevalence of over 5% is occurring in at least one defined subpopulation, and pregnant women in urban areas experience low prevalence (<1%). The third category is “generalized” whereby HIV “is firmly established in the population” and although some groups may continue to disproportionately contribute to HIV, sexual networking in the general population sustains the epidemic independently of sub-populations.<sup>6</sup>

An exploration of the HIV epidemic among different populations within Canada reveals that acquisition of the disease is not equally distributed among all peoples within Canada. Some populations are experiencing a prevalence of almost 16%<sup>7</sup>, resulting in the Canadian epidemic classified within the middle category of “concentrated”.

To this effect, the most recent surveillance report of HIV within Canada issued by PHAC explains that one of the limitations of the current exposure category system is that it is not able to distinguish between at-risk populations<sup>iv</sup> (or key/priority populations) and risk behaviors<sup>3</sup>. This is a limitation because certain groups of people are more affected by the disease and as such, necessitate targeted prevention efforts. Those groups disproportionately affected are referred to as “priority populations” or “key populations” within research and are thusly named due their status as priorities for prevention programming. Within Canada and Ontario, key or priority populations are identified as: men who have sex with men (MSM), people who inject drugs (IDU), Aboriginal peoples, women, and African, Caribbean and Black communities<sup>8</sup>.

### **On the Term African, Caribbean, and Black**

For no other group of people disproportionately affected by HIV in Canada is there such a disparity of meaning in terms between federal epidemiological surveillance and prevention as the population federally identified through the exposure category of “HIV endemic”. Although it is recognized that heterosexual endemic is an exposure category and not a population, for prevention efforts, the people within this category are often referred to, and self categorized as, African, Caribbean, and Black (ACB). Although these terms are not completely synonymous, as the definition of surveillance category “HIV endemic” as some countries that may be defined as HIV endemic are not within Africa or Caribbean, they are often described and referenced as equivocal within both surveillance and prevention publications and strategies.

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<sup>iv</sup> Current experts advise a move away from risk terminology and instead advise use of the terms key populations, or priority populations instead of at-risk populations.<sup>103</sup>

The term African, Caribbean and Black was produced through a federally funded Task Force created by and comprised of Black coalitions, African community organizations, Caribbean community organizations, as well as provincial and/or university stakeholders united towards the common goal of reducing the HIV epidemic within and among these communities. The Task Force was formed in the early-mid 2000's and ultimately resulted in the creation of the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO)<sup>9</sup> which currently serves as the leading organization in Ontario for providing culturally sensitive and relevant recommendations, inter-provincial research, and inter-partner facilitations for ACB peoples.

ACCHO describes the move away from the term HIV endemic to the term ACB as a purposeful, carefully chosen and deliberate move. They specify that this move was decided upon for two main reasons. The first was to highlight the large cultural diversity of the communities contained within the singular term "HIV endemic"<sup>v</sup>, thereby facilitating discourse across socio-cultural lines within Canada by acknowledging differences and commonalities of purpose at the same time. Secondly, the use of the term Black was decided upon as a conscious effort to demonstrate the commonality of racialized experiences among these different peoples within Canada. This term was created to both elucidate the variability of cultures within the federally defined term of "HIV endemic" while simultaneously demonstrating a commonality of experience.<sup>9</sup> Further, these deliberations were conducted for the purposes of HIV prevention and awareness within ACB communities as well as Canada as a whole. Therefore, the term ACB is a distinctly, purposefully Canadian phenomenon that includes recent immigrants, people with African or Caribbean ancestry that have never lived outside of Canada, and people who have immigrated to Canada years ago. Essentially, this term was co-created by those identified as "HIV endemic" and HIV prevention specialists and stakeholders for the specific purpose of HIV prevention within Canada.

However, despite the recommendation of the Task Force over 10 years ago to use the term ACB in an effort to highlight the racialized experiences of those people within the endemic category, a publication concerning population specific surveillance information issued around eight years ago by PHAC states that the term "HIV endemic" within surveillance terminology is

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<sup>v</sup> There are currently 71 countries included within the HIV endemic exposure category. However, the list of HIV endemic countries is continually updated as the state of the epidemic changes within and among countries. Therefore, the number of countries as well as the actual countries included under the term HIV endemic are subject to change.

to be used as a measure to prevent racialization of ACB peoples<sup>10</sup>. So, despite the request of those most informed on prevention needs of their communities, those applying surveillance terms decided to use a term that removed the racialized component of experiences of ACB peoples in Canada.

Interestingly, another publication by PHAC in more recent years states that “It is important to differentiate between this epidemiological population definition and other intersecting definitions, such as populations/communities defined by race, ethnicity or immigration status.”<sup>11</sup> These two rationalizations are obviously in conflict: the former views the removal of race within terminologies as a means to prevent racialization while the latter claims to be completely removed from any social structures completely. In one, epidemiology is an authority on social structures and effects of racialization while in the other, epidemiology is completely removed of social constructs or structures.

Coincidentally, this distinction between epidemiology and “such populations/communities defined by race, ethnicity or immigration status” was not contested for the term Aboriginal<sup>vi</sup>, which is also a term covering populations/communities defined by race and/ or ethnicity and continues to be used for surveillance purposes. Further, it is worth noting that this distinction between an “epidemiologic term” and a “prevention term” may be actively working against HIV prevention, as the removal of the term Black removes space for discourse on racialization concerns of HIV criminalization within ACB communities in Ontario, a conversation that is potentially very important for HIV prevention.

Recent research demonstrates that Black men are over-represented in HIV criminalization court cases in Ontario since 2004<sup>12</sup> but whether their representation in court cases is in proportion to all HIV-positive heterosexual men has been described as difficult to determine due to the lack of ethnic or racial information within the data.<sup>12</sup> However, although the empirical data confirming racialization of HIV criminalization in Ontario currently remain unclear, recent research demonstrates that the prevalent sentiment within ACB communities is that this issue *is* racialized<sup>13</sup>. The perception that HIV criminalization is a racial issue has real impacts in ACB communities in Ontario as it promotes the propagation of an already high burden of stigma

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<sup>vi</sup> There is currently a move away from the term Aboriginal to Indigenous in reference to First Nations, Inuit, Metis and other indigenous peoples of North America.

associated with the disease leading to fear of being tested for HIV, resulting in very real implications for HIV prevention.<sup>13</sup>

Further, this distinction between the federal surveillance agency and prevention organizations impedes evidence based policy. It is very difficult to compare federal surveillance data with provincial data, as Ontario data often use the term ACB in their HIV prevention efforts and therefore surveillance data, but also randomly removes the term Black from their publications. For example, the manager of the AIDS and Hepatitis C Programs within the Ontario Ministry of Health and Long Term Care defines those groups most disproportionately affected by HIV within Ontario as: “gay and bisexual men, African and Caribbean Ontarians, people who use injection drugs, Aboriginal Peoples and women”<sup>14</sup> while simultaneously stating that “the HIV epidemic in Ontario is unstable and increasing in most affected populations: gay/bisexual men, African/Caribbean/Black Ontarians, people who use injection drugs, Aboriginal communities, and women at-risk”. He goes on to state that “African/Caribbean/Black communities in Ontario” experienced significant increases in HIV/AIDS and now represent 29% of new infections (based on data from 2009).<sup>15</sup> To further complicate comparisons, the AIDS Committee of Toronto states that “people from countries with high rates of HIV infection,” accounted for 21% of all new HIV diagnoses in Ontario in 2010<sup>16</sup>. These statistics are almost incomparable yet in prevention practice are often used interchangeably.

This confusion results in odd measures. For example, the Ontario HIV Testing guidelines contains a pre-test counseling checklist where the HIV tester is encouraged to ask the client “Have you had sex with someone from a country where HIV is endemic?” with the helpful prompt of “e.g. sub-Sahara Africa, the Caribbean” and a list in the back of the guide with all of the countries contained in the term endemic from October, 2007<sup>vii</sup> that includes countries from South America and Asia. I am dubious as to not only the necessity of these data, but also the quality. What exactly is the purpose of the distinction between ACB and HIV endemic? It does not seem to be facilitating epidemiological research or comparisons. In fact, this “necessary” distinction seems to be adding little to epidemiologic research, creating unnecessary confusion, and preventing important discourse concerning racialization of criminalization in Canada and its possible effects within ACB communities.

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<sup>vii</sup> As the list is continually updated, this list is most likely out of date.

Finally, although people came together from many different communities to create the term ACB over 10 years ago, immigration is a steady process and newer immigrants, or those not aware of HIV prevention programming in Canada, are not likely to group themselves in these categories. People are more likely to group themselves according to language and culture instead of HIV prevention efforts categories, thereby adding another layer of complexity to the terms ACB and HIV endemic for HIV prevention purposes. In addition to the importance of unification of the term ACB for prevention and surveillance purposes, it is also important to recognize that when one “goes out into the community” to prevent HIV they are not walking out into the “ACB” community. They are working with HIV prevention specialists that work with various communities and attempt to locate and connect different peoples to encourage HIV prevention efforts. In essence, although “people from endemic countries” or ACB is one category of analysis, it is not one category of people and may therefore necessitate a multitude of different approaches to reach all of the peoples that fall within this one “group”.

### **Women and HIV in Canada**

Further, gender systems interact with other social structures as well as the social determinants of health in complex ways that may be affecting HIV transmission dynamics and risk. Although women in Canada accounted for only 23% of all new infections in 2014, the proportion of positive HIV tests among women (where the sex is known) each year data were collected has jumped from women representing around 14% of all positive test reports between 1985-2001 to almost double that proportion by the period of 2001-2014, where women represented between 23-28% of all positive HIV test reports in 2014- thereby demonstrating no significant reduction of the proportion of women comprising the epidemic within the last decade.<sup>17,5</sup> Further, the category of “women” is one of the eight key populations identified in the “Federal Initiative to Address HIV/AIDS in Canada”<sup>5</sup> and one of the “five at-risk populations” as defined by the Ontario Ministry of Health and Long Term Care<sup>14,viii</sup>.

In addition, a 2011 report from PHAC demonstrated that women are receiving their first positive HIV test at a younger age than men<sup>5</sup>. Further to this point, women appear more likely to be diagnosed with HIV below the age of 40, while men appear more likely to be diagnosed with HIV from the ages of 40 and above<sup>5</sup>, thus demonstrating differential age of diagnosis between

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<sup>viii</sup> While Ontario states these populations as “at-risk” the AIDS Committee of Toronto recommends moving away from language of risk, as this implies that it is membership of a particular group that puts one at risk instead of a particular behavior or practice.<sup>103</sup>

men and women and therefore differential experiences of the disease. This difference in age is unlikely to be due to a significant difference between early and late diagnosis, as preliminary results from an ongoing study among People Living with HIV/AIDS (PLHAs) has demonstrated no statistically significant difference between the rates of late diagnosis among men as a general category and women as a general category in Canada<sup>18</sup>. This age differential may in part be due to prenatal testing, which has a demonstrated high uptake, with around 98% of pregnant women undergoing tests for HIV in 2010 within the province of Ontario.<sup>19</sup> However, as there is no statistically significant lack of early and late diagnosis among men and women, these data may also simply demonstrate that women are acquiring HIV at a younger age than men.

In addition to differential age of diagnosis, many studies have found that women continue to experience differential barriers to accessing testing as well as experiences with the testing and counseling versus men. Studies have discovered barriers such as discrimination, fear of violence, stigma surrounding HIV, and cultural understandings of female sexuality<sup>20</sup> that may be interacting in particular ways to affect uptake of HIV testing among women and experiences of the test itself. Therefore, although women are not (proportionately) those most affected by HIV within Canada, their particular, differential experiences of HIV testing and counseling as well as service access necessitates understanding of what sensitive, tailored HIV testing and counseling entails.

### **ACB Women and HIV**

As women in Canada are differentially socially and spatially located, it is imperative that women as a category within surveillance is also examined with a critical lens. As many of the barriers to HIV testing among women are socially produced, it follows that differentially socially located women are experiencing different intersections of socially located barriers. Further, as the purpose of surveillance categorization is to inform prevention policy<sup>3</sup>, or control of the disease, it is important that the specific contexts influencing testing uptake and experience be examined within a particular socially and spatially located group of women.

For example, women within ACB communities are disproportionately represented within HIV rates;<sup>5,11</sup> 54.2% of all identified positive HIV reports within the sub-category of HIV endemic nationwide between the years of 1998-2006 occurred among women<sup>11</sup>. Further, in 2005 women accounted for 63.9% of those newly diagnosed for HIV in Ontario in 2005. Within that

same year (2005), women from countries where HIV is endemic accounted for 50.8% of all new diagnoses for HIV among women in Ontario<sup>11</sup>.

To this effect, the Ontario Women's Study was conducted in order to break down and expand boundaries/categories of identity, such as "women" vs. "ACB communities" for HIV prevention research. Instead of viewing the category of "women at risk" and basing prevention needs for this one category, women from different communities in Ontario (Latina women, Trans-women, ACB women, etc.) participated in qualitative interviews to express their experiences with HIV risk and their HIV prevention needs. This study helped to explain the intersections of identity and risk that are currently (re)occurring for women in Ontario, with both common and unique experiences and needs discovered<sup>21</sup>. One of the most significant themes to emerge from these discussions was the need cited by the women for an increase in HIV testing approaches and programmes for women.<sup>21</sup>

## CHAPTER TWO: HIV TESTING & PREVENTION

*“Epidemiology is the study of the distribution and determinants of health-related states or events in specified populations, and the application of this study to the control of health problems”-Center for Disease Control (emphasis mine)*

### HIV Testing as Prevention

While understanding of disease distribution is important, so too is the understanding of determinants and the application of both distribution and determinants to the control of HIV. One cannot begin to understand how to control a disease if there is no clear picture of who is affected and how. The control of HIV in Canada (or the prevention of) is a many layered and complicated issue; this study seeks to examine the determinants and control through one lens of prevention- namely, HIV testing. Many studies have demonstrated the efficacy of reducing the epidemic within the population by increasing the number of people being tested for HIV<sup>22,23,24</sup>; this study will examine the perceptions and experiences of HIV testing among ACB women in order to provide a set of recommendations that may help to address barriers to testing and encourage an increase in testing uptake within these communities.

Infectious disease epidemiology provides a useful model for understanding HIV transmission:  $R_0 = \beta CD$ ; where  $R_0$  is the basic reproductive number of an infectious disease,  $\beta$  is probability of infection per contact,  $C$  is the number of contacts and  $D$  is duration of infectivity. Based on this model, the goal of prevention of an infectious disease within a population is a reduction of the empirical value of one or more of these terms.<sup>2</sup>

One known method of reducing the duration of infectivity (factor  $D$  of the model above) is through early detection of HIV. It is well documented that people unaware of their infection are less likely to engage in prevention measures resulting in a disproportionate number of new HIV infections originating from those unaware of their HIV status.<sup>25</sup> Further, those unaware of their positive status are not accessing treatment and as such, are more likely to experience a higher viral load.<sup>26</sup> This is significant as it has been found that rates of transmission increase with increasing plasma load. Conversely, viral suppression achieved through anti-retroviral therapy (ART) has been shown to decrease the likelihood of HIV transmission.<sup>27</sup> Finally, timely access to care not only reduces infectivity of HIV, it has also been shown to optimize treatment outcomes, as ART has demonstrated greater efficacy if started before the immune system is too

severely compromised. Consequently, delays in treatment access are associated with higher morbidity and diminished life expectancy<sup>28,29</sup> Further, those aware of their status are more likely to adopt strategies to prevent onward transmission.<sup>30,31,32,33</sup> Therefore, early detection of HIV helps towards preventing ongoing transmission as it reduces the duration of infectivity as well as the number of contacts (factors C and D of the model above).

### **HIV Testing in Canada, Ontario, and Ottawa**

Canadian testing efforts are commonly differentiated between the concepts of provider-initiated testing, (whereby a healthcare professional asks a client if they would like to be tested for HIV, regardless of the provider's perception of the client's risk to HIV) and "voluntary"<sup>ix</sup> testing (whereby a person seeks an HIV testing service or healthcare provider specifically to be tested for HIV). The most recent guide to HIV testing issued by the Public Health Agency of Canada denotes much attention to the increase of provider-initiated testing, specifically to increasing the offer of testing within routine healthcare settings in order to address barriers to testing that have been reported by many HIV prevention stakeholders across Canada.<sup>34</sup> However, while the federal government provides guidelines for HIV testing and counseling, these services remain a provincial responsibility with access and services varying widely from one area to another<sup>20</sup>.

In Canada, HIV antibody testing is most often conducted either as a standard blood draw test or as a rapid, or point-of-care test. A standard blood test involves intravenous blood collected within a medical setting or blood lab. The collected sample is then sent to a lab for HIV antibody detection. This type of testing often results in a delay of approximately two weeks between the time of testing and the result. The rapid test involves collection of blood through a finger prick sample that is immediately placed in a reactive agent within a portable test kit. This method is able to detect HIV antibodies within 60-120 seconds and can occur in a wide variety of sites and contexts. Further, rapid testing allows for greater continuity in the pre- and post- test counseling experience.<sup>20</sup>

There are three forms of testing currently available in Canada, varying in how the test is tracked and reported: anonymous testing, nominal testing, and non-nominal testing. Anonymous testing is when the name, identity, or any proof of identification and/or medical coverage is not

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<sup>ix</sup> Although all testing in Canada is voluntary, this term is commonly used to denote a client specifically seeking HIV testing services.

required at the time of testing. The test is instead ordered using a code known only to the person being tested. However, should the test result be positive, some demographic information may be collected and if the person tested positive for HIV seeks treatment for the disease, they lose their anonymity. Nominal testing is when the service provider ordering the test uses the client's full name and if the test is positive, the laboratory is required to report this information to the local medical officer of health. A non-nominal test is ordered with only the client's first initials as the code, thereby ensuring only the clinician and client know the identity of the tester. If the test is positive, this information is included in the client's medical files and the local medical officer of health is notified. Further, in Canada prenatal testing is offered as both opt-in and opt-out, where opt-in means the client is asked if they would like an HIV test as part of their prenatal screening tests, and opt-out where the HIV test is automatically included in screening tests unless the woman refuses an HIV test.<sup>20</sup>

Anonymous testing is currently offered at 50 designated sites throughout Ontario with point-of-care testing available at all 50 anonymous testing sites.<sup>35</sup> In Ottawa, anonymous testing is currently offered at eight sites (mostly within community health centres throughout the city) and is usually conducted within certain hours or days, the details of which are site dependent and variable. There is currently one outreach tester in Ottawa who travels to other specified locations, such as universities or other community spaces to provide anonymous testing on certain dates and times.

At the provincial level in Ontario, the AIDS Bureau of the Ontario Ministry of Health and Long-term Care recognizes the importance of HIV testing in reducing the epidemic as they state: "HIV testing is an integral part of Ontario's care and prevention programs"<sup>15</sup>. Ontario currently has an opt-in approach to prenatal HIV testing and offers anonymous, non-nominal and nominal testing.<sup>20</sup> However, in Ontario, while around 80% of tests are conducted nominally with only around 5% conducted anonymously, "HIV positivity rates by test method show that 1.1% of anonymous HIV tests are positive compared to 0.27% of nominal tests."<sup>15</sup> This finding underlines the importance of anonymous testing provision, as it appears that those more likely to be experiencing HIV are also less likely to engage in traditional HIV testing.

### **The Three C's: Counseling, Informed Consent and Confidentiality**

The Public Health Agency of Canada has issued an HIV Screening and Testing Guide that provides recommendations for testing practices, such as the importance of the three C's

(counseling, informed consent, and confidentiality) and advises that these three C's be followed within a context of voluntary testing, which is defined as testing "without threat or coercion" and whereby the client provides informed consent to proceed with testing. They recommend that pre-test procedures include a discussion between the tester and the client to obtain informed consent for the test and to highlight the positive effects of knowing one's status as well as information concerning the wait times for results with accompanying assurances of anonymity and confidentiality. The guide recognizes that in the case of a positive result, the client may not be able to absorb as much information in post-test counseling and therefore recommend pre-test counseling as a good time to discuss some important post-test counseling, such as disclosure and HIV risk messaging.

Recommendations for post-test counseling include a strong emphasis on referrals to other health services, regardless of test result and that a negative test should be accompanied by referrals to risk-reduction counseling. In the case of a positive result, the guide strongly recommends that the result be given in person and that the appointment be given sufficient time for the client to process the results and ask any questions. The guide also states that clinicians should provide links to treatment specialists as well as risk-reduction information. Further, the guide advises that a partner notification strategy be developed between care providers and clients. In addition, the most recent guide recommends against risk-based testing and instead advises clinicians to open a general discussion of risk behaviors instead of asking about previous, specific risk behaviors of the client.

Comparatively, the Ontario HIV testing and counseling guidelines are in agreement with federal guidelines on the importance of both pre- and post-test counseling. The most recent guidelines highlight the importance of pre- and post-test counseling as spaces for information exchange on HIV testing, prevention, and services. However, unlike the federal guidelines, the Ontario guide recommends the continuation of risk-based testing whereby the tester is encouraged to assess the risk to HIV of the client seeking the test.

Despite the recognized importance of pre- and post-test counseling<sup>20,36</sup>, recent reports have noted a lack of both pre- and post-test counseling especially in reference to immigration or prenatal testing<sup>20</sup>. Further, a previously identified barrier for many women to seeking a testing is the denial of a test based on the assumption of the care provider that the woman is not at risk of

HIV.<sup>20</sup> Therefore, the Ontario guidelines promoting the continuation of a risk-based test may be serving as a barrier to test seeking, especially among women.

## CHAPTER THREE: THE ISSUE AND THE INVESTIGATION

### The Issue

Although great gains have been made in reducing the HIV epidemic in Canada since HIV reporting began in Canada in 1985<sup>37</sup>, the Public Health Agency of Canada recognizes that “ongoing HIV transmission remains an issue of concern in Canada”<sup>3</sup>. The first goal of the Federal Initiative to Address HIV/AIDS in Canada is to prevent the acquisition and transmissions of new infections.<sup>38</sup> As almost half of all HIV transmission occur in the early stages of the disease<sup>39</sup>, higher rates of testing with associated greater knowledge of HIV positive status in Canada is one method of preventing the acquisition and transmission of HIV.

We know that there has been no significant proportional reduction in the HIV epidemic within the last five years among women both as a category and within the ACB category. In fact, preliminary results of an ongoing study of PHA’s throughout Ontario demonstrate that 34% of the HIV positive women in the study experienced a late diagnosis<sup>x18</sup>. This same study found that ACB peoples are statistically significantly more likely than MSM and IDUs to experience a late diagnosis of HIV [adjusted OR: 2.2 (1.6-3.2)].<sup>18</sup> Further, ACB women are more likely to experience HIV compared to other populations of women in Canada.<sup>37</sup> To this effect, a study examining the prevention needs for many different women within Ontario was implemented with the findings including a need cited *by* ACB women for more testing available *for* ACB women.<sup>21</sup> Therefore, even though MSM and IDUs currently account for the highest proportions of those acquiring HIV, ACB women remain greatly in need of tailored testing. And more to the point, the women themselves pinpoint HIV testing as one of the means they believe will be most helpful in reducing HIV within their communities.

### The Objectives

This study aims to examine the experiences, perceptions, and knowledge concerning HIV testing among women who self-identify as being part of African, Caribbean or Black communities within Ottawa. It is hoped that analysis of these interviews will provide recommendations that may then be built upon to enact real change in HIV testing uptake, experiences and knowledge within the community.

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<sup>x</sup> Late diagnosis is here defined as a clinical status at or 180 days after an HIV diagnosis of: low CD4 cell counts (<200 cells/mm<sup>3</sup>) and/or presence of AIDS-defining conditions (ADC).

### **The Significance**

This study aims to provide strategies to improve HIV counseling and testing among women in ACB communities in Ottawa grounded within their experiences and emic perspectives. Current strategies are simply not demonstrably increasing voluntary testing uptake among ACB women in Ontario. This study will provide some insight into what may be acting as barriers to uptake and recommendations for possible solutions to these barriers through the words of the women themselves. In this way, policies and strategies may be developed that are created and enacted by ACB women for ACB women.

## **PART TWO: LITERATURE & METHOD**

## CHAPTER FOUR: PARADIGM & METHOD

*“Yes, the sample is biased; it must be biased!” -Janice Morse<sup>40</sup>*

### On Paradigm

The existence of a methods section within scientific study is founded on the premise that others may judge the quality of one’s work through determining if the results and methods are linked appropriately.<sup>41</sup> However, judgment of quality is grounded in a set of explicit or implicit assumptions on how the world works, or one’s paradigm. A paradigm refers specifically to a set of assumptions concerning: 1) The nature of existence and reality (ontology), 2) the nature of knowledge (epistemology), 3) ways of knowing that reality (methodology) and theoretical perspectives which are often grounded in epistemologies and help to guide methodologies<sup>42</sup>. Maxwell explains the importance of explicating one’s paradigm within research: “...a clear paradigmatic stance helps to guide your design decisions and to justify these decisions.”<sup>42</sup> Therefore, when discussing the study design and associated methodologies, it is imperative that the paradigm be made explicit.

However, it should be noted that while an explicit paradigm plays a key role in study design, it is not the design itself. A paradigm often carries a certain coherency that has already been established and serves to guide research by providing logical consistency as well as associated theories and methodologies; the combination of the research question, paradigm, theoretical perspective and methodology is a constructed process of the researcher referred to by Maxwell as the “conceptual framework”. Although this framework may borrow parts, such as theory, paradigm, or method, it is wholly unique in the sum of its parts. In fact, a researcher may jump in and out of paradigms, or choose to simply operate on a “paradigm of choices” as Patton explains: “A paradigm of choices rejects methodological orthodoxy in favor of methodological appropriateness as the primary criterion for judging methodological quality.”<sup>43</sup> However, as a beginning researcher I decided that it would be best if an established paradigm was followed, as this would allow me to “...build on a coherent and well-developed approach to research, rather than having to construct all of this {yourself}”.<sup>42</sup>

Much of epidemiological and clinical research is solidly grounded within an objectivist epistemology. This epistemology posits that the nature of knowledge is one immutable reality that can be studied and discovered if the appropriate method or experiment is conducted. The

purpose of a study is therefore to discover this one true reality. This epistemology is often accompanied by a positivist theoretical perspective which states that reality may be observed and attained if the method is correct and the human perspective, or human bias is removed. This focus on the removal of human bias is often equated with the removal of social structures from scientific inquiry, such as the beginning of the HIV epidemic where social structures were viewed as confounders.

However, this is not necessarily true. An objectivist paradigm can and does still exist within qualitative studies. This paradigm also assumes that if the methodology is accurately portrayed then the study should be replicable. The purpose of the methods section is then two-fold for this paradigm: 1) give clear demonstration that all bias has been removed and 2) be so clear that other researchers may reproduce the study and attain similar results. The theory being that if the other researcher produces differing results, then either the association found in the original study does not exist, the association found in the reproduced study does not exist, or either study is experiencing type I or type II error<sup>xi</sup> (although type I or type II error probability should also be clearly explicated within the methods). This is the backbone of positivist, scientific inquiry and is very much standard practice within epidemiological articles and journals.

### **Constructivist Epistemology**

However, this is not the only epistemology available to researchers within scientific inquiry or epidemiology as a field. Many qualitative researchers define themselves as operating within a constructivist epistemology. Constructivists posit that reality, or “data” are constructed between and among people, not outside of them. Therefore, if a researcher asks a participant a question, the “data” or reality lies within the interaction between the researcher and the participant and/or object, not just what the participant says, or means to say. In other words, reality does not exist outside of humans, but humans create it. It is through this epistemology that a social epidemiological investigation can examine and produce data that traditional positivist epidemiology cannot. Instead of the need to remove the human perspective from the data as is necessary in positivist inquiry, within a constructivist inquiry, doing so would eliminate the data. Therefore, the data are inherently “biased” and in fact, should be biased.<sup>40</sup>

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<sup>xi</sup> Type I error being the incorrect rejection of the null hypothesis and Type II incorrectly retaining a false null positive.

This brings us back to the purpose of method. If one of the main purposes of method in an objectivist, positivist paradigm is to remove bias and bias cannot and should not be removed from the constructivist, social epidemiology paradigm, what then is the purpose of a methods section? As data are biased, the purpose of a constructivist inquiry is to make clear the perspectives of the researcher, so that these perspectives may be taken into account during review of the data produced. As each data set is unique and co-constructed between the researcher and the participants, the methods section becomes an exercise in reflection and transparency on the part of the researcher. In effect, the purpose of a constructivist method section is to illustrate to the reader the perspectives of the researcher.<sup>44,41</sup>

From this perspective, as the researcher is literally part of the data (as data are co-created), reflexivity becomes paramount for thorough understanding of this co-created data. This reflexivity is applied both to theory and individual positioning, as a researcher is a person that exists within specific social and literal space and retains a history of theoretical influence. Therefore, the conceptual framework of this research operates from a paradigm of a social epidemiological analytic frame grounded within a constructivist epistemology utilizing intersectionality theory to produce and analyze qualitative data. Further, my personal positioning is as a Caucasian woman born in the rural Midwest of the United States, raised in a middle-class household and as a recent immigrant to Quebec, Canada. I operate from a feminist perspective and am a daughter, a sister, a wife, and became a mother during data collection of this thesis.

### **Intersectionality Theory**

Social epidemiology tends to rely upon methodologies built within other disciplines and theoretical perspectives. Therefore, other theoretical perspectives were utilized in the creation of this study; in particular, the theory of intersectionality. A perspective described as:

“Intersectionality is concerned with simultaneous intersections between aspects of social difference and identity (as related to meanings of race/ethnicity, indigeneity, gender, class, sexuality, geography, age, disability/ability, migration status, religion) and forms of systemic oppression (racism, classism, sexism, ableism, homophobia) at macro and micro levels in ways that are complex and interdependent.”<sup>45</sup>

This theoretical viewpoint reframes traditional perspectives that give primacy of one situated identity over others, such as gender theory and analysis which frames inequities and experiences through the single lens of gender. Intersectionality instead strives to move beyond the single lens

and incorporate the multiplicity of identities; in other words, the ways in which different identities interact and inform each other. For example, it is well documented that the decision to get tested for HIV is based on a multitude of factors that may or may not be informing each other.<sup>46,15,47</sup> In order to move beyond a simplistic, unilateral decision-making framework it is important that the kaleidoscope of identities be both teased out as well examined holistically.

Further, intersectionality seeks to understand not only the intersections of identity, but also the intersections of the power dynamics formulated through each identity. The term ACB is itself a conglomeration of various identities (being an immigrant from a country in Africa or the Caribbean to Canada and/or identifying as some visible minority combination resulting in the term “black”). Similarly, a woman exists within multiple identities as well (mother, daughter, wife, business owner, etc.). Therefore, it is apparent that women within ACB communities are experiencing intersections of identity and as such, analysis of these particular groups of women may be best suited to an intersectional framework of understanding.

As different identities incorporate differential power complexities, and as intersectionality theory concerns itself with “multiple systems of power”<sup>45</sup> that interact with “multiple modes of identification”<sup>45</sup>, this model is particularly helpful in helping to produce understandings of experiences and perceptions of ACB communities; especially ACB women, who are disproportionately represented in new positive HIV diagnoses.<sup>3,15</sup> In fact, ACCHO explicitly stated that the term ACB comes from a recognition of the individual experiences cloaked in the term “HIV Endemic” and the communal experiences of racialization<sup>9</sup>. As such, an intersectional approach was deemed not only appropriate, but necessary for understandings of both the communal and disparate intersections of identity and experiences among and between the women in this study.

## Qualitative Methodology

The methodology for this study was chosen based on the purpose of data collection and the nature of the problem. As quantitative surveillance methods have already documented a lack of timely testing among women in ACB communities, the next logical step was to develop an understanding of what is going on that may be influencing the decision to undergo testing for HIV among women in ACB communities in. As this question is not concerned with measurements (or the “what” and “how much”), but instead is exploratory and dependent upon emic perspectives (such as the “why” and “how”)<sup>48</sup>, a qualitative methodology was deemed the

most appropriate. A thematic analysis was decided upon over the use of other analysis methods (such as grounded theory, narrative or phenomenology) as this research prioritizes development of thematic points for policy implementation over theory advancement.

The decision to use the method of in-depth-interviews was grounded in the need for information that privileges the perspectives of the women themselves instead of providing a limited set of possible responses.<sup>48</sup> However, the interviews were semi-structured instead of completely open to ensure discussion centered on the subject of HIV testing. Finally, thematic analysis and the constant comparison method were chosen to analyze the data as these analytic methods provided the best fit for both comparing heterogeneities and commonalities between and among different groupings of identities while also developing meaningful analysis through generating themes directly applicable for programmatic needs

## CHAPTER FIVE: QUALITATIVE METHODS

### Informed Consent and Ethics

Ethical approval was sought from the Ottawa Health Sciences Network Research Ethics Board (OHSN-REB) for the thematic guide, overall study design, recruitment strategy, recruitment cards and consent form. Recruitment and data collection began once ethical approval was received.

### Sampling Strategies and Recruitment

The sampling method employed in this study was “purposeful selection”, which Maxwell describes as: “...a strategy in which particular...persons are selected deliberately in order to provide information that can’t be gotten as well from other choices.”<sup>42</sup> This sampling method was chosen as the needs of the study were to create information rich, contextual data concerning HIV testing through the interviews. Further, the type of purposive sampling employed was maximum variation<sup>43</sup>; a method that ensures a wide range of experiences and identities are included into the study by focusing on a few specific identities and ensuring a wide variety within those specified identities and experiences. For example, this study sought maximal variation of the following identities and experiences: age, time in Canada, immigration status, country of birth, testing status, and religion. This method was chosen to ensure a wide variety of lived experiences and perceptions that may be impacting current HIV testing among ACB women would be gathered. Therefore, participants were chosen based on a combination of the maximal variation factors and the individual’s ability to provide rich, contextual data. The specific eligibility criteria were:

#### Eligibility Criteria:

- Speak English fluently
- Able to give informed consent to participate in the interview
- Self identify as female and African/Caribbean/Black
- Currently living in Ottawa
- 18 years or older

As the sampling methodology required a priori knowledge of the participant’s backgrounds and ability to give voice to their experiences, recruitment necessitated collaboration

with frontline staff from community health centres serving ACB communities. Through participation in community forums as a member of the HIV and Hepatitis C Prevention Research Team, and through contacts previously developed through the team, I was able to establish working partnerships with frontline staff from Community Health Centres, AIDS Service Organizations and HIV prevention service providers. Over a period of six months, I developed partnerships to obtain confirmation of recruitment aid with two frontline staff.

It was decided during initial conversations with these frontline staff that it would be best to include them both into the study before other participants were recruited as a process of personal testimonials was described as best for recruitment. After participation within the study, frontline staff spoke with those they felt would be a good fit for the study about their own experience in the study to reassure potential participants about the process and the study. If a potential participant wished to participate, the frontline worker would then give me the appropriate contact information (most often a phone number) with an associated name. In a phone call that served as the first point of contact between myself and the participant, any questions about the study were answered and the interview was scheduled. All interviews were then held within a secure, enclosed room usually at a Community Health Centre.

## **Interview Procedures and Analysis**

### **Privacy and Confidentiality**

Privacy and confidentiality were respected at all levels of data collection and interaction with participants. Although the study recruiters would provide a name for me to use when making the call to a potential participant for identification purposes, all such information was de-identified for the interview and subsequent analysis. The consent form was read by myself to the women, but I also encouraged the participant to read it for themselves should they wish to. (APPENDIX I) Participants were encouraged to ask questions before the consent form was signed and were assured that they could stop the interview at any time they wished. The consent form was signed by myself after verbal consent had been obtained to ensure anonymity of the participant. At the end of each interview I would ask the participant if they wished to choose a name for their words to be represented by, as the study would not use their real name and I did not want their voices to be identified by a number within this thesis and analysis. Most chose not to provide a name, in which case I created one for them.

## Interview Process and Procedures

All in-depth interviews were semi-structured using the thematic guide (APPENDIX II). Once the interview was completed and the recorder turned off, I would ask the participant if they had any other questions and would debrief concerning HIV testing and prevention services within Ottawa as needed. Other prevention materials such as pamphlets and business cards of HIV prevention workers were handed to participants if they so desired. After the participant had left, notes were taken to ascertain first impressions and overall personal impressions of the interview. In addition, as this was my first qualitative study, careful attention was paid to the way in which questions were asked, the questions themselves, and probing techniques.

The first two interviews were also key informant interviews with two of the participants graciously allowing me time after the end of the interview to speak with them about cultural norms within ACB communities that could affect rapport building during data collection. I believe that as a Caucasian woman with little to no understanding of the different African and Caribbean cultural norms, this was important in maintaining cultural sensitivity and encouraging a positive experience especially in hindsight, as the topic of HIV proved difficult for many participants.

To ensure consistency, all of the interviews were transcribed and analyzed by myself, with transcription and analysis taking place concurrently. Immediately following transcription all recordings of the interview were erased. Each transcript was coded and analyzed using the atlas.ti software package to help organize the emergent themes. Main themes were identified within each interview, with each emergent thematic element added to the thematic guide and explored in subsequent interviews. This inductive process has been found to be integral in ensuring heterogeneity of themes and to ensure information saturation is reached.<sup>42,49</sup> Further, information saturation was assessed with each interview and analysis occurred concurrently with enrollment and interview procedures. This iterative process continued until no new themes emerged, or when information saturation had been reached<sup>42</sup>, which occurred at 10 participants.

The transcripts were compared and reviewed with the body of transcripts already produced in order to identify recurring thematic elements and to maintain flexibility of themes. The comparison of transcripts occurred multiple times for each theme as it emerged. This cyclical, iterative, and flexible process is referred to as thematic analysis.<sup>50</sup>

Analysis of the transcripts also involved a method of constant comparison between and among the different groups of women.<sup>51</sup> The constant comparison method has been explained as: “Simply put, constant comparison assures that all data are systematically compared to all other data in the data set. This assures that all data produced will be analyzed rather than potentially disregarded on thematic grounds.”<sup>52</sup> The comparators for the constant comparison method were the same as those used for maximal variation: age, time since immigration, religion, time in Canada, testing status, immigration status and place of birth. Each theme was compared by each comparator for commonalities among comparators as well as for nuances of difference by comparators within the same theme. Further, comparators were examined among different themes, as one theme may emerge within certain grouping(s), but not others. This comparative method enables a differentiation of experience, attitudes and perceptions as well as commonalities between and among different groupings of identities and experiences.<sup>53</sup>

## CHAPTER SIX: LITERATURE REVIEW

A review of the literature was undertaken to retrieve and examine documented general themes that could then be explored in more depth during the interview. Therefore, a scoping review was decided upon as the best fit. This scoping review included both “white literature” (peer reviewed publications) and grey literature (materials gathered from reports, community forums and other non-peer reviewed literature).

However, I use the term “scoping review” loosely; unlike a traditional scoping review whose purpose is to provide a general map of the current state of the literature<sup>54</sup>, this review was conducted to produce possible themes for the thematic guide to be used within the interview. Therefore, if any literature was missed or if I did not attain a full understanding of the current state of the literature, it was not viewed as detrimental to my goals. As the thematic guide is part of an iterative process, it was anticipated that any gaps in understanding would be filled through the interviews. Therefore, although I sought to ensure the review was as exhaustive as possible, it was purposefully guided by my experiences and understandings of the potential emic perspectives of ACB women in Ottawa and therefore, purposefully biased.

### White Literature Methods

A search strategy for the white literature was developed in conjunction with the health sciences librarian at the University of Ottawa Health Sciences Library utilizing the Medline (Ovid) database. Ovid was chosen as it is one of the most widely used within the health sciences and as such, provides one of the most comprehensive databases of health science research. Other databases were not explored due to both time restraints and the objective of this review being scoping, not exhaustive. That said, the review was as exhaustive as possible as I wanted to capture as many potential themes as possible.

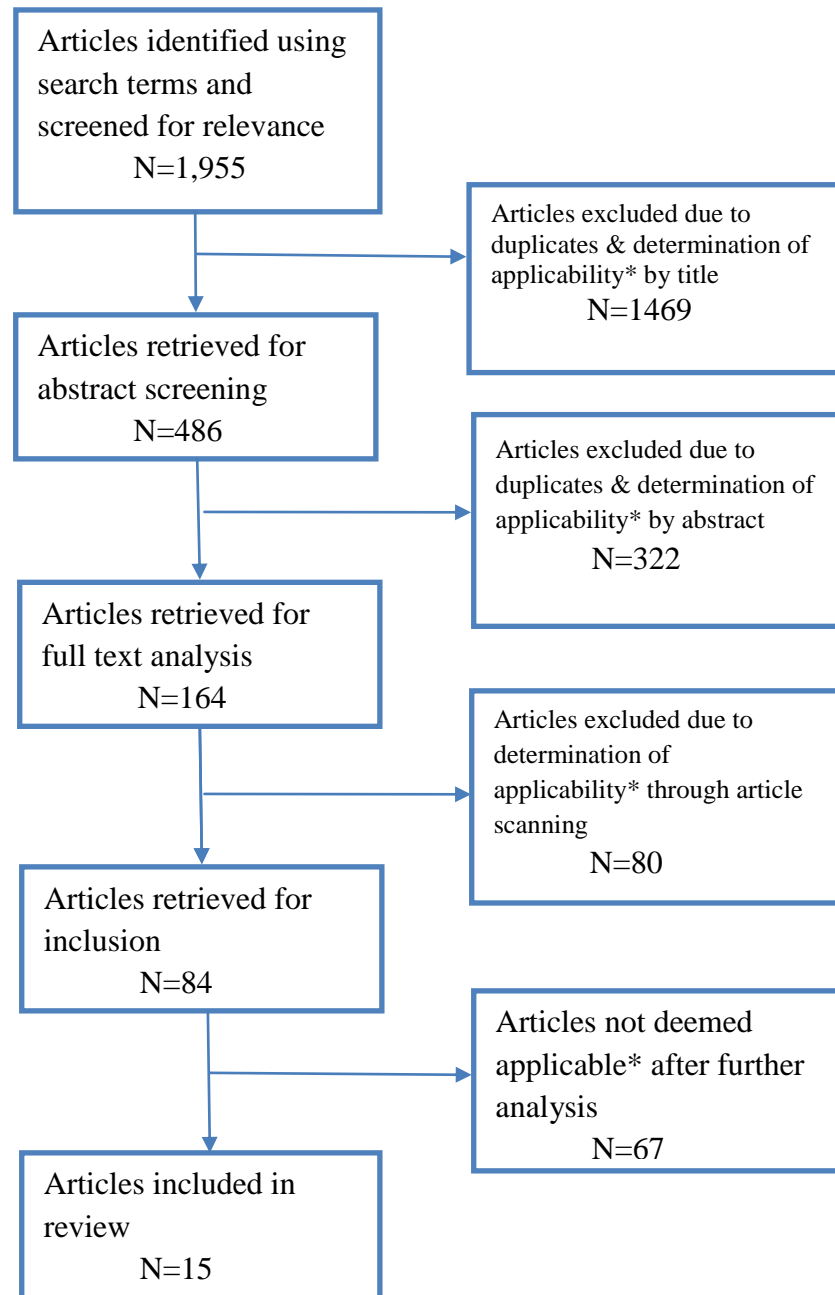
The search strategy developed with the librarian was kept purposefully broad. For example, the keyword “testing” was not used as the concept of “testing as prevention” may result in some papers discussing linkage to care with testing filed under key word “prevention”, resulting in these papers not being included with the keyword “testing”. A free text strategy utilizing the following terms<sup>55</sup> was employed: (women OR female OR Gender Identity) OR (African continental ancestry group OR African Americans OR Caribbean OR West Indies OR African OR Africa) AND HIV infections AND (diagnosis/ or “diagnostic techniques and

procedures”/or diagnostic tests, routine/ or mass screening/ or anonymous testing/ OR attitude to health/ or health knowledge, attitudes, practice/ or health behavior/ or sexual behavior/ or social behavior/ or population characteristics/ or “health care quality, access and evaluation”/) with limits: year 2004- current AND English language. Please see Figure 1 below for the general process of narrowing the articles after using such broad search terms.

The approach towards the scoping literature review was guided by intersectionality theory, which informed both the criteria of inclusion as well as the analysis of the literature. The choice to start broadly was grounded by the theory that multiple identities may be interacting. Therefore, to “catch” the breadth of identities, myself and the health sciences librarian decided it was best to start broadly and then refine. Applying a more narrow focus at the outset might result in missed experiences and/or identities that may inform HIV test seeking behaviors or testing access. Further, the evaluation of each paper was not conducted with a specific end-point as a criterion of inclusion, but instead inclusion decisions were based on my assessment of the probability of an article tapping into experiences, social locations or cultural norms that may be affecting HIV testing for ACB women in Ottawa. These decisions were not blind, as I used my own experiences in Ottawa ACB community forums and meetings to inform them. In sum, the review was purposefully biased, as I was unconcerned with missing themes or experiences existing in the literature, as important themes would be emerging within the data.

### **Grey Literature Methods**

The attended community meetings and forums also heavily informed the grey literature review. The grey literature search was also scoping and includes materials obtained from community meetings and forums attended with the HIV and Hepatitis C Prevention Research team, online reports, and other Master’s theses. A few organizations emerged as great resources for this study: ACCHO (African and Caribbean Council on HIV/AIDS in Ontario), CATIE (Canadian AIDS Treatment Information Exchange), and PHAC (Public Health Agency of Canada). These organizations created the bulk of grey literature information obtained for this study. In addition, the attended community meetings and forums also heavily informed the grey and white literature reviews.

**Figure 1**

\*The determination of applicability was a decidedly subjective process. For example, it was unclear whether articles about HIV testing and African Americans should be used. I felt that although African Americans may not have the same needs and experiences with HIV testing as Canadian ACB communities, there may be some overlap in experiences and perceptions that could be affecting both African Americans and African, Caribbean and Black communities in Canada. When I was unsure of applicability, the article proceeded through the process described above until I decided it should be included. Therefore, there was a large number of articles reviewed fully that were not included into the review. This chart was created as a visual aid for the overall process, not an exact justification of each decision for inclusion or exclusion into the review.

## Analysis

As the white literature articles were reviewed, an analytic frame emerged and was subsequently confirmed and informed by the grey literature. This frame was then applied to the analysis of the white literature to create a structure for comparison and consists of three levels of engagement with HIV testing: 1) **individual** needs and/or experiences with HIV testing, 2) **community and group** needs and/or experiences with HIV testing and 3) public health and other **policies** affecting HIV testing needs and/or experiences. These three thematic elements of the frame seemed to appear again and again in the scientific articles in various permutations and were made explicit within the *Ontario HIV/AIDS Strategy for African, Caribbean and Black Communities, 2013-2018*<sup>56</sup> which labeled the three elements as “levels of action” within the report.

As the diagram demonstrates, a large number of articles were sifted through the review. However, many were not included in the final analysis because they were largely descriptive of interventions or policies in Africa concerning HIV testing or prevention programming. As this review was conducted with an eye towards possible experiences or perceptions towards HIV testing, or more emic perspectives, studies with outcomes focused on increasing testing and not on experiences or perceptions were excluded. Further, all papers focusing solely on youth perspectives (<18 years old) were not included, as an eligibility criterion for the study specified identification as an adult woman (>18 years old).

### Individual Level

There were three articles concerned with the individual level of HIV testing; these studies focused mainly on predictive variables and correlates to individuals seeking HIV testing. One Nigerian study compared personal risk perceptions with stated risk behaviors to produce knowledge on accuracy of personal risk assessment which was then linked to health seeking behaviors.<sup>57</sup> The other two studies used questionnaires to find predictive variables for individual test seeking behaviors: one examined the social and cognitive variables predicting voluntary HIV counseling and testing in Tanzania<sup>58</sup> while the other used a country-wide demographic health survey to investigate correlates of HIV testing among women aged 15-49 in Ghana<sup>59</sup>.

The first article was a cross-sectional study among 592 women and men recruited from out-patient clinics at a University teaching hospital in Nigeria. The study examined HIV knowledge and self-perception of HIV risk in relation to sexual risk behaviors. Despite the

participants having a wide variety of backgrounds in terms of age and socio-economic status, the study found that while knowledge of the modes of transmission and HIV prevention methods were high among all participants, only around 53% of participants perceived themselves to *not* be at risk of HIV despite around 80% stating that they engaged in high risk behaviors within the year preceding the study.<sup>57</sup> Further, a statistically significant portion of those engaging in high risk behaviors were more likely to believe that they were not at risk than their less risky counterparts. The authors posit that this may be due to optimism bias, which is a documented tendency to believe in one's own invulnerability to HIV and/or AIDS.<sup>60,61</sup> Further, around 73% of participants believed they were invulnerable or at most, had little risk of contracting HIV, which is similar to other studies that had found that over 70% of Nigerian youths "commonly expressed optimism bias about HIV susceptibility"<sup>57</sup>. The authors posit that this bias is unsurprising, as "stigmatization is rife and has been noted to prevent people from HIV testing or accessing treatment"<sup>57</sup>. Therefore, the authors suggest that prevention energy should be spent on improving self-perception of risk, as many studies have demonstrated a strong relationship between self-perceptions of HIV risk and risk-reduction behaviors.<sup>62,63,64,57</sup> More specifically, the authors suggest health education through risk-appraisal as a means of improving both risk behaviors and health seeking behaviors.

In the second article, Vermeer et al. assessed cognitive predictors of voluntary testing among Tanzanian medical students using the health belief model as an analytic frame to examine specific variables found to facilitate uptake of voluntary testing in Sub-Saharan African countries. This sample was comprised of 186 medical students; it was largely male (about 72%), with around 43% of participants having ever been tested for HIV (42% of men and 46% of women). The reasons found for participating in voluntary counseling and tested were: fear that one could be infected with HIV, wanting to donate blood, and having (had) a partner who was unfaithful. Of those tested, around 61% participated in seeking the HIV test. Further, among those who sought testing on the advice of another: around a quarter of participants<sup>65</sup> got tested on the advice of their partner; around 20% got tested on the advice of a friend; 14% upon advice of a doctor; and around 40% from other people. The variables found most significant to test seeking using regression modeling were: self-efficacy; fear of being HIV-positive; and perceived susceptibility. These variables accounted for 31% of the variance of intention to participate in Voluntary Counseling and Testing (VCT). Interestingly, no statistically significant correlation

was found between risk behavior and perceived susceptibility. The study also found that fear of stigmatization was greatly reduced once one obtained an HIV test and that fear of a potential HIV diagnosis was greater among those who had not obtained an HIV test than among those who had.<sup>58</sup> Finally, the study concludes that the limited account of variability within the regression model may be due to the lack of social and cultural variables within the model.<sup>58</sup>

The third study was the only one to engage only with women and focused on a national health survey to determine HIV testing correlates among women in Ghana.<sup>59</sup> This study states that three factors prevent test seeking behaviors in Ghana: doubt of sero-negativity, fear of inappropriate disclosure of results, and lack of awareness of testing. Further, improper disclosure has been linked to discrimination, familial abandonment, violence and loss of employment. Therefore, the authors posit that women in Ghana may be seeking treatment in places far from their own residence in an effort to maintain confidentiality of their positive status. This study found that while around 90% of the women in the sample had not tested for HIV, around 76% stated they wanted to be tested, but 53% did not know where they could get tested. They found that those most likely to have been tested were: those women who knew someone who had died of AIDS; those more likely to endorse HIV positive people continuing their jobs and teaching; and those more highly educated. Further, ever having been tested was also correlated with religious affiliation, as some denominations have introduced mandatory HIV tests for couples getting married and therefore Christians and Muslims were more likely to have been tested than their non-religious counterparts. The authors conclude that one of the main factors affecting testing uptake depended on simply knowing where one could access an HIV test. In light of this information the authors recommended routine testing at clinics and hospitals as well as encouragement of home and work-based testing.<sup>59</sup>

### **Community and/or Social Level**

The bulk of the articles discovered through the white literature review focused on group, or community/cultural levels of analysis and/or action. A good proportion of these articles focused on the role faith-based organizations may play in prevention and HIV testing messaging. Others focused on the communication about HIV and HIV testing while one article analyzed HIV testing perspectives through a gendered lens.

As the Eastern Caribbean is home to a mix of cultures and languages (including English, French, Dutch, and Creole) one commonality and a “great influence on public opinion” is the

role faith-based organizations play in Eastern Caribbean life.<sup>66</sup> One recent poll of four countries found that in St. Kitts and Nevis, none of the respondents claimed no religious affiliation and in Antigua and Barbuda, only around 7% claimed no religious affiliation.<sup>67</sup> As faith-based organizations (FBO's) play a large role in daily life in the Caribbean, many FBOs are already engaged in health promotion and sexual health messaging to some extent. Therefore, one study focused on the types of health programming already offered by FBO's in four Caribbean countries (St. Kitts and Nevis, and St. Vincent and Grenadines) to better understand the types of messages conveyed and willingness to engage in more HIV prevention and response activities. The authors conducted mixed method analysis comprised of 9-10 in depth interviews conducted among leaders of FBOs and up to 50 structured surveys completed by FBOs within each of the 4 countries. Generally, respondents were male (over two-thirds of respondents) and were the pastor of their FBO. However, in all in-depth interviews, respondents stated that female congregants outnumbered male members within their FBO-particularly single or unmarried mothers and the majority of respondents confirmed that they offered health programs to members, but that these programs were largely focused on physical health and nutrition.

Despite 98% of respondents citing the importance of strengthening or establishing HIV/AIDS programming in their organizations, slightly less than half reported current programs including HIV and/or AIDS-related content and that these programs focused predominantly on education and/or counseling. Only 7% of respondents felt that they were well informed of the available HIV services for themselves and their congregation. The study found that the overall messaging around sexual health and HIV was very much centered on abstinence programming. However, around 8% of respondents from FBOs with HIV-related health programs reported that their organization either promoted HIV testing, or had a formal referral program. However, the attitudes towards promotion of HIV testing varied: some FBOs provided pre- and post- test counseling while delivering the results themselves through certified and trained staff and others did not want congregants to get tested in the church for confidentiality reasons, or because they felt that other people would judge that the person seeking the test was having sex. The study reported much variability in the degree to which FBOs felt they should proactively promote or refer congregants for HIV testing.<sup>66</sup>

The article concludes with the general overview that although FBOs perform health services to their congregation, these services are driven by doctrinal beliefs rather than public

health evidence. Further, in the English-speaking Eastern Caribbean, FBOs role in HIV prevention may be better among targeted populations, such as women, who are disproportionately affected by the epidemic in the region and have demonstrated strong participation in FBOs. However, due to the need of FBOs to work within their organization's doctrines, collaboration with outside organizations is most likely the best fit for sexuality-related topics. Still, the authors believe that FBOs could play a large role in de-stigmatizing HIV by emphasizing compassion and reframing HIV as a chronic health condition requiring compassionate care.<sup>66</sup>

A similar study conducted among FBOs serving mainly African-Americans was undertaken to determine what role FBOs would be able to serve in HIV prevention programming, as they had historically engaged in prevention initiatives for cancer, heart disease and other health initiatives and could play a powerful and effective role in HIV prevention.<sup>68</sup> The results are similar to the Caribbean study, with almost 70% of faith based leaders being male and most of the prevention discussion centered on abstinence messaging and the authors concluding that although FBOs have an important role in prevention messaging, this role is currently limited.<sup>68</sup> However, a third study implemented an HIV awareness and screening intervention among African-American FBOs and found that after the intervention, over two-thirds of participants believed that FBOs should offer HIV screening; the authors attribute this success to a community-based participatory research (CBPR) approach.<sup>69</sup>

One study explored the relationship between communication and uptake of voluntary counseling and testing (VCT), as informal, interpersonal communication about HIV and AIDS has been shown to increase knowledge and reduce stigma<sup>70</sup> and uptake of VCT has been found to vary partly due to community norms and stigma around HIV.<sup>71,72,73,74</sup> This study was cross-sectional and took place in 48 communities across five sites in four countries (Tanzania, Zimbabwe, South Africa and Thailand).<sup>74</sup> The study sample was comprised of around 55% women with a mean age of around 25 for both genders. Around one third of women had been tested for HIV in pregnancy and only around 16% had been tested voluntarily once or more, with over half never being tested.<sup>74</sup> Conversely, the majority of men had never been tested (80%) and only around 20% of men had been tested at least once voluntarily. However, the study found that across sites, those who engaged in common conversations were significantly associated with having received an HIV test. The authors posit that this association may be a result of increased

conversations leading to greater acceptance and uptake of testing, or it may simply be that those more likely to seek testing are those more likely to speak openly about HIV or testing to others.

The authors assessed gendered differences in testing at all sites and found that although women were more likely to have been tested for HIV in four of five sites, this was most likely due to prenatal testing. The authors suggest that while increased communication about HIV between spouses or sexual partners has been shown to encourage testing, partner agreement about whether communication has taken place can be poor. In light of this, they recommend development of greater communication in social networks, such as peer and familial networks, with the caveat that in order to increase testing, it is necessary to already be familiar with the existing HIV-related conversations, such as frequency, participants, topics, etc.<sup>74</sup>

One study focused specifically on the role of gender in HIV testing and promotion illustrated that women in Kenya were less likely to have participated in VCT than their male counterparts. The authors concluded that this asymmetry was due to gender dynamics directing communication about sexual health and governing who may access services. They therefore recommended programmatic responses to tackle gendered stigma associated with VCT, such as men being the ones to make the final decision to seek testing and that voluntary testing and counseling is only for prostitutes.<sup>75</sup> Another study looking at young women in Kenya found that not knowing if one's partner had tested, or not knowing a partner's results was an independent predictor of HIV infection for the women in the study; those who did not know their partner's status found to be 14 times as likely to be HIV-seropositive compared to their counterparts who were found to have open communication about results.<sup>76</sup>

Another study addressed communication between couples through a couples counseling intervention as previous research has demonstrated that couples focused programming reduce unprotected sexual intercourse and increase condom use compared to programming focused on the individual.<sup>77</sup> Further, other research has demonstrated that couples counseling has been found to be feasible, acceptable and cost-effective.<sup>78</sup> The authors posited that couples counseling and testing can be used as a mechanism to balance the asymmetrical gender testing dynamics by transferring the motivation for health seeking behaviors from individual health beliefs and self-efficacy to relationship-oriented motivations whereby the partner "interprets health events as meaningful for the relationship or their spouse, rather than simply for themselves."<sup>79,80</sup> The authors focused on ten sero-discordant couples from Uganda and found that there was little to no

communication concerning sexual health, except within the counseling sessions of the research and that this communication was key to encouraging behavior changes, such as condom use or microbicides. They posit that this change was due to men acknowledging that their wives could leave them or not take care of them or that if they infected their wife and both of them died there would be no one to take care of their children. The study made sure to quickly address problems as they arose within the couple and also provided home visits and further counseling sessions as needed.<sup>80</sup>

In Zambia, men largely did not participate in the research, as they felt that if their wife was negative, then they were not at risk. Due to the culturally accepted norm of men having more than one partner while the women do not, married women in the study expressed concerns about HIV risk and attempted to participate in the study. However, their participation was dependent on their husband's permission. If they attempted to participate in the study to obtain microbicides without their husband's permission, they ran the risk of physical punishment from their husbands and were therefore not as likely to successfully participate in the study as their counterparts in Ghana as the men in Zambia were not willing to participate nor have their wives participate.<sup>80</sup>

The authors state that the dynamic of asking a husband for permission to participate challenges Western liberal aspirations of individual autonomy with the informed consent process and that this asymmetrical gender dynamic largely skews control over behavior to the male spouse. Therefore, the study ultimately concluded that although couples testing and counseling has the potential to turn "Africa's largest HIV at-risk group" (serodiscordant couples) into a protective resource, consideration needs to be given to the ethics of individual participation in an unequal relationship. However, ultimately, the authors conclude that there is a place for HIV testing and prevention within a relationship context in which both partners have a stake in the outcome.<sup>80</sup>

### **Public Health/Policy Level**

A number of studies focused on HIV testing from the perspective of policy development or programming, such as preferred types of testing and counseling for the general populace in the country or region of interest and comparisons of different testing approaches.

One study examined the current state of testing within Botswana, the first African country to introduce routine HIV testing (an opt-out approach where the patient is informed an

HIV test will be conducted and that he or she has the right to refuse).<sup>81</sup> The authors found that acceptance of opt-out routine HIV testing by clients and health care workers was greatly increased by the introduction of rapid tests as this type of testing removed the barriers of delay in obtaining results and subsequent loss of patients to care.<sup>81</sup> Further, the authors found that men chose to opt-out of testing more frequently than women and may be more likely to wait to test until they experience symptomatic HIV disease. Overall, the authors conclude that although there was fear in adopting an opt-out, routine approach to HIV testing due to concerns over confidentiality and increased stigma, the acceptability of opt-out routine testing by Botswana adults is over 80% with around sixty percent of adults believing that routine testing will actually help to reduce HIV stigma.<sup>81</sup>

Similarly, another study focused on opt-out routine HIV testing via a clinical trial comparing HIV detection rates using routine opt-out provider initiated HIV testing and counseling versus a standard care approach in rural Zambia.<sup>82</sup> The study provided HIV testing and counseling services to 1,221 adults who presented at any one of four rural, mobile clinics. At each site, some providers offered standard HIV testing procedures while others offered the routine, opt-out provider initiated HIV testing and counseling. The authors found that the routine opt-out testing policy detected more than three times more HIV infections per clinical practitioner than standard non-routine HIV testing and counseling and 96% of all patients (both tested and not tested) within the study reported being “in favor” of opt-out provider initiated routine testing and counseling.<sup>82</sup>

However, another article discussing the current state of HIV in South Africa,<sup>83</sup> described how studies have found that opt-out strategies may lead people to feel coerced and those who felt that they were not given the opportunity to decline often would not return to receive the test results.<sup>84,85,83</sup> The author states that it may be more culturally preferable to take the test and not return for the results instead of declining a test outright and that this is sometimes the only strategy left for patients to retain their autonomy within an opt-out system.<sup>83,86</sup> Further, routine testing still operates from within facilities, which people may avoid due to stigma, discrimination, lack of privacy, and fear that results will not be kept confidential.<sup>87,88,89</sup> Finally, some studies have found that patients may believe that testing is no longer voluntary and refusal to be tested will compromise their care.<sup>90,91,92,83</sup>

The author posits an alternative to these problems with home testing kits. With the accuracy found with the OraQuick device (99% accurate for high risk populations),<sup>93</sup> the possibility of home test kits negates the barrier of testing facilities and can be done in the privacy of one's home.<sup>94</sup> However, a common critique of this method is the lack of counseling before and after the test, which the author believes can be overcome by "providing some form of anonymous telephone counseling with toll-free numbers as part of the testing service for clients who wish to make use of it."<sup>83,91,92,94</sup> Self tests are now available over the counter in South African pharmacies, but are not officially supported or recommended by the South African Department of Health.

Routine, opt-out testing was implemented in South Africa in 2007, but without appropriate explanation or consultation with the general public, resulting in many South Africans being confused and scared by the mass-testing message.<sup>83</sup> A study of test preferences (using a convenience sample) found that around 66% of participants preferred client-initiated testing and counseling, with around one-tenth preferring provider initiated counseling and testing, and almost one quarter preferring self-testing for HIV. However, almost 73% of participants felt a new testing model would motivate more people to be tested, as none of the current testing models were sufficient. Further, while the majority of participants valued both pre- and post- test counseling (68%), around 10% did not want any counseling and almost a quarter of participants stated that they would prefer to be able to ask for counseling if they felt they needed it.

The author therefore posits that the best approach to testing in South Africa would be a multi-faceted testing strategy, as despite efforts to reduce stigma, people still avoid facility-based testing and other options need to be available for individuals who need to test in private. Also, a multi-faceted approach for counseling has been suggested, whereby pre-test counseling is streamlined for those in routine testing,<sup>84</sup> traditional counseling is reserved for those seeking a test and those at high risk,<sup>94</sup> with requirements manufacturers of self-test kits to provide some form of telephone counseling facility with toll-free numbers.<sup>83,91,92,94</sup> Finally, van Dyk suggests that if routine opt-out testing and counseling is implemented, it is important that providers be trained in ways that promote the voluntary nature of the testing and counseling and thereby avoid experiences of coercion by clients.<sup>83</sup>

## Grey Literature

Almost all of the grey literature focused on ACB people in Ontario and aligned with the research parameters of this study, is produced by ACCHO (African and Caribbean Council on HIV/AIDS in Ontario) as this organization creates the bulk of studies concerning ACB peoples and HIV in Ontario. Members of ACCHO include various stakeholders of HIV prevention and surveillance, thereby enabling ACCHO to coordinate the work of agencies, facilitate community development, and identify research needs, priorities and opportunities to inform the response to HIV in ACB communities in Ontario. As such, they developed an overall Strategy for 2013-2018 that was used to guide this review. The strategy identifies three levels of action and response to the HIV epidemic: strategies that focus on the individual and familial level, strategies that focus on strategies on the community level, and strategies that focus on a provincial level.

Similar to the white literature, increasing uptake of HIV testing is identified as a priority with an increase in testing rates of ACB peoples an indicator of success. The high prevalence of stigma surrounding HIV and HIV testing present in the white literature is also identified and highlighted within the grey literature. The bulk of identified priorities within the Strategy are dedicated to reducing stigma associated with HIV and increasing HIV knowledge on all levels of action. Further, the strategy also highlights the importance of faith leaders in ACB communities and their roles in opening discussions and communication about HIV.

Unlike the white literature however, the strategy focuses on enacting change in criminalization laws and policies that negatively affect ACB peoples in Canada. Also, changing the discourse in media coverage is identified as a priority at a provincial or policy level. Further, ACCHO identifies linkage of stakeholders as a priority in order to produce a more holistic understanding of the intersection of HIV vulnerability with culture, biology, education, employment, access to resources, migration experiences and identity.<sup>56</sup>

## **PART THREE: RESULTS & DISCUSSION**

## CHAPTER SEVEN: RESULTS

### Study Sample Overview

Information saturation was judged to have occurred when the total number of participants interviewed and included into the study reached 10 women. Maximal variation was achieved for: age (ranging from 18-over 60 years old); time in Canada (ranging from less than one year to over 20 years); testing status, (with an almost equal number of participants having never been tested for HIV, having undergone testing, but never receiving a positive result, and having tested and received a confirmed positive); immigration status (ranging never immigrating to Canada, to arriving through refugee status, sponsorship, or skilled worker immigration applications). However, maximal variation was not achieved as desired for both religion and country of birth. The majority of participants identified as Christian, with only one woman identifying as Muslim and all participants born outside of Canada were born in an African country.

### Testing Experiences and Perceptions

While a wide variety of experiences with testing was described by the women in the study, one of the more prominent themes to emerge within discourse on testing experiences and perceptions was a concern with confidentiality within the testing process. So much so, that testing experiences were perceived through confidentiality terms: successful testing was defined as achievement of confidentiality while unsuccessful testing was defined as a breach in confidentiality, or an otherwise perceived infringement on one's personal life. As one woman describes:

*...some people don't like it. You know, so, in that case, you have to be confidential. You have to go to people that doesn't know your inner thoughts. Some people don't like it.(Gabrielle)*

Further, experiences of testing within Africa were largely described as a process of navigation through services to achieve confidentiality. Some women relied on family and friends to provide sources of testers that they knew would keep confidentiality, as this woman describes:

*I remember that day, my sister she was-she worked at night, she told me, "you go you look for my friend, my colleague will take your blood." Then I went to look for the friend, she took my blood (Jessica)*

However, others described being unable to utilize social networks to preserve confidentiality and were instead forced to test with people that they would not have chosen. For example, one

woman describes being tested for immigration requirements by her family doctor, who was also her religious pastor:

*When I was-when I was come to Canada, I had to like, a medical...whatever. And then, um, when I went in, the doctor was like, doing like, a um...body check-up...Then he asked me if I-if I was sexually active, and I said yes. But then I was 17. So then, then he actually was almost going to tell my mom. It's supposed to be private, right? Like, doctor-client, confidential... (Catherine)*

Further, although all participants spoke of the need for confidentiality, many also described experiences in Africa where testing was a public affair and in fact, a requirement for marriage, jobs, or other important life stages, thereby problematizing confidentiality while also removing agency in HIV testing. As these women describe:

*I had to[to test] for orientation and training. (Gabrielle)*

*Yeah, once you get married, you have to do the HIV in the-in a hospital...In a government hospital. You don't with the private or a specific because they want to be sure you are not bringing any fake results [...]So do it in a government place-hospital. (Fiona)*

Although many participants described seeking personal acquaintances for testing, they did so in an effort to preserve confidentiality, as this was one way they perceived they could achieve it. However, if one did not seek a test in Africa, a public, involuntary testing experience was described. Further, most of the women that had undergone HIV testing at least once in their lifetime explained that they were tested for HIV as a Canadian immigration requirement. Therefore, even though participants were largely tested within their home country for immigration procedures, their first experience with testing in Canada was not a wholly voluntary experience and contributed to their perceptions of HIV testing as a requirement to necessary life goals or stages, even within Canada. In other words, the perception of HIV testing as a necessary procedure for important life stages within their home countries of Africa was re-enforced by their experiences with Canadian immigration procedures.

Few of the women had actually been tested within Canada, but most of those that had were tested by their family doctor and found the experience to be problematic, especially in terms of confidentiality. One woman described being contacted via contact tracing and seeking a confirmatory test with her family doctor where she experienced a positive diagnosis. Again, her experience of receiving a positive test result is described in terms of confidentiality and the perception of a breach in confidence:

**Participant:** *So he did the test. His nurse called me. And said, that—you know, the tests were ready to show up so I went to the clinic and as soon as I came in—“Oh! Yes it’s you! You’re (participant’s name)! Okay, yeah, um--.” You know, she’s—this is a woman I have seen for over a year!*

**Interviewer:** *So you felt like there was a definite difference in the way that she talked to you?*

**Participant:** *I wasn’t feeling, I saw it! Yeah! Yeah, yeah, yeah. And she’s calling people—“That’s the person I was telling you about.” ...I’m thinking this is unfair!... “That’s the person I was telling—that’s the one I was talking to you about” And she says it loudly enough for me to hear! (Angelica)*

Another woman describes her experience with a family doctor providing risk-based testing:

*You know, I felt like when I told my doctor that I want to get tested, she said, “You know, are you sexually active? How many partners do you have?”, you know? And I said, I’m actually not sexually active, and I don’t-which means I don’t have any partners- “So then, why do you want to get tested?!” and I said, “I want to know my status!” So actually-honestly, for me, it was-to say, she did give me this look like-“Okay, so you’re lying to me, maybe you’re sleeping around,” you know? So if someone, someone is not firm enough they will-of course you will feel judged, because as much as she’s a medical practitioner, she-she’s like, “Why do you want to get tested if you’re saying that you’re not doing anything that puts you at risk?” “’Cause I want to know, you know?” So, and-and the test is free and I’m not going to ask for the test everyday, I don’t-you know, use the resources just for nothing, but right now I want to know, you know? So...So I can imagine another person who is not in the HIV field if they-if they already feel that their doctor is looking at them in a certain way, or starts-or puts them in a certain box now that they didn’t belong to... (Beatriz)*

Here too, there is a focus on a breach in confidence, or an intrusion of privacy as the participant felt that she had to not only defend her request for a test, but also defend her moral integrity.

The described experiences and perceptions of testing in Canada were by and large not described as positive and did not dispel the common narrative surrounding HIV testing within the countries of birth of participants. In other words, the HIV testing experiences described in Africa were not demonstrably different to described experiences in Canada, and thus no counter narrative of a safe, secure test is being (re)produced.

## Stigmas and Taboos

In this case, it is especially important to note that the woman above describes feeling judged, especially in a moral sense. This is extremely problematic when one understands the complex stigmas and taboos associated with HIV and sexual morality within ACB communities in Canada. No theme emerged as prominently, or with as much weight, within the study as the theme of HIV stigma. HIV stigma within ACB communities is in some ways a many headed hydra, as it is so abundant and so difficult to eradicate. The miasma of stigma clouds discussions

and communications concerning HIV as well as associated HIV testing via cultural taboos. As these participants describe:

*Um, errr...from what I've heard though from other people and what it's like in the ACB community here, it's just really hush, hush, and we don't talk about it. If you feel like something's wrong, you don't talk about it, you just handle it privately.(Denise)*

**Interviewer:** *Mm-hmm. Okay, and how do you think HIV testing is viewed in your community?*

**Participant:** *Taboo. Yeah. It's not something people talk about it, it's not something that people- just ignore-that this-there's nothing there like HIV um, or there is, but it's not um, in our community it doesn't belong here.[...] Something that I never thought would be a comfortable topic...and something that I never thought um, that I'm comfortable talking about it...[...] So this is something that I know people in Africa had HIV, but never talked about it, or never discussed anything about HIV. I heard more about TB than HIV! [...] So, for that matter I would just say it's not something people talk about it. It's just hidden and people don't know about it (Aminata)*

This taboo creates a culture of silence around the topic of HIV in general, resulting in strong discomfort and/or refusal concerning any discourse of HIV or associated HIV testing, even within private settings, such as among close friends and family. This complete lack of open discourse creates a barrier to any HIV prevention messaging and HIV testing information.

Further, participants explained that this taboo is not limited to HIV, as it is largely grounded within cultural taboos surrounding sexuality and sex that existed prior to the introduction of HIV. Therefore, as HIV is primarily viewed as a sexually contracted disease, the cultural taboo surrounding sex is extended to HIV as well. As this participant describes:

**Participant:** *Yeah, like a lot of ACB groups, anything that has to do with sex is more taboo. Um...so yeah, I think that's really it. It can be anything else, but it's HIV and it's an STI, so there you go. It's just a sex thing. Even if you didn't get it by having sex with someone, even if you got it by sharing a syringe or something...And so, when it first came out and even now, it's just like, "Oh, it's sex, it's sex,"...sexually transmitted thing. I think it's just the fact that sex is really taboo.*

**Interviewer:** *Okay. And you mentioned before that's like culturally and religiously, that's why....*

**Participant:** *Yeah, culturally and religiously sex is something that you don't-it's never a public conversation and it shouldn't be a public conversation...If it's happening in public, it's happening in a private-public place, as in your doctor's office kind of thing. (Denise)*

This conflation of sexuality with HIV makes understandings of HIV risk problematic, as current HIV prevention and testing messaging cannot penetrate the layered taboos surrounding sexuality and HIV.

## HIV & Morality

In particular, as sexuality is also closely monitored within religious teachings and gender dynamics, some participants spoke of the difficulty in accessing testing specifically as a woman.

They described seeking HIV testing as a potentially stigmatizing endeavor, as seeking a test is equated with participating in acts against religious and cultural teachings:

*How...men....like, men are like the be-all end all and like, the women are just there to serve, right? And that-that actually also has-it also affects like, STDs and getting tested, because if the woman is like, being her own person and she's doing what she wants, and having sex with a lot of people...And she like-getting tested might be difficult for her, in like, an African community, because then, she's like, they'll single her out like, "She's the one. She's the one who's' going around and sleeping with different people. She's a slut, she's a whore." So, it's very difficult in African-well, in Africa, it's very difficult for like, yeah, things like that and....(Catherine)*

*There's the assumption that, like if you're getting tested for anything like that, you must feel that there is a good chance of you having it. Yeah, so that's like, people are like, "Oh, are you sure you're not just getting tested because you're worried that you have it?" As opposed to just have peace of mind and have it out there. (Denise)*

As these participants explain, the link between HIV and morality results in members of the ACB community assessing their HIV risk based on self-assessments of their moral character instead of risk behaviors. As these participants explain:

*—'cause when I went in to do the test I said, "you know, I don't even know why I'm doing this test, 'cause I know it's going to be negative." I know for sure I don't have HIV. I'm not the kind of person who gets HIV, I'm too hard working and I have three kids who depend on me (Angelica)*

*A lot of the people uh, who-a lot of-especially African-Caribbean people...Are faith based. Are-are-are spiritual and they associate with a certain faith, whether is it Christianity or-or-or Islam...So they are-you know? So, they...so their spiritual-they belong to a certain faith. And then, when you come and look at those faiths, they usually expect people to be (sighs/laughs), you know? Whether there is such a thing as holy, but they are expected to behave in a certain way, you know? So, there is no- and then, unfortunately, HIV is associated with-with uh, sex, or promiscuity, not even just sex. People don't see that you can-you can have sex with your husband or your wife and get HIV. They think you must be sleeping around, so there is promiscuity associated with that-and people who are Christians, who are good people, don't do stuff like that, you know? (Beatriz)*

Therefore, as the participants illustrate above, good morals would dictate *against* test seeking behaviors. The taboos surrounding sexual health and HIV enact wide gulfs of silence that serve as barriers in attaining necessary information about HIV risk behaviors, leading to misconceptions of HIV risk being grounded within self-perceptions of morality that continue to remain unchallenged due to the lack of discourse. Further, these taboos and stigmas are re-enacted via social judgement, which polices women's sexual health in particular and ultimately creates a climate in which seeking an HIV test requires navigation through personal and social judgements of one's character and willingness to culturally transgress.

Unsurprisingly then, HIV testing was not often sought as a means to routinely check one's health. Instead, testing was only sought after first being encouraged by others to be tested. This encouragement was usually at the behest of people occupying positions of authority within the lives of the participants, (such as a doctor), or positions of trust, (such as family members). However, this encouragement to be tested occurred only *after* the appearance of HIV/AIDS symptoms within the participants, or after it was known that they were in contact with HIV due to contact tracing, as these women describe:

**Interviewer:** *The doctor sent you?*

**Participant:** *Yes, because I was very, very sick. I don't know...He sent me to the laboratory to test. (Ingrid)*

*Yeah, I was tested in my country-I was sick. I was really sick. And uh, I had to do it, because I was really sick...I had a sister, I had a sister who was a nurse, and then she told me, "you know what" [...] So my sister told me, "Why don't you go and test if you are positive" (Jessica)*

*Yeah, what happened was --I didn't, I mean-- I was in a monogamous relationship and I got a call from public health saying to me that I was exposed to the HIV virus and I needed to get tested so I booked an appointment and I went in. (Angelica)*

Therefore, test seeking was depicted as either a confrontation with one's morality and sense of self that carried real risks of confidentiality breaches resulting in intense social stigma and isolation, or a confrontation with one's mortality. It is not surprising then that most participants in the study did not seek testing and those that did usually did so only after the urging of loved ones or clinicians.

Further, social judgements of character and associated stigma were described as not restricted to the individual obtaining an HIV test. If a positive diagnosis is given, or if the community believed a positive diagnosis has occurred, the person living with HIV (or suspected of living with HIV) is then burdened with the knowledge that their families may also be stigmatized. Therefore, participants described not undergoing testing as a resiliency strategy to protect loved ones. As this participant describes:

**Participant:** *So it is uh,- there is stigma associated with that as well...And people would easily say, "Oh! That's little Mary" "Oh! The one who's mother has HIV", you know?So...*

**Interviewer:** *So it extends...*

**Participant:** *Yeah.*

**Interviewer:** *With family as well. Okay.*

**Participant:** *It extends with family, so people don't want that as well. So people don't want that. And it will go further like, even when this little Mary is getting married, it's like, "You're getting married to the girl whose mother died of HIV?" (Beatriz)*

Therefore, yet again, stigma serves as a barrier to accessing testing, as a woman belonging to ACB communities in Canada may also consider not testing as protecting not only themselves from stigma, but also their family and descendants. The cultural logic being that not testing for HIV ensures no stigma will be conferred upon one's loved ones, while testing for HIV creates a possibility of a positive status and familial stigma; thereby grounding the belief that it is better not to know.

This belief that it is better not to know is compacted with the reality of criminalization in Canada. Fear of judicial effects in the case of a positive test result also emerged as a barrier to accessing testing. Participants explained how not getting tested could be used as a resiliency strategy in cases of criminalization, as technically not obtaining a confirmed positive diagnosis could be protective in a court case:

*So, that's what that is, and also, I think in Canada, now most of us know that if you don't tell your partners that you don't have any STI and you go around with them, that is a crime. um, and it's just-it's illegal but then people want to be able to-if anything were to happen, like worse case scenario, you want to be able to stand in a court, put your hand on a bible and say, "I didn't know", because even if you knew, knew, you didn't technically...Down to the very medical truth about... (Denise)*

*Nobody wants to get tested. 'Cause if you get tested, then you know, and most likely you'll get criminalized. Yeah. Nobody wants to get tested anymore. Everybody's really scared. (Angelica)*

Therefore, criminalization serves to underline the existing cultural belief that "it is better not to know" as well as the association between HIV and morality. Again, undergoing an HIV test creates a space for grave, negative consequences if the results are positive, such as criminality, and not seeking a test serves as protection from such negative consequences.

### **Taboos and Silence**

While the association between HIV and morality interacted and intersected in varied ways to act against accessing HIV testing, the continued silence due to social taboos ensures this association remains uncontested. The lack of a counter-narrative to the stigmatizing effects of a positive HIV diagnosis within communications among those in ACB communities results in misinformation about HIV disease progression, risk, and transmission that continues to be perpetuated without challenge.

Participants widely described that one of the largest barriers to HIV testing in their communities is the belief that HIV diagnosis is equivalent to a death sentence and that not knowing one's status is better than receiving the death sentence of a positive HIV diagnosis. The

emergent theme of “it’s better not to know” again appeared, as participants described the common narrative that if you are not confirmed as being HIV positive, you cannot die from HIV.

As these participants explain:

*A lot of people are afraid to get tested. So, whether they are-whether they perceive themselves at risk or not, they are afraid to be tested. Um...they are just afraid, you know, they don't know what the results will be and a lot of times, it's like-and I think, some of this comes from their countries of origin where HIV is equal to a death sentence, so I lot of times they're like, "I'd rather not know. If I'm dying, let me just die slowly." (Beatriz)*

*But you know, it's normal, it's normal. Even for me, that I am even-I know everything about it. I got scared. So I can't blame people for that. But there are many people that are running away-"Ah! No, no, no, no, no. I don't want to hear my death sentence. I don't want to hear! It's better for me to not know!" (Gabrielle)*

Despite acknowledgement that HIV is no longer a death sentence, the lack of space within ACB communities to discuss living with HIV perpetuates an uncontested climate of fear. The only narrative remains that of death, as there is currently a lack of space to create a narrative of living with HIV. Therefore, test seeking becomes a confrontation with one’s own mortality, resulting in a huge barrier to testing.

The combined effects of internalized stigmas and enacted taboos surrounding HIV discourse result in a lack of communication and therefore knowledge and understanding of HIV risk. These misunderstandings negatively impact testing as people believe themselves not to be at risk despite participation in risk behaviors. As one participant explains; her friends do not access testing due to their perceived safety owing to their own methods of prevention:

*I know that most of my friends are sexually active and um, they're fairly open to things as well, but they trust their own methods of prevention for anything and they are very secure in that, as opposed to trying to get a second opinion. So that's about as far as that went, but again, it's not very personal or directly targeted towards anyone. It's more general. [...]...for example, somebody knows like, "oh, my screening process for the people that I get involved with sexually is safe and it's secure and it's worked so far." So, if anything were to happen, I would be the first to know and there's no need for me to go get tested for anything. They just feel as though there is nothing they can find out through testing that they wouldn't already know. (Denise)*

Further, even if one decides to get tested, the lack of communication results in not knowing how or where one would attain an HIV test. As this conversation demonstrates:

**Interviewer:** Okay...okay. Um...Oh, if you wanted to get tested in Canada, how would you go about it?

**Participant:** I don't see- I don't know. I don't know.

**Interviewer:** Yeah? Have you ever been encouraged to get tested in Canada?

**Participant:** Not at all. Not at all. (Fiona)

The silence enacted through internalized cultural taboos results in misunderstandings of HIV and perpetuation of commonly held erroneous beliefs, such as one has to “look HIV” before they should access testing, as this participant explains:

*So, people would feel, "I have to feel very sick and start losing weight to have HIV. I don't have that and I'm fine." And I tell them, no, you don't have to- anyway, you don't have to lose weight, you don't have to be very sick to have HIV-especially because we know people in the ACB community are getting the HIV diagnosis when-either when they are very, very, sick, or when women are going through prenatal. (Beatriz)*

*Oh no, no, no, no. "It's okay. Ah! You haven't got tested, you're good. You don't look like—you don't look HIV." (Angelica)*

In particular, misinformation concerning HIV transmission was prevalent:

*And that obviously, people who have AIDS, they're already there- like, (uncomfortable chuckle) they kind of infect you like-just by touching you.[...] And I didn't know that you couldn't um, transmit HIV through spit! (Catherine)*

*It's not all-even if you kiss them-someone who is HIV [...] but still I can't kiss someone I know is HIV! Ah-hah, so you know?(Fiona)*

*...because in the village, if they know someone is HIV positive, maybe there is party somewhere, and the one who is HIV positive coming, maybe touch something-maybe a food or thing, you gonna throw it away.(Jessica)*

These misunderstandings are perpetuated and recreated through time and space and immigration waves, as the silence enacted by cultural taboos remains uncontested. The lack of a counter-narrative with as much strength as the stigmatizing narratives currently operating within ACB communities serves to maintain a climate of fear and stigmatization resulting in the general concept that it is simply better to not get tested for HIV.

Further, no counter narrative was described through pre- and/or post- HIV test counselling, largely due to the fact that few women in the study described receiving either pre- or post- test counselling. This may in large part be due to the fact that many participants were tested for immigration or other requirements, and as such, negative tests resulted in not being contacted again, as blood was taken in labs or other venues where one would only be contacted in the case of a positive result.

However, even the women in the study who *had* received a confirmed positive diagnosis of HIV in Africa did not describe receiving counseling, contributing to their belief that they had just received a death sentence instead of a manageable disease, as one woman makes clear:

*...after two weeks, we used to go there for two weeks, then it was positive. Okay. I was not surprised anyways, I was not surprised. I was walking...I found those-uh, in Africa, we have kids on the road, they have where you can weight your weight. You pay some coins then you stand on- so I did. Oh my goodness! I had 56 kilos! 56! Normally I have 80's...I was asking that boy-"is this working right?" "Yeah, it's working". I said, "Aha. Now I'm gonna die." My sisters was telling me, "Come to our house, maybe we can take care of you". I said, "No. I don't want to bother people." I was dead. So okay, I'm gonna go and die. I'm not gonna stay for long- I don't die at my house alone. I went to my sister, for dying. I knew I was dying. (Jessica)*

In Canada, however, counseling experiences for those who received a positive diagnosis or test result in the study were mixed. One participant described her counseling experience with her family doctor as non-existent:

*So I came back and they're like "Oh, we don't know how you're gonna take this." I was just in the room with the doctor-"yeah, but uh, you're positive, and uh, yeah, we can give you a list..." I'm like, "Okay, so what do I do now? What does that mean?" "Oh, we don't know, we're not specialists here. We don't know how it works but we'll just give you a list of doctors you can call and uh, see somebody and get help" (doctor saying this to her) That was it. I said, "Help for what?" "Oh, they'll tell you how to manage your HIV." (pause) That. Was. It. (Angelica)*

This lack of counseling even within Canada, again served to keep cultural taboos and misinformation unchallenged. However, even when one woman's doctor in Canada attempted to provide post-test counseling due to a confirmed positive diagnosis through refugee immigration screening, she described how she was not able to listen to or absorb the information at the time due to previous trauma within her home country:

*Why is it now that I am positive? I said that I'm not it. Why did I seek asylum if I knew that I am already dead? When I came to Canada...please no. The doctor was just talking to me, telling me "No! Don't say that you-you will come back to me in five years time." I said, "I'm not living 'til five years." No. Then, I went-he was talking to me, talking to me, I didn't listen. I left the doctor. (Helena)*

Pre- and post- HIV test counseling in Africa was simply not a common theme among participants in this study regardless of whether the test was reactive or not. In Canada, this lack of counselling went largely unchallenged resulting in missed opportunities for provision of a counter narrative while also allowing the perpetuation of misunderstandings of HIV risk, transmission and disease progression. Further, the internalization of HIV diagnosis as a death sentence proved so engrained that even when counselling was offered, it proved extremely difficult for one participant to be receptive at that point in time suggesting the importance of continued outreach and counseling.

The internalization of stigma and cultural taboos surrounding HIV and the link between HIV, morality, and sexuality leads to a palimpsest of layered stigma where teasing out where one

begins and the other ends is extremely difficult. Although it could be argued that an exact understanding of the cultural stigma and taboos surrounding HIV is unnecessary, I believe it is vitally important for HIV prevention messaging. If HIV is associated with taboos surrounding sexuality, then messaging needs to navigate around these taboos, while also navigating morality norms and mores, as well as the association between HIV and death. It is obvious that the current messaging methods are simply not penetrating enacted cultural silences and layers of associated stigmas.

### **Living with HIV: Provision of a Counter Narrative**

For those who participated in the study and had received a confirmed diagnosis of HIV, descriptions of living with the disease were focused on a process of un-layering of internalized stigmas and silences. Essentially, living with HIV was described as a counter narrative to those previously described as being produced and reproduced within ACB communities. Participants spoke of the first thoughts after a positive HIV diagnosis as centered on the concept of HIV diagnosis as a death sentence. As these women illustrate:

*You know, they said once have it, you are gone...And they say once you have HIV, the next step the person dies. So, it's very scary up 'til some years back now they said "no, you can take care of yourself, we have drugs to care for HIV". [...]yeah, and you know it kills people..so....I think now that....I think the fear is once you know you will not be balanced. [...]If I found out I'm HIV positive, that's the end of-to me that's the end of the world. Because....I will not see anything good-I would not be ready for my test-'cause i would not believe it. 'Cause I know someone who has it, and she died.(Fiona)*

*I was freaking out every day and my kids—I couldn't even tell them yet 'cause I didn't know—I wanted to have you know, positive, you know, information to give them. I'm not just gonna say I'm positive, I'm dying. And, you know, I didn't even know if I was dying or not. I didn't know what I was gonna do with this thing; Okay, how does this work, how do I manage this? (Angelica)*

As the women described, even though awareness of medication is demonstrated, common misconceptions within the community contribute to an instinctual fear that a positive HIV diagnosis is equivalent to a death sentence. Further, women in the study described how this misconception of a positive HIV diagnosis as equivalent to a death sentence often lead to a process of self-isolation, as these women describe:

*Then, I went back to the shelter but I couldn't stay in the midst of people. I thought everybody had known. I don't want to stay with people. I was so much scared, I was ashamed of myself. How did I get this?! I was thinking back from-where? when? how?! I was just thinking of so many things that were-then, I -I isolated myself there-I had been in the room but the workers at the shelter they came to me every morning. They checked the room, "Come out. You have to come*

*downstairs-“Have you had your breakfast?” They checked me every second. But, I don't want to see anybody. I thought everybody had known. They spoke to me, but I couldn't. (Helena)*

*No, I didn't have it because I didn't go anywhere. You know...I was home and if I had to go out, I had a care there taking me out. I didn't want even go where people are, only my family and my friend come to see me inside my house. (Jessica)*

As Helena describes above, even with others not isolating her and in fact, trying to communicate with her, her internalization of the stigmas associated with HIV prevented her from social interactions. These patterns of isolation were described as both self-inflicted due to internalization and fear of stigmatization *and* as witnessed experiences of others, as one participant describes of her experience of witnessing extreme social isolation of an elderly woman who was diagnosed with HIV in Africa:

*Like, I went back home a couple of years ago and we went over to visit one of my mom's uncles and when we were leaving, this old lady was just you know like, in um, in like a room that is detached from the hut, almost like a smaller house. She was just chillin' out there. And I figured it was maybe because she was sick or something like that, because she was just lying down all day, blah, blah. But that's when my mom told me that it was actually because she had been diagnosed with HIV and because even like, her uncle wasn't really sure about how to handle it. A lot of people in the village just stopped coming to see her and so they knew she had HIV and she became ostracized for it. And in a lot of ways, it actually deteriorated her health, because there was nothing to keep her active, and healthy and happy and all she had to do was pretty much stay home all day because she became a pariah. (Denise)*

Therefore, fear of anticipated stigma due to past experiences of witnessing the social stigmatization of others produced a process of self-isolation. This isolation was seen as a death in and of itself, as one participant explains:

*To live with HIV alone can kill you. No one to talk to. This is different. The first medicine better than the medicine we are taking-to have someone to talk to. To be free with you, with your situation. (Jessica)*

As described above, women in the study spoke to the importance of socializing those who had been positively diagnosed with HIV as soon as possible. This process of re-integration of those living with HIV was seen as providing a powerful counter narrative to all of the negative misconceptions and experiences of HIV in ACB communities, as Jessica explains:

**Participant:** *Let me tell you something, I have been with the community-there's some people comes here, you know when you come, the first thing you do is medical. [...] You don't know anyone here. You've just arrived. You went for-through immigration papers. They're telling you you are HIV positive. I saw them. Two of them, they wanted to kill themselves. They wanted to-they were crying. So now, they-the counseling helps allot. To meet other people who are like you-I remember I met one, she came to you know (community worker's name). She was crying, crying. You were crying, don't worry, tomorrow it will be okay. Come Saturday, (you know sometimes we have a group on Saturdays)*

**Interviewer:** *with the food?*

**Participant:** *Yeah. So. We were there, some beautiful women, it was summertime, we put our African clothes-they look at those-all of them, "Do you think-do you see any HIV with them?" Are you sure this one is sick? This one is sick too? Are you sure this one-Yes. So don't worry. Wipe your tears. Now she's like "Ah!" (laughs) I think to talk about it, to be with other people like you, helps really, really, allot. [...] No way. I'm telling you now, that woman is telling me she's really happy. She's the happiest woman in my life, she's happy! She was crying from morning from night. When she met other people.... (Jessica)*

Further, participants expressed the importance of providing social connections to those recently diagnosed as soon as possible as this was seen as an important first step, as the misconception of HIV as a death sentence may be leading some women to suicide ideation and other harms.

However, although the importance of timely social integration was expressed as extremely important, participants described how timely integration was an exception, with long wait times the rule, as Jessica explains:

*Yeah. That woman, she was going to find a bridge somewhere...me I was lucky. [...] And when they come, the first, you know when you go to-they, they should right away to direct you to the ACB community board or immigration doctors; they are the ones who see you the first time-they should-because I met some people who stayed there even three-five, years! Without knowing. It's a big group. They didn't know that. Me, I was lucky, the second day I showed up, they gave me the number of (ACB worker). I called she told me, "Okay, you come here and here" Me, I didn't know where to go.(Jessica)*

The few who were able to access timely services did so due to their own social networks, as Ingrid demonstrates:

**Interviewer:** *Uh, how did you find out about [AIDS service organization]?*

**Participant:** *I have my friend, she's HIV positive, she was living with me in [wester ontario town] and she came before me to Ottawa and when I came to Ottawa she showed me too.(Ingrid)*

Again, the process of access to services is similar to some participants' previous experiences in Africa where health services such as HIV testing, were best found through social contacts.

Therefore, even though living with HIV and experiencing social integration is itself a counter-narrative to previous experiences in Africa, the pathways to care mimic those experienced in Africa. Further, participants expressed the importance of connections to other ACB women living with HIV as being greatly facilitated by those of similar linguistic or cultural affiliation.

As Helena explains:

*And, so yes, I started coming. I went there. She told me that every last-second to the last Saturday of the month there used to be a group of African-Caribbean women-a help network I should come and join them. Then I went there the first time. The second time I went there, that was when I met*

*[another person who works with AIDS service organization]. I was just talking on the phone and uh, just-somebody just said on the phone my language. "Oh! You are my sister!" (said by person working with AIDS service organization) Because I heard her speaking French, I never thought...So I said, "How can I be your sister?" and she spoke my language. Then I said, "Oh." Then she said, "Okay" Then, I said I didn't have-"You have anybody?" I said no. "Okay, tomorrow we'll take-" she brought me to, she took me to a um, some places you have to go this, you have to do this, do that. I started coming, she comes to me like, I go with her. I started going to [AIDS service organization] every time. (Helena)*

The linkage to medical care was not described as enough to truly counter the narratives produced and reproduced within ACB communities; participants described linkage to care as particularly successful when they were approached by those of similar linguistic and cultural affiliation and that this care was focused less on medication and more on social integration with others of similar backgrounds also living with HIV.

### **Disclosure of HIV Status:**

Perhaps not surprisingly, participants were much more concerned with their mortality and social isolation than disclosing to their sexual partners. Despite much public health emphasis placed on the importance of disclosure to sexual partners, women in the study expressed reluctance to disclose to sexual partners. As Catherine explains when asked if she would tell her sexual partner if she received a confirmed diagnosis of HIV:

*I mean, probably 'cause then, like-and like, if I had a partner and then I got HIV I'd probably want to know how I got it...So then, yeah...Probably, yeah. Probably...But if I knew I got it from somewhere else...I don't know...(Catherine)*

Further, as an HIV prevention worker explains, even with appropriate supports, complex gender dynamics interact to create situations in which non-disclosing may be preferable:

**Participant:** *Yeah, we-I've had- I've not had very many experiences, but the few experiences I've had, the woman will not go home and tell their husband, "By the way, I tested positive." They usually, uh, work with someone, either from public health or an AIDS services organization to- to share-to do the disclosure to their partners. Yeah, they are very much afraid. They are like, "Oh, my god, how am I going to tell this to my husband, he is going to kill me." or whatever, you know? So, it's always very difficult because the man will be like, "You got AIDS, you brought AIDS to the family." And um, so it is always difficult for the woman, and uh-and uh-yeah. (nervous laugh)*

**Interviewer:** *Right, so there's that idea of you brought AIDS to the family.*

**Participant:** *Yeah, so regardless of how it has happened-so-so that is always a problem. And um, we usually help-so we always have to come and step in and encourage the woman to tell the husband, uh, definitely to disclose their status. Uh, um...but it is always, it is always the biggest fear that they have, "How am I going to tell him, what is he going to say to me?" Stuff like that and you see men walk away and divorce, or separate from the women and refuse to get tested. So, so the woman carries the whole burden and they will swear that they never stepped out of this marriage and I never slept with anyone. And unless they got HIV through other means, which is*

*not likely in Canada, if they were negative when they came to Canada, it's unlikely that they got through blood transfusions or anything like that. But, sometimes you see the men saying, "You know what? You have AIDS, I'm leaving." You know, but they-to my own knowledge, to the best of my knowledge, the experiences that I've heard supporting people, the men walk away or they do not get tested. Or, they go and get tested secretly but we do not know about it.*

**Interviewer:** *Okay. So it carries a lot of consequence if you do find out.*

**Participant:** *Yes, if you do find out. Okay, and the burden, actually the guilt. I've seen a lot of times it's the guilt the woman carries a lot of guilt because she has been told, "You brought AIDS", "You have AIDS", "You've got AIDS", you know? So, that is-that is-the women do have that. They are more likely to get tested. One, they are more likely to get tested because they are accessing health care services more so they are likely to take the test if the doctor recommended it, or whatever, even if they don't request it. Depending on their symptoms, especially the compulsory testing-the almost compulsory testing during prenatal...So they might need to get-get the diagnosis before the men do, but that does not translate into a better life for them. And then we have hard cases where the men do know their status and they don't share it with the woman, so she comes to learn much, much, later and the woman still doesn't disclose. So the man knows what he knows and the woman is killing herself, thinking, wondering how she got HIV because her husband is negative, which is not necessarily the case. Yeah, so -so women have disadvantage as well, and I think women are more likely to share any diagnosis with their spouses more than men, you know? Because they are macho, they're strong and whatever it is. They might get a diagnosis and keep it to themselves, whatever it is. But uh, but the woman shares it, sometimes to her detriment, but in most cases, the doctors and public health encourage the woman, the person to disclose, to share the diagnosis with their partners, they are supposed to disclose. Yeah, so there is always a fear of "If I test positive, what am I going to do?" (Beatriz)*

Others expressed apathy toward disclosure as it was simply not possible for them or others they knew based on their particular experiences and circumstances, as one woman explains of the Rwandan genocide:

**Participant:** *I knew where I got it, I knew how I got it. Not only me, but all women, most of them.*

**Interviewer:** *Experienced the same thing....*

**Participant:** *Yeah. Because they are killing our husband, raping women....if you are lucky you don't get it, if you are bad lucky, you get it. (Jessica)*

Therefore, women in the study expressed that if they were to disclose their status to anyone, it would be to mothers, sisters and children instead of sexual partners, but usually only to protect those they loved. As Helena describes:

*You want to know by yourself. Keep it to yourself. Like, one time I wanted to disclose with my sister. So when I heard the way they were talking about it, as if the life of that person has ended, I stopped. So....I didn't say it. I didn't tell anybody from my family. I don't want to say it. I can say it later, but I don't want-the only thing I did was-when my daughter (because I still have one daughter) was telling me "I have fever". I said, "Go and do HIV test." She told me she did and sent me a copy and said it's negative. (Helena)*

It is apparent that the focus on those living with HIV within the study was focused on living with the disease and negotiating social stigmas within their communities. They described how the

diagnosis of HIV is a process of removing internalized stigmas and misconceptions that lead one to believe that they have received a death sentence. Therefore, culturally sensitive counselling procedures should place focus on dispelling these fears and providing cultural and linguistically similar linkages to care instead of focusing on partner disclosure, so that those living with HIV may then be able to provide a counter narrative to common misconceptions among ACB communities for themselves as well as others.

### “And then what?": Strategies to Improve Testing

Just as the most prevalent theme within conversations of testing was stigma, the recommended strategies for increasing testing largely focused on the need to decrease stigma and internalized cultural taboos that inhibit open conversations of HIV and sexual health. Therefore, all recommendations and strategies for increasing testing were centered on eliminating or navigating around stigma and cultural taboos. As this participant explains:

*Target the stigmas that surround it. Um, make it more of just like, a regular health thing. Because usually if you attach so many things, then it seems like it's a special area of health as opposed to a general area of health. So if it's more than just, just a sexual health thing within a general health structure, Then I think that's the thing-like, if you find yourself in 15 years being able to go to the doctor and having HIV testing be part of your regular screening....I think that's something that would help this-little steps to take away the stigma. Um, but beyond that I think that a lot of the other things you can do are already in place. Like, anonymous testing is offered and it's widely available, we just don't know about it. And not for lack of people advertising, just because we tend to pay attention to the things that we think we need. So if we don't think it's relevant to us then we don't need it. And we just don't pay attention to it.(Denise)*

As another participant explains:

*Maybe I agree; testing should be—testing is very important, but let's fix the “and then what?”(Angelica)*

Furthering the idea of “and then what”, integration into society and reducing isolation associated with stigma was identified as key components to one’s mental and physical health:

*And then yeah, just how to help somebody make sure they're taking extra care of their health because they'll have to now. And how to be aware of that. (pause) 'Cause generally we're not isolated people, so if you forget to take medicine for something you have to be able to make sure people you're around the most often can tell you-remind you. So things like that.(Denise)*

*To live with HIV alone can kill you. No one to talk to. This is different. The first medicine better than the medicine we are taking-to have someone to talk to. To be free with you, with your situation. Not just to hide inside. (Jessica)*

Therefore, although types of testing were discussed, they emerged as peripheral to the theme of stigma reduction and navigation. Anonymous testing was largely endorsed as a good method as it was perceived to mitigate stigma and the possible after-effects of testing. As this participant describes:

*...I know you can be tested for HIV and become anonymous which would give me more security to feel like, "Oh, if I get tested uh, not like before, if I get tested maybe police will come after me or the community or somebody that now I know if I get tested it is for my own sanity and I will be cautious and I'll be careful and I'll take medication for that" than uh, just ignoring and uh, just thinking about uh, anonymous part is what makes it easier. That I know I can be anonymous. And get tested and go through point B and point C and you see what I mean? Just to go and find-look for help or medication or counseling...and just prepare me to-to deal with it. (Aminata)*

As another participant explains, optimal testing was described as the testing method which provided the greatest amount of privacy:

*Except, strangely enough-well, not strangely, but I suppose because usually it is such a taboo topic or, it surrounds such taboo topics it seems more secure than other testing forms...From whatever. Like, if I go to the doctor now as opposed if I come here[community health organization]-to choose to get tested or whatever, to choose to get anonymously tested, I don't know if the experience at the doctor's would feel as private and secure as HIV testing here.(Denise)*

However, participants were much more concerned with the after effects of a positive test, or even the after effects of simply being seen seeking a test within their communities. Thus, strategies largely focused on opening communication, navigating cultural silences, and increasing education as means of combating embedded stigmas.

### **Opening communication and negotiating cultural silences**

One method of reducing stigma surrounding sexual health and HIV provided by participants is through opening communication and negotiating cultural silences. Participants explained that one of the biggest obstacles for increasing HIV messaging is the cultural silences concerning sexuality and therefore HIV; as one woman describes:

*So, but most of the people we have, you know, we're not—many of us do not speak English or French as a first language. There's a linguistic barrier. There's a cultural barrier. We don't talk about sex like that. There is—there is a context in which you talk about sex. We don't have that context here. (Angelica)*

Therefore, opening communication and negotiating cultural silences was viewed as an appropriate method of increasing HIV testing and messaging. As another participant explains:

*So I guess in ways like that—you just—this is where talking is really important, just getting people comfortable with the idea of talking about these, not just privately, but openly. So that the shame is removed from it. A lot of ACB communities come from very religious backgrounds, or from very culturally private backgrounds where information specific to you is private to your immediate family or your close friends. So being able to bring big conversations into smaller spaces, I think. Being able to say, "Hey, I just went and got HIV tested. That's what I was just up to, what's going on with your day?" Yeah, something like that. Have it not be something that warrants its' own conversation or that needs to be taken into another space.(Denise)*

*So, anyway, the more you talk about it, the more people learn about it—the more people—to talk about it here, I don't know how you can do.(Jessica)*

Although many participants described the importance of opening communication, many were confused on how to go about this. Some described a grass roots approach by encouraging and empowering individuals in their communities to subtly open conversations about testing and HIV:

*Personally, just bring it up. You know, like, I don't have a big prescription for general groups of people, but I just bring up things like that...Um, I try not to wait for a specific time to be able to talk about something. Uh, um. And I think that's worked fairly well so far...(Denise)*

*If we have more people getting tested and giving their testimonies as well....And I- I was getting tested and showing people my experience, but I think the fact that I'm a service provider they—they have the feeling that you are not us, you're different from us. you're a service provider. So, if we can have women getting tested and giving their testimony, maybe that will encourage more people to get tested. (Beatriz)*

Others described employing this grass-roots approach by utilizing already existing pathways of communication, such as conversations among close family members to encourage testing:

*'Cause, I know myself and I know that it happened. I encouraged my parents to do it and they did it. My siblings too. Thank god! (Gabrielle)*

*Because when I come there, I have a sister too, the husband was killed she was okay, I told her "you guys, you see where I was. I was almost gone! Why don't you go and test yourself?" So you can see before you get sick, before you reach the way I was! What happened—they were positive too! They had never been sick.(Jessica)*

Many spoke specifically to the importance of empowering people living with HIV (PHA's), as these people were seen as providing a strong counter-narrative to the common misconceptions within ACB communities:

*Yeah. So what—the good thing would be—to probably empower PHA's (people living with HIV/AIDS)Let's get to a place where we can say, "you know what, you're positive--"--You're managing it well, what can we do to help you to speak out? Maybe you don't need to come out. 'Cause most Black PHA's don't want to go into community and say, "Oh I'm a PHA, I take meds, that's why I look so good" (in a big, cocky voice) Most people don't want to do that. But, we can empower—if PHA's only work in HIV already, it's kind of outing yourself. (Angelica)*

*A lot of times when we get uh, people from this-because we are talking about experiences of people living with HIV, that really helps. So we have another kind of speakers where people will say, "I got tested and this is how it felt". You know? So, that would encourage-it is through word of mouth-it is through encouragement and talking about their own experiences that will encourage people to get tested. Also, the fact that you know, if you know your status, oddly enough, you will, you're-you know you're going to get the needed support that you need, so we need to encourage people. And once they know that they are not positive that is a good thing too. You know? Then they can move on with their lives and do everything that they need to do to make sure that they don't-they don't get infected.(Beatriz)*

Empowering PHA's was discussed as a helpful strategy for reducing stigma surrounding HIV by dispelling notions of common misperceptions, such as one must "look HIV" or being morally corrupt to contract the disease and providing counter narratives. As one participant describes from her own experience:

**Participant:** *Yeah! So, I was okay with prayers, I started feeling alive. I was not scared of dying. I was-even I was asking God to take me that way-I could see the family was suffering, they could see me...eh. And one day, another lady came to visit me, she told me about those groups for people who are living with HIV. And then she told me, "Why don't you come with me and see what is happening there?" She came to pick me up from home! Only then, I was home, only hospitals, and church, that's it.*

**Interviewer:** *Okay, so you didn't go outside the home, or hospital, or..okay.*

**Participant:** *No. My daughter was working-had a good job. She put a taxi on me-when I need to go anywhere from hospitals and called a taxi to pick me, wait for me. I was okay. I was really happy with my family. They were there for me everywhere else. And then the lady came to visit me. She was HIV positive. Very young. Very young lady. She took me to those groups for HIV positive people. When I was there-kids, old women! I said, "Who am i? Look at those kids! Look at that old woman, look at-" I said, "No!" I went to see the chairman of the group, I said, "I want to help you" "Are you sure you want to help me?" I said, "Yes! I want to come here and start help you to help those people! Those are vulnerable people, poor people, without food, without anything. I started working there. Go-wake up and go there, we go to knock the door to ask for money...so. That was me. The HIV's gone. I don't feel anything! That uh, the vomiting is gone! I became me! That's it. So I was working with them, and we go, like, to see people to ask for money, anything. Ask for school fees, those kids who can't afford to pay school fees. I was okay. I think about I'm HIV positive. At that time, the medicine came for free, because the first lady in my country put effort in the HIV. So, we had medicine, everyone now gets medicine for free. So, that's it! I was okay! ...The small kids, the small girls, the old women...I said, "Why am I doing this to me? Look at those kids! They are young! They are born with it! They didn't do anything!" They are living, going to school, so-since that day, I was okay. Never, never go back to depression. I don't even think that I have HIV. (Jessica)*

Another identified pathway to opening communication and negotiating silences was utilizing communication foundations already in place, such as woman-to-woman. As this participant describes:

*I think more education which we are trying to do is going to be important and talking to women alone. Like, exclusively without other people there. Uh, then they will feel safe that they are asking the right questions and not being judged, especially when there are no men making it difficult for them to speak. Uh, so whenever we have the training, we should have the training as much as possible with the women alone? (Beatriz)*

The theme of utilizing existing networks of communication was furthered with discussions of using already created relationships between family physicians or general practitioners and patients as spaces to discuss HIV. As these participants describe:

**Interviewer:** *Yeah, so you're saying that doctors-maybe talking to doctors, the health centre having a good relationship with doctors and then using doctor's to also the get word out-*

**Participant:** *To the client!*

**Interviewer:** *-to the patients. 'cause everyone goes to doctors so...*

**Participant:** *Mm-hmm. Everybody believes mostly what doctors says.*

**Interviewer:** *Mm-hmm. So doctors have a lot of authority.*

**Participant:** *Yeah, yeah, they have voice.(Aminata)*

*I don't know to make people to do test-it's what we are looking for now to make people understand they have to know their status. Which-which strategy we gonna take? You hear people are busy, busy busy! Maybe we can use like, our family doctors? [...]Yeah, our family doctor's now the best way we can get. Yeah, the doctors can talk about it. And your doctor can convince you about it. It's the only way we can make-because flyers-how many people stay in flyers and read? You see so many flyers you pass, you don't care. But I know family doctors can do better than that. You go there they ask you, "Have you had your flu shot?" Even nurses, before you go to their doctor, I don't know if the nurses, maybe the doctor is busy, you can have time to talk about it? Maybe when you go there the nurse taking your...blood pressure, you can mention about something like that.(Jessica)*

Interestingly, as previously discussed, many participants did not obtain testing from their family physicians and in the quote above Jessica actually describes visiting the doctor for a check-up such as for blood pressure. Therefore, although participants did not describe seeking testing from their doctor, they do describe being comfortable with the offer of testing.

Further, utilizing cultural and linguistic similarities to create inroads between community members and frontline workers was another possible strategy to open communication about HIV and associated issues within ACB communities. As one participant describes:

*I think for somebody like [community health centre worker's name] because she's from Kenya, I'm from Kenya, but she's from a different tribal from my own tribal, but the same culture. Almost-we think the same..In-in so many different ways. I mean same ways, but at the same time she thinks the same way I would think or family or anybody else, but I think somebody like [community health centre workers' name] could come into my community here in Ottawa. (Aminata)*

Another venue of opening communications of HIV and related issues was identified as reframing conversations about HIV. One participant describes how it is often disassociated with other diseases, but that the more it is discussed, the more it can be similar to other diseases:

*It's a sickness like health-people here, they think it's a dirty, dirty sickness. It's not like-like diabetic, like cancer, cancer it's okay. Yeah. So the more you talk about it, the more people know about it, take it like another sickness...(Jessica)*

One participant in particular explains a provided a specific strategy to navigate cultural reticence around the term HIV and instead focus on the term “health”:

**Participant:** *But education, education, education. and awareness, awareness in the community. Yeah. And until now I haven't heard [community health care workers' names] uh, here, maybe-i'm not here everyday, I'm just a part-time person, but for them to bring a group of-uh, a number of people to just come and talk about it and say, maybe [community health care worker's name] has discussed that with you-I mean-they go to university, they go to centres, they go to communities but not everybody can come and approach them, because this big name when they put on their kiosk that says, "HIV". People just read and look at it and say, "Wow. If I go there people will think I have HIV to go and talk to those-that-that group there." So they don't, so I would say a few people would approach, just to know "What are you guys doing here? With so HIV?" or it takes-the poster says "Take control of your HIV status-get tested", what does it mean? But some of them they look at the name HIV and they're like, "Ah, few-" not Canadians, I'm talking about other different cultures, obviously Canadians would just go and ask straight up-"Well, you know, can I get your poster or can I get your card?" or they have question, they'll call here at the clinic. But a lot of our people here mostly, they just never get bothered.*

**Interviewer:** *Ah, so um, if-if they do go to these fairs and like you said, they have the poster, what's something else that they could put there to encourage people to just approach and then..*

**Participant:** *This past Thursday [community health worker's name] sat us together to see what topic should we write. Something that will not scare everybody and make it simple and easy-maybe "Get tested". If they come and ask, "Tested for what?" or "Take control of your health" and "get tested" that something that they'll be like, "Okay, they say take control of your health-get tested. What does that mean?" So they can come and ask you, "Oh, we saw that what do you mean by that?" [community health worker's name] can say, "Oh, we-I work in a clinic, I'm an outreach-I'm HIV worker, and this is and that, this is what we do, and here's my card, feel free to call me. And if you want to talk, let's talk."(Aminata)*

Although Aminata was the only participant to provide a specific example or strategy to skirt cultural silences and taboos around HIV, other spoke to the theme of shifting the focus from HIV to more general health. As one participant explains:

*Yeah! So people they have, they have terminal diseases. So okay, they are dying the next three years. For this, HIV is not. You can live as long as you want yourself! Just make-live a positive life that's it. Live a positive life! It's-good diet. Eat vegetables, eat fruits, and you'll be fine! Wear condoms, many things! (Gabrielle)*

### Increasing HIV knowledge and eradicating stigma through education

The need to dispel these common ingrained misconceptions and assumptions among ACB communities emerged as vitally important to reducing stigma and opening conversations.

Participants spoke of eradicating these misunderstandings through various education campaigns.

In particular, the two assumptions viewed as important to dispel were that HIV is a death sentence and that one must be physically demonstrating HIV and AIDS symptoms to be HIV positive. As these participants explain:

*So, people would feel, "I have to feel very sick and start losing weight to have HIV. I don't have that and I'm fine." And I tell them, no, you don't have to- anyway, you don't have to lose weight, you don't have to be very sick to have HIV- especially because we know people in the ACB community are getting the HIV diagnosis when- either when they are very very sick, or when women are going through prenatal. So, you can imagine, you're a woman, planning your life, and you're pregnant, two months pregnant and you go to the doctor and they say you have HIV. That is very devastating, you know? Why not learn this earlier? so that you can get the intervention that you need to have a healthy baby? (Beatriz)*

*Oh. Information. Information is life. Finally, they are really trying. I can see that they are really trying. They should not victimize them. They should improve in the information. Keep improving and um WHO is trying I guess. They are trying. They should just keep on improving. I know some people are not ready to listen. My husband is an MSc and the fear is still there. It's more psychological. The fear is still there. What- whatever it- it would even be the one to encourage- go and do your test- what is the result? He will ask me. But for him to go to get it (laughs) The fear is there. So they should- even if they are- it's not the end, you know? There should be this kind of information through media houses through the um, social website and it's not the same things they should go for. (Gabrielle)*

Further to the need for education, similar to utilizing existing communication networks, the theme of utilizing existing education spaces was identified as a method of increasing HIV knowledge. Specifically, some participants described Canadian school systems as a means of circumventing cultural silences:

*I don't know how comfortable here, now things are different and a few weeks ago I heard now they're going to be teaching in schools- I'm like, "Yes! That's fantastic! Because why? It brought a lot of issue to parents who say "we don't want our grade 2 or grade 3 to learn about sex." It's there. It's gonna be there whether they like it or not. Kids are just gonna be sexually active, teenagers are going to be sexually active no matter what. So parents cannot just be blindfolded by saying "Oh, we don't want our kids to talk about sexuality" because that will reduce um, pregnancy, reduce HIV, will reduce all this stuff that everybody's fearful. And just teach them and educate the young kids who are in high school now and elementary school. (Aminata)*

*In the schools, teach the small- [...] Before they get to the age of making sex and doing that! They started in primary school, our teacher told us, "HIV what? what? you don't use the razor other people use" the kids, they grow up and know HIV. [...] Secondary school! They started having girlfriend and boyfriends. They have to know! How they gonna protect themselves! They have to know how they gonna test themselves. They do we have- first of all, they have to know about HIV.*

*They don't know about HIV. They still think it's uh, a sickness which kills, doesn't have medicine, that's it. If you have it, you gonna die. That's what they know. (Jessica)*

Interestingly, a prevalent theme in terms of strategies for increasing education about HIV was through the medium of TV and radio. Many participants spoke of how both television and radio were utilized within their countries of birth with success. Therefore, applying that strategy to Canada often emerged as a means of increasing education:

*Yeah, actually that helps a lot. Because again, if you turn on the TV and you just want to watch like, a regular soap opera, but the entire half hour of the show, the entire story line surrounds sexual health awareness, but it's just part of your regular TV and it's not treated like you can't watch or whatever...maybe the only difference is that at the end or at the beginning it says that it's sponsored by the ministry of health. That's it, and it's really little. Everything else is like a really good story; it's really dramatic and it's very engaging. It's just that, instead of it being about I don't know, crimes or whatever, it's about these kids who are living their lives, but sexual health plays a really important factor. And you have varying degrees of concern or what-not and I think that's great way, because you're learning without feeling like you're learning. And it sucks you in whether you want to or not, everybody, if you like TV shows...Or radio shows. There's some radio shows that do that as well.[...]for example, if you have a radio show, there's a radio show that's put on in Kenya, it's called "Salluga" and it's just like, a little dramatization of I don't know, let's say, this girl who moved from the village to the city on her own and she's trying to navigate the world and people are like, "Yo, you should watch out with the people you get involved with because all of this stuff is going on" let's say she gets involved with an older man, he gives her HIV, now she has to figure out what to do-how she's going to tell her family. Through that you get to see the varying points of view you have surrounding this and how you're supposed to tackle this. And then she goes to the clinic, she talks to these people, blah blah, there's that. Sometimes that gets expanded into a TV show, or there's a totally separate TV show. Suga' got taken over by MTV and it was made into a tv show; it started out in Kenya and now they have a Nigerian version of it as well and yeah, things like that, so it's really just a...either the characters are brought to life through TV or they bring characters and it's the same show; it just really follows a bunch of young people and the same thing happens with the shows I watched in Ghana. I think they might have started off as radio shows but I never listen to radio, so I don't know...But, a lot of the shows I think like, 3 of the shows that I watched as a kid-this is like, 10, 8 years old. Three of the shows- at least the major ones, targeted for university youth all had to do with sexual health awareness, like, that was the main point. You couldn't miss it. And because everybody watched it, it was just a part of watching TV-we retained a lot of information without even really knowing it. They had catchy songs- (laughs) about getting tested as well! (Denise)*

*You have to use like, uh, radio-we talk about-you see-you see advertisement, to help people with their-channel shopping, you can put a channel for HIV like that! I see-when I open my TV everyday, since I came to Canada, I see- Howard is selling jewels. Everyday he is there, everyday he is there. I know- (laughs)[...] Why don't we find something to explain about HIV? Maybe 20 minutes like they do everyday. So people, they gonna know, "Hey, I was thinking HIV..is this...they say you can live"-some people now in Canada they think when you have HIV, you are dead. You can live with HIV for-the whole life! Some people they don't know. For the start, maybe we can use TV. (Jessica)*

Although television and radio were identified as extremely useful in promoting HIV education and messaging, it was acknowledged that to do so in Canada would take a lot of buy-in from the government and health agencies. The theme of the need for a multi-pronged approach was very prevalent throughout the study and perhaps best summarized by Jessica:

*Long time people suffered about stigma, and then they started talking, talking, preaching and talking and teaching in school. They teach people how not to share, everything-we cut our nails with razor, don't share about that. They really teach people about AIDS. Everywhere, on the roads.[...]Me, I'm thinking it's too hard [discussing this in Canada]. You can't do it without help of uh, the ministry of health. Because those things work out, because it was coming from on top. The government can put that on HIV on TV. You-you can't do it. The government can do it. Those flyers all over-so, if the ministry of health can put too much effort, you can reach the goals to-to talk about it. To teach about it. Some people they don't know-here in Canada they don't know. They still thinking-that's a bad sickness they're talking about! (Jessica)*

In essence, the participants spoke of the need to dispel common ingrained misconceptions of HIV disease progression and transmission through educational campaigns using an integrative approach with schools, family physicians and community health centres while simultaneously producing a counter narrative to the current ones being (re)produced within ACB communities using TV and radio. Participants acknowledged that it would be a vast undertaking, but as stigma is a many headed hydra it follows that the eradication of may require a herculean effort.

## CHAPTER EIGHT: DISCUSSION

This study provides context to previously identified barriers to accessing HIV testing and counseling among women in ACB communities in Canada. This context has important implications in regards to: improving the experience of an HIV test, increasing the uptake of HIV testing and counseling, identifying important partnerships, and building upon existing partnerships to increase multi-pronged approaches towards these aims. The emergent themes and data collected within the study are grounded within the words, perceptions, and experiences of the women to which these aims serve; thereby creating possible strategies *by* ACB women *for* ACB women.

### Improving the Test: Consent, Confidentiality, Counseling, and Connection

The experiences described in this study demonstrate that HIV testing was problematically experienced both in Canada and Africa among the women in the study. The lack of pre-test counseling resulted in dubious informed consent and missed opportunities for important HIV prevention and transmission knowledge, while the lack of post-test counseling impacted understandings of disease progression with adverse effects on mental health for those testing positive. Further, although confidentiality was perceived and described as vitally important to the prevention of stigma, few participants described achievement of the preferred level of confidentiality. Therefore, there remains work to be done in improving the test for women in ACB communities, or in ensuring the test is appropriately sensitive to both culture and gender.

#### Pre-Test Counseling & Consent

At the beginning of this document, I touched briefly on the recognized importance of the “Three C’s: Counseling, Informed Consent, and Confidentiality” to HIV testing in Canada as described by the federal guidelines to HIV testing and counseling. The Public Health Agency of Canada’s most recently issued recommendations for HIV testing furthers the concept of the three c’s by explaining that “HIV testing remains voluntary and based on informed consent,”<sup>36</sup> while defining voluntary informed consent as: awareness of the advantages/disadvantages of HIV testing; understanding of how HIV is transmitted; and the ability to interpret the meaning of the test result.<sup>95</sup> Further, the guide stresses the importance of pre-test counseling as a means of ensuring proper voluntary consent is given, as it “is widely regarded as the best way to provide

the level of information needed to ensure informed consent, a requirement as part of sound, ethical practice and by Canadian law”<sup>96</sup> for HIV testing.

However, many participants in this study described undertaking an HIV test in order to complete an important life event, such as marriage, job opportunities, or even immigrating to Canada- all of which did not include the important pre-test counseling. Therefore, consent was not assured as the pre-test counseling was not conducted. Further, if we understand voluntary consent as being an informed act of free will, these experiences where important life goals are only accomplishable after an HIV test, create problematic understandings of voluntary consent. This deserves serious consideration for improvements within testing guidelines for Canadian immigration practices my benefit from further study. Further, regardless of discussions of coercion and free will in reference to voluntary consent, consent was also not assured as pre-test counseling was not conducted among the women in this study.

To this point, as few of the women who participated in the study described obtaining pre-test counseling, it is not surprising then that the experiences of the women within the study also largely did not demonstrate a full understanding of HIV transmission, the meaning of a positive test result, nor the advantages or disadvantages of HIV testing. Despite the recognized importance of pre-test counseling to HIV prevention messaging both provincially and federally<sup>36,97</sup>, many of the described experiences of the women that obtained an HIV test in Canada, or for Canadian immigration purposes, demonstrated a decided lack of pre-test counseling; a lack that is in accord with other studies that have found dubious consent for HIV testing among women in Ontario. One report examining HIV testing among women in Ontario found that prenatal testing is often conducted without fully informed consent,<sup>98</sup> with another study reporting similar results among HIV testing experiences of ACB peoples for immigration requirements<sup>13</sup>. Therefore, the findings in this study are in agreement with others citing the lack of fully informed consent in past experiences of HIV testing among ACB women.

Further, when pre- test counseling was experienced in Ontario it was within a risk-based model. While the federal guidelines to HIV testing and counseling in Canada recommend normalization of HIV testing and counseling and a move away from risk-based HIV testing and counseling, HIV testing and counseling remains a provincial responsibility.<sup>98</sup> Thus, the Ontario provincial guidelines currently continue to recommend a risk-based approach to HIV testing and counseling. Not only is this against federal guidelines and other studies which have demonstrated

the need to move away from a risk-based approach towards a normalization of the test<sup>36</sup>, it is extremely problematic for ACB women. The association between HIV, sexuality, and morality creates a huge barrier to test seeking; an association that is reiterated when asking for a test involves stating participation in sexual acts that may not be culturally permissible for ACB women. Therefore, risk-based testing seems to exacerbate the existing barriers to testing for ACB women instead of reducing them.

Further, the demonstrated lack of space within ACB communities to discuss HIV observed within this study highlights the importance of utilizing the only spaces that currently exist to discuss HIV and HIV risk for ACB peoples, namely pre- and post- test counseling within clinicians' offices. Pre- and post- test counseling have been found to be very useful for discussions of risk behaviors and function as important spaces for answering any questions clients may have concerning HIV.<sup>97</sup> As such, counseling functions as an important space for HIV prevention, while a lack of counseling results in missed opportunities for HIV prevention messaging.

Family physician's offices are currently the most sought spaces for HIV test seeking among ACB women in Ontario; with one study concluding that ACB peoples are less likely to access community health centers due to fears of confidentiality breaches, therefore resulting in HIV testing and counseling access only through their family physician<sup>13</sup>. This study agrees with this finding, as all of the women who sought HIV testing and counseling in Canada did so through their family clinician, while one of the only places in which participants in this study received appropriate pre- and post- test counseling was through a community health centre. Therefore, to improve the test, it is of paramount importance that clinicians are providing the appropriate pre- and post-test counseling, as this may be the only time a woman within ACB communities may be obtaining HIV prevention messaging and risk information.

### **Post-Test Counseling, Connection, & Disclosure**

Despite Ontario and Federal guidelines recommending post-test counseling with both positive and negative test results, few women within the study described receiving post-test counseling within Ontario. Of those who did receive counseling, the experiences were mixed, with some women who had tested positive describing multiple follow-up appointments and links to care while others described receiving a pamphlet and a phone number with no additional counseling or supports.

The mixed results in terms of counseling found in the study may in part be due to the divergent messages within provincial and federal guidelines concerning post-test counseling. The Ontario guide describes the importance of assessing the emotional state of the client immediately following a positive diagnosis. Testers are advised to assess the client's ability to retain any more information other than the diagnosis and to schedule a follow-up appointment if the client is too distraught to retain any more information<sup>97</sup>. Further, the guide advises stressing life after diagnosis and to reassure clients to take all of the time they need to come to terms with their diagnosis; there is little to no emphasis on partner disclosure. However, the federal guide for post-test counseling emphasizes the importance of partner disclosure for HIV prevention and recommends testers open discussion of disclosure within the same appointment of communication of HIV results<sup>34</sup>.

This study seems to suggest that the Ontario model of care for post-test counseling is more culturally appropriate for ACB women than the federal guide. Although I recognize the importance of partner disclosure for HIV prevention needs, the results of this study imply that this emphasis is not appropriate for many ACB women. Further, the documented poor partner communication about HIV and HIV testing grounded within complex gender dynamics found within some African countries<sup>59</sup> was also identified within this study; dynamics which can potentially place women within ACB communities at great risk for social or physical harms should they disclose to their partner<sup>99</sup>. Therefore, conversations of disclosure with women in ACB communities demand a high level of cultural sensitivity and recognition of potential harms by clinicians and those delivering positive HIV results.

Instead, this study seems to suggest that disclosure discussions should be based on the unique needs of the person newly diagnosed with HIV. After a determination of specific needs, perhaps a disclosure plan can then be developed with the person now living with HIV over multiple follow-up appointments. This plan should also incorporate conversations and counseling on familial disclosure in addition to partner disclosure, as well as other supports more appropriate for ACB women. Essentially, familial support may be needed before discussions of partner disclosure, but this may be dependent on the individual.

This study demonstrates a process of removal of misinformation and stigmatizing narratives about living with the disease needing to occur before discussions about partner disclosure can occur. Participants described rapid spirals into poor mental health, suicide ideation

and other harms if not immediately linked to care and support. Therefore, this study seems to suggest that a positive diagnosis be accompanied by multiple follow-up appointments not only to develop a disclosure plan, but also to ensure that the mental health of the person living with HIV (PHA) does not deteriorate. Further, this study suggests that appointments should include clinician or frontline support and oversight to ensure the newly diagnosed person is attaining the necessary supports and links to care.

However, successful links to care necessitate multiple and variable paths towards connection. For example, there is currently one person in all of the Ottawa/Gatineau area responsible for ACB women diagnosed with HIV, thus creating a bottle-neck effect. Those recently diagnosed are experiencing large wait times for contact with this one person to obtain the resources they need, with others never achieving contact. Further, the participants spoke of the importance of multiple outreach workers from a variety of cultural and linguistic backgrounds to opening communication and facilitating comfort between and among ACB women. Essentially, a diagnosis of HIV to ACB women can lead to intense social isolation (self imposed or otherwise) which may lead to deteriorating mental health that can be combated through social re-integration; often through social groups of other women living with HIV. Further, as specified by the women, a similar linguistic and/or cultural background can be extremely helpful in achieving successful social re-integration and links to care. Therefore, this study suggests more impetus be placed on the fourth C of Connection<sup>100</sup> within both federal and provincial HIV testing and counseling guides to improve the cultural sensitivity of HIV testing and counseling for ACB women in Canada.

### **Confidentiality**

Finally, the stigma and discrimination described within ACB communities by the women in this study emerged as perhaps the most crucial factor preventing access to both HIV testing and HIV messaging. It is therefore not surprising that discussions of HIV testing focused on the importance of confidentiality, as confidentiality and privacy provide protection from social stigma. However, despite the great importance placed on confidentiality, few participants achieved the level they would have preferred. Those that did were able to accomplish it through utilization of their social networks. However, as confidentiality is one of the “Three C’s” that have been recognized for years<sup>95</sup> as important for HIV testing, it is of concern that this is still a large issue, especially within Canadian clinician’s offices, and speaks to the need of more studies

concerning increased training for providers and other office staff on what appropriate confidentiality for ACB peoples entails.

Further, participants within this study described how confidentiality is not achieved simply by ensuring confidentiality of results, but also through being able to maintain personal privacy throughout testing procedures. However, although a move away from risk-based testing is currently recommended for HIV testing in federal guidelines, Ontario guidelines continue to recommend risk-based testing. This is problematic, as risk based testing is perceived among women in the study as an intrusion of privacy and furthers stigmatized associations between morality and HIV. Thus, risk-based testing itself may act as a barrier to HIV testing and counseling among women in ACB communities. Therefore, many participants described the ideal testing experience to be normalized and provider initiated, which is in accord with federal recommendations.<sup>36</sup>

### **Culturally Sensitive HIV Testing and Counseling**

In sum, this study as well as much of the literature depicts culturally sensitive HIV testing and counseling as: routine, provider initiated with appropriate pre-and post- test counseling and connection procedures that maintain confidentiality and privacy throughout all steps as much as possible. Further, upon a positive diagnosis, focus should not be placed on disclosure. Conversations of disclosure should be flexible and based on the disclosure needs of the clients that are continually assessed within multiple follow-up appointments. Much focus should be directed towards the creation and maintenance of connections and links to care instead of on partner disclosure.

Further, while many of the findings of this study are in accord with federal guidelines, others are in accord with Ontario guidelines. This demonstrates that perhaps neither guide is currently appropriately gendered and culturally sensitive. There is thus more work to be done to ensure that they become so for ACB women in Canada.

### **Increasing Uptake of HIV Testing through (Re)Production of Counter Narratives**

While improving the HIV testing and counseling experiences among ACB women is important, it is only one component to improving the barriers, access, resources and knowledge concerning HIV and HIV testing among women within ACB communities. A perfect testing experience does little if the uptake on HIV testing is not increased. This study offers some

insights into some possible strategies to increase HIV testing uptake; a feat perhaps best accomplished through the recommendations of the women themselves. The documented low rates of voluntary testing uptake among ACB women discussed in the first part of this document<sup>18</sup> is not surprising upon review of the emic perspectives provided by this study. Many studies have documented the high prevalence of stigma surrounding HIV within ACB communities and its effect as a barrier towards HIV testing and counseling. However, the data produced by this study demonstrate how HIV stigma has become entwined with core cultural tenants such as: religion and morality; gender; sexuality; and mortality. These stigmas and associated cultural taboos are described by participants as interacting in complex ways to enact multiple barriers to test seeking as well as discourse of HIV in general and as such, may contribute to the current low rates of HIV testing uptake in Canada.

Although stigma has often been cited as a barrier to testing uptake within ACB communities, one of the more surprising findings of the study was the congruence of stigmatized narratives surrounding HIV. These common narratives crossed political, linguistic, and cultural boundaries without erosion. For example, many women in this study described their perception of HIV as irrespective of their knowledge of HIV, with participants describing HIV as a death sentence despite knowledge that medication exists to ensure the disease is manageable. This discord between knowledge of the disease and perception of HIV was not only congruent among the participants, but also with literature describing knowledge and perceptions of HIV in African countries. The articles by Adegun and Vermeer et al. found self-assessment of HIV risk to be irrespective of risk behavior,<sup>57</sup> with the authors stating that they did not find this to be overly surprising due to stigma. However, the emic perspectives provided by this study demonstrate that risk-assessment, or perceived susceptibility to HIV, is determined by a self-assessment of morality, not risk behavior. Therefore this study seems to provide some context to the seemingly confusing finding in African countries and communities demonstrating self-assessment of susceptibility to HIV as irrespective of knowledge of HIV prevention and risk behaviors.

In fact, the findings of this study further demonstrate the ability of these narratives to remain unchanged across time as well, as the studies mentioned were conducted over five years ago. In other words, these socio-historically located stigmatized narratives created in Africa are crossing boundaries of time and space to be (re)produced within Canada through intergenerational cultural teachings. As these narratives are tied to core cultural teachings, they

are passed down within a broader cultural package, and as such, stigmatized narratives of HIV are continually being brought to, and (re)produced inter-generationally through cultural teachings in Canada. These stigmatized narratives are operating and replicating regardless of advances in knowledge of HIV within ACB communities. Further, taboos associated with these stigmatized narratives act as barriers to improving knowledge of HIV. Therefore, these stigmatized narratives are socio-historically produced and transmitted through culture, while taboos ensure that they remain unchanged and unchallenged through time and space. It is not surprising then, that the recommendations of the women centered on the need to erode and navigate these stigmatized narratives and taboos in order to increase uptake of HIV testing and counseling.

As many studies have described the strong presence and impact of faith within and among ACB communities, much of the literature focused on increasing HIV testing within ACB communities both within and outside of Africa and the Caribbean was dedicated to faith-based approaches. However, this approach has not been found to be a perfect fit for all ACB women, as the literature demonstrated that although women are more likely to belong to a Faith Based Organization (FBO), pastors or FBO leaders are largely male<sup>66</sup>. As such, complex gender dynamics preventing communication between genders about HIV and sexuality may be creating a barrier to communication with religious leaders for ACB women.

Further, faith-based approaches are reliant on the pastor delivering the HIV messaging and testing information, who is also bound by religious doctrine and not public health needs<sup>66</sup>. Therefore, while this approach may have the possibility to be culturally transgressive by eroding the association between HIV and morality through teachings of compassion instead of stigma towards those living with HIV, the findings from this study seem to provide context that suggest associating HIV messaging with faith may be emphasizing existing associations between HIV, sexuality, and morality; associations that are also gender based and currently act as barriers to test seeking. To this point, none of the participants of this study suggested collaborations with faith based organizations as spaces for HIV communication and messaging. In fact, when prompted about their opinions of FBO's as spaces for HIV messaging, participants described discomfort with speaking with their pastor about HIV or HIV testing. This study seems to suggest that communication between a male religious pastor and a female member of an ACB community HIV would involve transgressing complex stigmas of intra-gender communication

and gendered beliefs of sexuality. As such, although much of the literature focused on increasing testing uptake through faith-based organizations, the data from this study seem to suggest otherwise.

Instead, participants' recommendations centered on the production and dissemination of counter narratives. In essence, they focused on providing counter-narratives to the current stigmatizing ones that remain un-contested within Canada. They described the production and dissemination of these counter narratives as achievable through a number of different approaches within a number of different spaces.

One such approach was through the utilization of existing social networks within the community, such as between friends and family. They described how the normalization of HIV testing could be furthered through word of mouth among individual women. For example, one ACB woman could tell close friends and family that she had sought and undergone an HIV test for no other reason than for her personal health. This simple act was described as a production of a counter narrative, as the decision to test was not due to sexual promiscuity, but as part of health maintenance. In essence, they described creating a counter narrative to the stigmatized narrative in which a woman would only seek an HIV test if they had been sexually promiscuous. The dissemination of this counter narrative is then occurring through woman-to-woman discourse and eroding taboos surrounding discussion of HIV and HIV test seeking.

This method to increase testing is congruent with the literature, which found that people were more likely to seek a test on the advice of a loved one or acquaintance. The article by Vermeer et al. examining cognitive predictors of voluntary testing found that many participants only sought voluntary testing on the advice of a friend or loved one<sup>58</sup>. This study supports that finding, with many of the women describing only seeking a test based on the advice of a doctor or loved one, furthering other findings citing the importance of word of mouth in encouraging testing uptake among ACB communities.

However, as this approach also carried a high potential of risk for the individual stating they sought a test, others spoke of utilizing existing physical spaces, such as doctor's offices, or elementary schools. These spaces were described as ideal for dissemination of HIV testing and prevention knowledge as they already exist, and there are very little to no social repercussions of participation. However, as previously described, the appropriate provision of pre- and post- test

counseling as well as the normalization of provider initiated testing would provide the necessary space for the production of these counter narratives and increase HIV prevention messaging.

Perhaps the two most prevalent recommendations by the women in the study concerning erosion of internalized stigmatized narratives and circumventing taboos, were to utilize media such as TV and radio and empowering those currently living with HIV to speak their story or offer testimonials. They described how narratives could literally be produced within radio and TV programs that challenged existing stigmatized narratives, such as one must “look HIV”, or that HIV is a death sentence, or that only extremely sexually promiscuous women are at risk of HIV. Further, they described how in effect, PHA’s are actually the embodiment of a counter narrative based on their existence: they are living and healthy, and have a full life ahead of them. The experience of seeing someone living with HIV that did not “look HIV” was described as particularly powerful and thus a great source for eroding stigmatized narratives. Therefore, provision of images of what HIV can look like was also described as a very powerful tool to eroding stigmatized narratives.

However, the production and dissemination of these powerful counter narratives was also recognized as difficult in Canada. They described these efforts as needing to be mass campaigns, thus requiring cooperation among community organizations and TV and radio programmers to develop and distribute appropriate counter narratives. This unity of messaging would also have to occur within clinician offices, community programs, and public health campaigns. However, although perhaps a large undertaking, these recommendations are not fantastic, as the strategy for 2013-2018 for ACB peoples by ACCHO also affirmed these recommendations of media as of central importance for HIV prevention and testing messaging among ACB communities.<sup>9</sup>

### **Intersections of Action: The Importance of a Multi-Pronged Approach**

In sum, the production of a counter narrative to combat ingrained stigma and its associated taboos as well as the creation of culturally sensitive HIV testing and counseling for women in ACB communities, would require cooperation and initiatives among differently positioned stakeholders and governmental agencies-both federally and provincially. Directional focus on only one identified issue, such as improving the test, is not sufficient. The stigmatized narratives as identified in this study will most likely continue to be reproduced and operate as barriers to HIV testing information and messaging, as well as uptake of the test itself. In other

words, improving the test means less when stigma continues to persuade people in ACB communities that it is “better to not know”. Therefore, impactful change that will generate erosion of stigmatized narratives and dissociation from core cultural values and tenants will most likely require a multi-pronged approach.

Currently, the federal government of Canada recognizes the importance of creating partnerships in order to reduce the burden of the HIV epidemic in Canada. To this effect, the original Task Force that developed into ACCHO was partially funded by the federal government in order to bring together disparate stakeholders. Further, the Canadian federal government has developed and implemented a Federal Initiative to Address HIV /AIDS in Canada that has formalized partnerships between the Public Health Agency of Canada, Health Canada, the Canadian Institutes of Health Research, and Correctional Services Canada. They state the development of this initiative to be grounded in the need to learn from past strategies by moving towards a fully integrated Government of Canada approach to HIV/AIDS.<sup>101</sup> Therefore, a multi-pronged approach towards increasing testing uptake and improving the test is already largely recognized as beneficial to addressing the complex barriers that continue to fuel the epidemic.<sup>101</sup>

I therefore suggest building upon existing structures of integration by possibly including Citizenship and Immigration Canada into the Federal Initiative to Address HIV/AIDS in Canada. Inclusion of Citizenship and Immigration Canada may improve testing experiences of women in ACB communities and help to ensure that experiences are matching federal guidelines-guidelines specifically developed to reduce the burden of HIV within the Canadian population. Currently, immigration requirements are not operating within Canadian standards of human rights<sup>36</sup>, and as such, must examine practices concerning pre- and post-test HIV counseling. Further, a more open dialect between the criminal justice system and public health needs may help facilitate greater access to HIV testing and erode barriers created by the criminalization of HIV.

In addition, conversations concerning increased integration should focus on strengthening the dialect between federal and provincial partners. For example, ACCHO has continually recommended improvements of HIV testing implementation within immigration procedures and development of more media approaches towards HIV testing and prevention messaging that have largely remained un-addressed. Federal and provincial systems should increase focus on communication about best practices for ACB peoples, because although we are describing a

particular Ontario experience, ACB peoples reside all over Canada and with the great continuity of stigmatized narratives crossing boundaries of time and space, many of these findings are most likely applicable. Therefore, the addition of more partners within the initiative and increasing communication between federal and provincial partners may help to remove existing barriers to HIV testing and counseling among women in ACB communities.

However, work can be done beyond utilization of existing frames of integration. I contend the development of a more nuanced approach towards partnerships be utilized in conjunction with existing partnerships. For example, current surveillance categories rely on assessments of risk. However, federal guidelines to HIV counseling and testing are currently recommending a move away from risk-based testing<sup>36</sup>. Therefore, a surveillance strategy reliant on risk assessments is problematic and out-dated. In the absence of an identified risk behavior, either the clinician provides a guess of the risk category, a risk category is assigned based on demographic information, or that information is absent in surveillance data. This does not seem to be a sound practice either for surveillance data, nor evidence based prevention practices. As the Public Health Agency has already stated, these categories should be re-evaluated in conjunction with HIV prevention specialists within the provinces<sup>3</sup> and federally to create more meaningful categories.

Further, links to care and connection to services rely on an integration of services. Therefore, to create smooth and immediate links to care and connection, such diverse services as housing needs, immigration, mental health services and community engagement should maintain a close dialect. The intersection of needs, experiences and perceptions of ACB women as identified in this study, requires an approach addressing the complexities of this intersection and must maintain sensitivity to these needs in order to create impactful change.

That said, there are currently movements underway within Ontario and Ottawa to integrate services for ACB peoples, such as the ACB Hub in Ottawa that brings together leaders from many different parts of the community (such as religious leaders, researchers, frontline workers, members of the community and others). However, this should not be solely based on the provincial level. The scope of the media needs, service integration, and variability of government partners is at a federal level. The integration should occur among immigration policies and procedures, the criminal justice system, public health services, surveillance, and other stakeholders to create and maintain a narrative powerful enough to erode the stigmatized

narratives currently circulating among ACB communities. The status quo is simply not enough. As Jessica states: “...*without help from the top, we'll never reach anything.*”

## CHAPTER NINE: LIMITATIONS

One of the limitations of this study was the open-ended search strategy, as the Medline database search resulted in an unwieldy number of papers (1,955), with few focusing on emic perspectives for HIV prevention. Unfortunately, this resulted in a large use of time that could have been spent in discovering articles more focused on patient and client perspectives more commonly found in other databases and grey literature. However, perhaps this speaks to the necessity of search strategies concerned with omitting bias. As I was using the database to ground the thematic guide and was therefore unconcerned with bias, perhaps a less formalized approach is more appropriate for qualitative studies grounded within a constructivist paradigm.

Further, I was unable to obtain the desired variability of country of birth for this study (e.g. the lack of Caribbean participants). Therefore, while this study maintains its focus on ACB communities, there remains a lack of Caribbean peoples represented within the study. I believe that this is attributable to the recruitment strategy; a strategy reliant on HIV prevention workers and AIDS Service Organization partners. Which, as this study discovered, are all of African origin. Therefore, this may speak to the need for a wider variety of backgrounds of frontline staff serving ACB communities. Further, the small absolute number of frontline staff in Ottawa may be acting as a barrier to provision of staff with wider cultural and linguistic backgrounds.

## CHAPTER TEN: IMPLICATIONS

This study has important epidemiological implications, as it provides context to quantitative findings demonstrating that HIV testing uptake remains low among ACB women in Ontario. This study provides contextual, emic perspectives from the women themselves thereby shedding light on why some ACB women may not be seeking and accessing testing in Canada or Ontario. These perspectives and experiences elucidate various barriers that can be investigated through future policy research and the contextual findings of this study provide possible directions for future research concerning HIV testing among ACB women in Ontario.

Beyond the provision of contextual data, this study identifies possible policy strategies to remove barriers to testing for ACB women in Ontario. These strategies do not only include the purveyance of public health, but also connections between and among public health officials, community groups, members and associations, and federal and provincial surveillance methods and testing guides. The findings from this study can help to facilitate the opening of discourse among public health officials, the community, and federal partners. This study provides possible strategies to improve and build upon existing partnerships as well as increasing partnerships and communication across boundaries of policy, epidemiology, culture, community, and governmental jurisdiction for the common goal of reducing the HIV epidemic among ACB women in Ontario.

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## Participant Information Sheet and Consent Form

### **B.A.R.K. (Barriers, Access, Resources and Knowledge): An Analysis of HIV testing via Women's Voices in Ottawa**

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Principal Investigator: Dr. Lynne Leonard

Tel: (613) 562-5800,  
extension #8286

Funded by the University of Ottawa, Department of Epidemiology and Community  
Medicine

Participation in this study is voluntary. Please read this Participant Informed Consent Form carefully before you decide if you would like to participate. Ask the study team as many questions as you like.

#### **BACKGROUND OF THE STUDY**

You are being asked to participate in this research study because you are a woman who belongs to the African, Caribbean or Black community.

This study is being done since more and more studies are showing that ACB women (African, Caribbean and Black) are finding out that they are HIV positive later than other groups of women in Canada. Also, ACB women are more likely to experience HIV than other groups of women in Canada.

The purpose of this study is to hear and record the experiences and feelings about HIV testing from ACB women in their own words. This way, HIV testing services can be improved by ACB women for ACB women. We want to learn about positive and negative experiences that you may have had with HIV testing or why you chose not to get tested. We also want to know how you feel about HIV testing and how you feel your community views HIV testing. We want to use the information you provide us to help improve HIV testing in your community.

We estimate that 40 participants will be enrolled in the study from Ottawa.

#### **STUDY PROCEDURES**

Experiences and feelings towards HIV testing will be discussed during a one-on-one interview. The interview will take between 45 minutes to one hour to complete. The interview may be audio recorded, with your permission.

During the interview, you may:

- Choose not to answer any question;
- Choose to stop taking part in the interview at any time; and,
- Choose to stop the tape recorder at any time.

**STUDY DURATION:**

The entire study will last approximately one year, however, your participation will end after the interview is complete.

**STUDY RISKS:**

It is possible that talking about some of your experiences during the interview may be painful or bring up bad memories. After your interview you will have a chance to ask any questions, concerns or worries that you have. Information about counseling services will be given to you if you want it. You do not have to answer any questions that you do not feel comfortable answering.

**STUDY BENEFITS**

You may receive no direct benefit from participating in this study, however, your participation may allow the researchers to improve HIV testing services for women within the ACB community.

**ALTERNATIVES TO PARTICIPATION**

You can choose not to participate in this study.

**WITHDRAWAL**

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now, and then change your mind later without affecting the medical care, education, or other services to which you are entitled or are presently receiving at this institution.

**COMPENSATION**

We very much appreciate your part in this project. If you agree to take part in the interview, you will receive \$30 for participating in the study. The interview will take about forty-five minutes to one hour of your time.

**CONFIDENTIALITY**

The interview will be private and anonymous. Your name, address, or any other identifying information will not be asked for and you may choose any name you would like to be known by for the interview.

The interview will be audio recorded to help us remember everything that is said. The audio recordings will be given a number so that your answers will not be able to be linked back to you. Only people directly involved in the study will have access to the audio recording. It will be kept safe so that no one can steal or copy it. The audio recording will be transcribed, and then the audio recording will be deleted. The transcription will not include any identifying information.

You will not be identifiable in any publications or presentations resulting from this study. All study records will be kept for 10 years after the study ends. During this time, all records will be password protected and safely kept in a locked cabinet at the University of Ottawa. This means paper transcripts of the audio recordings with all identifying

information removed will be kept in a locked cabinet. Electronic transcripts will be kept in a secure file at the University of Ottawa until they are transcribed at which time they will be destroyed. At the end of the storage time, all other paper records will be shredded and all electronic records will be securely deleted.

The Ottawa Health Science Network Research Ethics Board and the Ottawa Hospital Research Institute may review study records under the supervision of Dr. Lynne Leonard for audit reasons only.

### **CONFLICTS OF INTEREST**

There are no conflicts of interest to declare related to this study.

### **QUESTIONS**

Should you have any questions, please feel free to contact the Principal Investigator, Dr. Lynne Leonard at 613-562-5800 ext. 8286.

If you have any concerns related to your rights as a research participant you may contact the Chairperson of the Ottawa Health Science Network Research Ethics Board at 613 798 5555 extension 16719.



## INFORMATION SHEET AND CONSENT FORM

**B.A.R.K.****(Barriers, Access, Resources and Knowledge):****An Analysis of HIV testing via Women's Voices in Ottawa**

For Interviewer:

I confirm that:

- I have read every page of this Information Sheet and Consent Form to the participant.
- The participant has had a chance to ask me any questions they have about the study.
- Their questions have been answered to their satisfaction and they have agreed to participate in this interview.
- I have provided the participant with a copy of the Information Sheet and Consent Form for their use.
- To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

\_\_\_\_\_  
Name of person obtaining consent

\_\_\_\_\_  
Signature of person obtaining consent

\_\_\_\_\_  
(dd/mm/yy)

Date

## THEMATIC GUIDE

### 1) **Experiences** with HIV testing

- a. Can you tell me about your experiences with HIV testing?
  - i. What do you think prevented you from getting tested?

### 2) **Personal value** placed on testing

- a. How do you feel about getting tested for HIV?

### 3) **Community value** placed on testing

- a. How is HIV testing viewed in your community?

### 4) **Communication**

- a. Do you have anyone you talk to about HIV and HIV testing?

### 5) **Acceptability**

- a. Do you think HIV testing is well accepted in your community?

### 6) **Trust**

- a. Do you feel comfortable discussing traditional models of healing with your doctor or health provider?
- b. Do you trust your health care provider?

### 7) **Future**

- a. Do you think that HIV testing could be improved in your community?
- b. In what ways do you think it could be improved?
- c. How would you like to see HIV testing services improved for you?