HIV HEALTH LITERACY FOR AFRICAN, CARIBBEAN, AND BLACK MEN LIVING WITH HIV/AIDS

by

Angela Palangi

A thesis submitted in conformity with the requirements for the degree of Masters of Arts
Department of Applied Psychology and Human Development
Ontario Institute for Studies in Education of the University of Toronto

© Copyright by Angela Palangi (2015)
Abstract

This qualitative study explored the experiences of immigrant, refugee, and non-status men from the African, Caribbean, and Black (ACB) communities living with HIV/AIDS in Toronto regarding gaps in current HIV health literacy initiatives, and propose appropriate solutions. The focus group was conducted at a local AIDS Service Organization (ASO) with 8 ACB men living with HIV/AIDS who self-identified as either gay or heterosexual. Based on a modified Grounded Theory analyses of the transcripts and on thematic coding, a range of issues faced by the ACB men emerged that increased the risk for HIV infection, delayed seeking and getting timely and appropriate care, and created obstacles to testing and treatment. Our findings suggest the need for more culturally specific support services; greater involvement on the part of ASO’s, greater sensitivity from Canadian immigration officials, more specific guidelines regarding HIV disclosure for healthcare providers; and extra efforts to tackle HIV related stigma.
Acknowledgements

I owe my deepest gratitude to my thesis supervisor, Dr. Joseph Roy Gillis, for his endless support and guidance. Thank you for being so supportive and meeting with me every time I knocked on your office door. I am particularly grateful for your support and assistance during the focus group. Your invaluable advices and mentorship have allowed me to better myself both as a student and a researcher. Thank you for believing in me and allowing me to learn from my mistakes and teaching me into being more of who I am.

I would like to thank APAA (Africans in Partnership Against Aids) for their help in the recruitment process. In particular, I am grateful for the help of Mary Ndungu and Fatimatou Barry in meeting and helping me recruit participants. I also thank all of the men who took part in this research because without them this research would not be possible.

I also want to thank my family for their unconditional love and support. I particularly want to thank my mother, Malihe Ardekani, without whom I would not be the person I am today. Thank you for being the person you are and teaching me the meaning of love. Your mentorship has given me the strength to be where I am today.
# Table of Contents

Abstract.............................................................................................................................. ii
Acknowledgements .......................................................................................................... iii
Table of Contents ............................................................................................................. iv
Introduction........................................................................................................................1
Health Literacy and Why is It Important........................................................................1
HIV Health Literacy ..........................................................................................................3
African, Caribbean, and Black Population in Canada and HIV/AIDS.............................5
HIV/AIDS Among Men Having Sex with Men (MSM)......................................................6
Immigrant, Refugee, and Non-Status (IRN) Individuals and Health Literacy...............9
Stigma................................................................................................................................14
Cultural and Religious Beliefs and Norms ....................................................................18
Masculinity .......................................................................................................................20
The Present Study............................................................................................................23
Methods.............................................................................................................................23
  Qualitative Research Design ..........................................................................................23
  Participants .....................................................................................................................24
  Sampling Procedures ......................................................................................................25
  Ethics ..............................................................................................................................25
  Data Collection ...............................................................................................................26
  Data Analysis ................................................................................................................26
Results ...............................................................................................................................27
  Perceptions of HIV in African, Caribbean, and Black Communities in Canada ...........27
  Key Themes....................................................................................................................29
    Canada Vs. “Back Home” ..........................................................................................29
    Further Training...........................................................................................................32
    Immigration ................................................................................................................34
    Stigma ........................................................................................................................37
    Gossip .........................................................................................................................38
    Masculinity ................................................................................................................39
    Community Resources ...............................................................................................39
    Interventions ...............................................................................................................41
Discussion..........................................................................................................................45
  Limitations ....................................................................................................................50
Introduction

Approximately 71,300 Canadians were living with human immunodeficiency virus (HIV) at the end of 2011 and nearly one quarter of them were unaware of their status (CATIE, 2013). HIV affects all people from around the world, however, the HIV epidemic in Canada in concentrated in specific populations. Individuals of lower socioeconomic strata and those from countries where HIV is endemic, such as African and Caribbean countries (CATIE, 2013), have become increasingly more impacted by HIV. In response to this increase, the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) was established in 2005 to address issues related to HIV faced by African and Caribbean people in Ontario (Lawson et al., 2006). Many education interventions, introduced by ACCHO, have sought to improve African and Caribbean peoples’ knowledge regarding HIV transmission and access to treatment and services (Hicks et al., 2006), however, little remains known about the direct effect of individuals’ health literacy on such prevention interventions.

Health Literacy and Why is it Important?

Health literacy is defined as “the degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts in order to promote and maintain good health across the life-course” (Kwan, Frankish & Rootman, 2006, p.80). It has become an emerging concept that links levels of literacy with the ability to act upon health information and health status (Canadian Council on Learning, 2010) and is considered as a pivotal pathway linking education to health outcomes (Health Literacy in Canada, 2007). Studies have
shown that the overall level of health literacy in Canada is low and an estimated 60% of Canadian adults and 88% of seniors have difficulty understanding and acting on health information and services, and also the capacity to make appropriate health decisions on their own (Mitic, & Rootman, 2012; Canadian Council on Learning, 2007). Factors such as education, income levels, race, and language have been found to impact individuals’ health literacy skills.

Studies have shown that people with low “health literacy” tend to have poorer general knowledge of medical issues and worse health-related personal behaviors, such as diet and exercise (Hicks et al., 2006; Kwan, Frankish & Rootman, 2006). They are also likely to get less regular preventive care, including fewer routine physician visits, and to show poorer compliance with prescription medication regimens (Cho, Dee, Arozullah, & Crittenden, 2008). Furthermore, persons with limited health literacy often experience personal shame in their interactions with the health care system and health care providers (Mitic & Rootman, 2012). In turn, these factors may lead to delays in their seeking and getting timely and appropriate care when it is needed, as well as increasing the use of emergency and hospital services which can result in them experiencing poorer health outcomes (Lee, Arozullah, & Cho, 2004; Nutbeam & Kickbusch, 2000).

While health literacy levels are lowest amongst Canada’s aging population (Canadian Council on Learning, 2007), recent studies have consistently documented that a significant proportion of Canadian immigrants also experience low health literacy (Zanchetta & Poureslami, 2006; Rootman & Gordon-El-Bihbety, 2008). According to Canadian Council on Learning (2010), only 25% of immigrants and refugees in Canada have the requisite health literacy skills to maintain health. In particular, immigrants who
do not speak either French or English, possess much lower levels of health literacy skills compared to non-immigrants (Canadian Council on Learning, 2006). In fact, they are found to be more than two-and-a-half times as likely to be in fair or poor health as those with the highest skills levels.

Health literacy has become an emerging area of national interest in health research and health promotion. A recent review of health literacy interventions in the USA and Canada (Canadian Public Health Association, 2006) identified several strategies used, which include (1) focusing on improving individuals’ health-literacy skills by optimizing health communication tools for consumers, (2) improving skills through adult-education programs (literacy, numeracy, and ESL), (3) working with families, and (4) building the cultural knowledge, skills, and sensitivities of health providers. Health literacy interventions can be found in the areas of smoking cessation (Meade & Byrd, 1989), drinking (Howard, Gazmararian, & Parker, 2005), arthritis (Buchbinder, Hall, & Youd, 2006), and diabetes (Schillinger et al., 2002) among others.

**HIV Health Literacy**

We define “HIV health literacy” as an individual’s ability to use his/her literacy skills in a health-related context to enhance and promote health among those dealing with or susceptible to HIV infection. In Toronto and across Canada, community-based organizations provide a wide range of skills-building programs which constitute a lifeline for people living with HIV/AIDS. For community-based agencies, HIV health literacy efforts focus on assisting clients to effectively utilize existing health resources, and providing linkages to other needed health services (Van Servellen, Brown, Lombardi, & Herrera, 2003). In addition to recent investigations of the overall social determinants of
HIV health in a population, the importance of determining and intervening to improve patients’ “HIV health literacy” has become an increasing focus of health-education and disease-prevention efforts by AIDS service organizations.

Studies that have assessed the level of health literacy in HIV/AIDS have found that limited health literacy is associated with several adverse health-related variables including less knowledge about one’s own health status (Mitic & Rootman, 2012) and misconceptions regarding treatment and transmission of human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) (Mooss, Brock-Getz, Ladner, & Fiano, 2013). For example, studies that have looked at health literacy levels among persons living with HIV/AIDS have found that HIV/AIDS knowledge differs significantly between patients with inadequate health literacy and those with marginal or adequate health literacy (Hicks, Barragan, Franco-Paredes, Williams, & Rio, 2006; Kalichman et al., 2000). Specifically, one study found that persons of lower health literacy were less likely to know their CD4 cell count and viral load, and were less likely to understand the meaning of each number (Kalichman et al., 2000). Moreover, the study indicated that persons of lower health literacy were more likely to report practicing unsafe sex due to greater optimistic perception about anti-HIV treatments and its effect on reducing HIV-transmission risks.

In Canada, HIV health literacy remains an issue of concern as the number of people living with HIV/AIDS continues to increase, from an estimated 64,000 in 2008 to 71,300 in 2011 (Public Health Agency of Canada, 2011). While, this increase is partly due to new HIV infections and improved life-prolonging anti-HIV treatments, recent research has found individuals’ HIV health literacy levels significantly impacting the
HIV epidemic (Kalichman et al., 2000). It has been documented that African, Caribbean, and Black (ACB) populations are amongst the groups of people most affected by HIV/AIDS (ACCHO, 2013). ACB men are particularly affected, accounting for 60% of ACB people living with HIV in Ontario in 2009 (ACCHO, 2013). In spite of the existence of numerous capacity building initiatives for people living with HIV/AIDS, there remain gaps in knowledge in relation to effective, evidence-based interventions focusing on the context-specific health literacy needs of African, Caribbean, and Black (ACB) people living with HIV/AIDS (Tharao, Massaquoi, & Teclom, 2006).

**African, Caribbean, and Black Population in Canada and HIV/AIDS**

People from HIV endemic countries are over-represented in Canada’s HIV epidemic (CATIE, 2013). HIV endemic countries are defined as those where “HIV prevalence in the general population is 1% or greater and where heterosexual contact accounts for more than 50% of infections” (ACCHO, 2013). The majority of these countries are located in sub-Saharan Africa or the Caribbean and, thus, the term “ACB” is used to refer to people from the African, Caribbean, and Black communities.

Persons of the African, Caribbean and Black (ACB) populations form unique and diverse communities and have mostly came to Canada through immigration waves in the last 50 years (ACCHO, 2013). According to the 2011 Census (Statistics Canada, 2011), Black communities comprised 4.3% of Ontario’s population, most of which have origins in HIV endemic countries in Africa and the Caribbean (Shimeles et al., 2011). In Ontario, the majority of the African and Caribbean immigrants are of Jamaican origin (111,475), Guyana (80,070), Trinidad and Tobago (54,680), South Africa (18,405), Nigeria (17,220), Kenya (14,170), and Ethiopia (13,150) (Statistics Canada, 2011).
Studies show that people from the ACB communities account for a disproportionately high share of the numbers of people in Ontario living with HIV/AIDS (Husbands et al., 2013). In 2011, an estimated 17% of new HIV infections were attributed to people from countries where HIV is endemic which is 9 times higher than among other Canadians (CATIE, 2013). From 1985 to 2011, an estimated 4,348 persons from the ACB population were diagnosed with HIV in Ontario, of whom 2,119 (49%) were male (ACCHO, 2013). Of all new HIV diagnosis, persons from ACB population accounted for the majority of heterosexually acquired HIV infection (Barrett & Mulugeta, 2010) with a relative rate of 24 times higher than among others infected heterosexually (ACCHO, 2013). In 2013, the African and Caribbean Council on HIV/AIDS in Ontario suggested that the proportion of incipient HIV infections among people from HIV-endemic countries will likely perpetuate to increment, as it has over the last 20 years.

**HIV/AIDS Among Men Having Sex with Men (MSM)**

During the early stages of the HIV epidemic, over 80% of all cases in Canada were attributed to men who have sex with men (MSM) (Public Health Agency of Canada, 2012). Over the course of the epidemic, however, this proportion has decreased significantly. In fact, in 2012, the largest proportion of AIDS cases, in Canada, among adult ACB males, was attributed to heterosexual contact (Public Health Agency of Canada, 2012). Despite this increase, and the decrease proportion of MSM cases, many researchers, policy makers, and community-based agencies have persisted to focus their efforts on ACB women and gay and bisexual men and have failed to acknowledge and address the HIV-related needs and challenges of heterosexual ACB men (Husband et al., 2014).
In 2012, 13.2% of ACB people living in Canada were infected through heterosexual contact (Public Health Agency of Canada, 2012) and men comprised the majority of heterosexually-infected ACB people (Husband et al., 2013). A recent study that looked at HIV risk perception and distribution of HIV risk among ACB people in London, Ontario, found that the underrepresentation of heterosexual ACB men at AIDS service organizations and the belief that heterosexual men cannot become infected acted as barriers to ACB men protecting themselves from HIV infection (Baidoobonso, Bauer, Speechley, & Lawson, 2013). Moreover, Husband et al. (2013) found that heterosexual Black men in Toronto, Canada were generally concerned about services not being sufficiently available for them. The study also found that Black men did not possess the resources to negotiate and challenge cultural and social scripts in the same way that White heterosexual men did.

The increase in proportion of HIV infections among heterosexual men has led to the rise in HIV infection among women (Centre for AIDS Prevention Studies, 2001). In 2011, 77% of new HIV infections among females were attributed to heterosexual sex (CATIE, 2013). Men’s reluctance to testing, irregular contact with doctors, and compliance with prescription medication regimens, are all contributing factors to this increase (Sandman, Simantov, & An, 2000). A survey that looked at American men and the health care system found that 33 percent of men did not have a regular doctor to go to and more than half of all men did not have a physical exam in the year prior (Sandman, Simantov, & An, 2000). According to one Ontario study, “heterosexual men need to be more aggressively targeted for HIV prevention” (Leonard, 2013; Husbands et al., 2013),
as changes in sexual behavior among heterosexual men will be pivotal to halting the HIV epidemic for men, women and children (Centre for AIDS Prevention Studies, 2001).

In spite of all the multi-stakeholder efforts to decrease the impact of the HIV/AIDS epidemic, the African and Caribbean Council on HIV/AIDS in Ontario (2013), found that a substantial proportion of ACB men living with HIV are not receiving regular, HIV-specific, guideline-concordant care. Factors such as heightened levels of poverty, stigma and discrimination, religion, unemployment, criminal justice system, cultural norms, immigration and settlement status, and the lack of access to adequate health care characterize the epidemic among ACB men. A study conducted in America, found that Black men are less likely to receive preventive health services compared to women (Viera, Thorpe, & Garrett, 2006), are generally out of touch with the health care system, and avoid seeking medical attention or delay getting care despite symptoms (Sandman & Simantov, 2000). In turn, Black men face greater risk for physical and mental health problems compared to women and white males (Sandman & Simantov, 2000) and account for higher mortality rates than women in many places in Africa (Skovdal et al., 2011). Therefore, given the clear levels of barriers among ACB men, a more comprehensive understanding of factors that affect general health care and health seeking behaviors among ACB men is needed.

Emerging literatures have shown health literacy levels as contributing determinants to the overall health of African, Caribbean, and Black men and their vulnerability to HIV/AIDS (ACCHO, 2013). For example, in a study by Wolf et al. (2006), African-American men were found to be three times more likely to have low literacy skills (sixth grade or less) compared to white men. To confirm the association
between race and health literacy levels, Osborn and colleagues (2007) analyzed a preliminary regression model with African-American race as the independent variable and low literacy skills as the dependent variable and found a significant association between African-American race and low literacy. The study further examined race disparities in HIV-medication adherence and found that African Americans were 2.4 times more likely to be nonadherent to their HIV-medication regimen than non–African Americans. Similar findings were found in another study where those with low literacy were three times more likely to be nonadherent to their anti-retroviral regimens than those with adequate literacy (Wolf et al., 2006).

**Immigrant, Refugee, and Non-Status (IRN) Individuals and Health Literacy**

According to Statistics Canada (2011) Canada’s population has surpassed 35 million over the past years, accounting for a 5.9% increase between 2006 and 2011. It has been estimated that immigrants represent 20% of the total Canadian population, the highest proportion in 75 years (Statistics Canada, 2006). Furthermore, Canada receives approximately 250,000 new immigrants per year (Statistics Canada, 2011) most of whom are from Africa, Caribbean countries as well as Central and South America (Statistics Canada, 2011).

The growing number of immigrant population plays a critical role in Canada’s level of health literacy. More than half of Canadian adults have low health literacy scores and one of the most important contributors is the increasing number of immigrants coming to Canada (Canadian Council on Learning, 2010). Rootman & Gordon-El-Bihbety (2008) indicate that some parts of Canadian society including immigrants, individuals with lower levels of education, and persons receiving social assistance, are
over-represented among those with low health literacy skills. For example, they found that 24% of foreign-born men and 32% of foreign-born women have low health literacy levels compared to approximately 10% of Canadian-born men and women. The findings of this study were in concordance with another study that examined health literacy level among immigrants in Canada and concluded that factors such as low levels of education, language, and culture are associated with low health literacy of immigrants (Zanchetta & Poureslami, 2006).

It has been estimated that approximately 75% of immigrants and refugees do not have the necessary health literacy skills to negotiate and navigate the healthcare system regarding their health (Ng & Omariba, 2010). According to Rootman and his colleagues (2008), immigrants with lower levels of education and whose mother tongue is not French or English, have lower levels of literacy and health literacy. Level 3 in prose literacy is considered to be the minimum level for coping with the demands of everyday life and work in a knowledge-based economy. The Canadian Public Health Association (2006) found that approximately 60% of immigrants fell below Level 3 in prose literacy compared to 37% of individuals who were Canadian-born. These studies suggest the impact of health literacy is greater among immigrants and, thus, deserves particular attention.

Recent studies have found a strong correlation between health literacy and health disparities between racial groups. For example, Howard and colleagues (2006) examined the impact of health literacy on socioeconomic and racial groups in terms of health status and revealed that blacks, immigrants, other minority groups, and people with fewer resources had lower health literacy skills than members of other racial groups and people
with more resources. Cultural and linguistic differences among patients have also been found to directly impact their health literacy levels, which in turn, contributes to an increased prevalence of health disparities among elderly adults, racial/ethnic minorities, recent refugees and immigrants, low-income individuals, and non-native speakers of English (The Department of Health and Human Services, 2010; Benjamin, 2010).

When immigrants, refugee, and non-status (IRN) persons come to Canada, they face resettlement stresses linked to experiences of discrimination, poverty, racism, and isolation. More importantly, refugees and non-status individuals encounter all the barriers new immigrants face with the added challenges of low levels of education, high levels of stress and difficulties navigating the Canadian Government and community services (Toronto Public Health, 2011). IRN individuals may also face challenges to accessing health care services and maintaining good health due to low health literacy. According to Zanchetta & Poureslami (2006), barriers to health literacy, such as lack of meaningful information regarding health issues, knowledge of where to find the right health care provider or how to navigate and access preventive services, can contribute to the deterioration in health status of immigrants over time.

Emerging literature indicates that upon arriving in Canada, immigrants, as compared to Canadian-born individuals, are generally as healthy or in better health, have as good or better health behaviors, and have similar or less frequent use of health services (Ali, McDermott, & Gravel, 2004). However, following immigration, their health status may deteriorate due to language and cultural barriers, as well as difficulty accessing information and navigating through the health care system. Moreover, lack of access to support services often stops new immigrants from utilizing preventive services.
effectively which can result in experiencing negative health outcomes (Zanchetta & Poureslami, 2006). Interactions between health professionals and IRN patients have also been recognized to be an important factor in IRN patients’ health status and preventive behaviors. It has been found that immigrants with limited health literacy generally have poor understanding of written and spoken medical advice which negatively impacts their health (Barragan et al., 2005). Furthermore, inadequate health literacy limits IRN’s ability to read and understand educational brochure, appointment slips, informed consent documents, and most importantly, labels on medication bottles (Council on Scientific Affairs, 1999; Barragan et al., 2005). Thus, the roles of healthcare providers as well as individuals’ health literacy levels are critical in how well IRN’s comprehend essential information regarding their health.

It has been indicated that many health professionals are not aware of their patient’s low health literacy levels (Kickbusch, 2001) and, thus, have particular difficulties in transmitting health information and risk taking behaviors, to their patients, due to language, religion, and cultural barriers (Hughes, 2004). Such barriers could have a negative impact on patients’ health status and lead them to feel vulnerable, isolated, and uncomfortable to discuss their needs, as well as traditional practices with their health care providers (Zanchetta & Poureslami, 2006). More importantly, IRN patients may feel embarrassed to ask their health care providers for additional information and consult with them when they have not completely understood the treatment instructions given to them. Thus, this lack of connection between health professionals and patients can result in patients making more mistakes with their medications intake and be at an increased risk
of hospitalization compared to those with adequate health literacy (Zanchetta & Poureslami, 2006).

A Canadian study conducted in-depth interviews with adult immigrant and refugee newcomers in order to understand their perception of discrimination in health care services and its impact in the health care environment (Pollock, Newbold, Lafreniere, & Edge, 2012). Using a thematic analysis, the researchers found that many participants were denied medical services on the basis of their immigration and refugee status. For instance, one participant described being refused medical services because the family doctor did not take refugees as patients. Furthermore, newcomer’s language ability, accent and cultural differences were seen as potential sources of discriminatory behavior by the clinic staff as well as the health care providers. Three participants described being treated like they were “stupid”, “mentally disabled” or “their IQ is lower” because they spoke English with an accent. Interestingly, participants explained a positive change in health care providers’ behaviors immediately after they revealed their education level or professional credentials. Inadequate communication, poor listening, and unclear exchange of information were also viewed as major obstacles to accessing health care services.

In Canada, a great amount of money is spent each year on disseminating educational health materials for individuals to use. However, studies show that such information is not easily accessible or usable for people with language barriers or limited health literacy (Zanchetta & Poureslami, 2006). For example, Birru et al. (2004) showed that adults with low literacy encountered informational obstacles on the Internet when searching for health information in part because most Web health information required a
grade 10 reading level or above. Another study with African American populations showed that those with lower health literacy levels did not use a computer to access health information or to store personal health information (McCleary-Jones, 2013). Furthermore, information from websites, DVD, CD-ROM, and distant communication technology have been found to have limited impact for non-white, less educated population (Balka, 2004; Zanchetta & Poureslami, 2006).

Although the aforementioned studies show many challenges and barriers faced by IRN individuals with limited health literacy, there exists a number of studies that have provided several means to enhance the health of IRN people. These include (1) using clear and multiple forms of communication (Zanchetta & Poureslami, 2006), (2) increase the diversity of healthcare providers, (3) community-based development and mental health services, and (4) ensuring immediate and adequate health insurance coverage (Pollock, Newbold, Lafreniere, & Edge, 2012). Thus, the need for ongoing attention to social determinants of ACB IRN individuals’ health is essential in order to ensure effective and accessible services, including physical and mental-health rehabilitation.

Strong cultural norms and religious beliefs can have a huge impact on African, Black, and Caribbean men’s HIV status and health outcome. Additionally, stigmatizing attitudes as well as societal ideologies of masculinity have particular influences on ACB men risk taking and preventive behaviors. The next section will address these issues in more depth and explain how they each influence the health of HIV-positive ACB-IRN men.

**Stigma**
HIV/AIDS stigma is defined as the prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the groups and communities with which they are affiliated with (Herek, 1999; Lawson et al., 2006). When people act on their prejudice, stigma turns into discrimination, referring to the unfair and unjust treatment of people based on their actual or perceived HIV status (CATIE, 2014).

African, Caribbean, and/or Black men living with HIV/AIDS are considered to be a vulnerable group as they are dealing with a chronic illness and are often stigmatized within society. Having a profound effect on the global HIV epidemic, HIV-related stigma influences men’s responses to the disease, prevention practices and access to treatment and support services (Gardezi, et al., 2008). According to ACCHO (2013), men from the ACB communities are reluctant to test and often fail to seek out the services they need due to fear of being stigmatized. In a study that looked at pathways to HIV testing in Black African and white communities, Black Africans were found to be twice as likely as white people to be worried about future discrimination if test results were positive (Erwin et al., 2002). Therefore, stigma and discrimination surrounding HIV can lead one to be unaware about their serostatus and the possibility of a late diagnosis in the course of HIV progression when the illness can no longer be concealed (Lawson et al., 2006).

According to ACCHO (2011), HIV-related stigma is interconnected with stigma and discrimination associated with race, sexual orientation, and gender. In Canada, HIV-positive men from the ACB communities are often reluctant to seek support services because of fear of stigmatization that already exists due to racism. For example, in a
study that looked at the experiences of people from African and Caribbean communities in Toronto, one of the major themes discussed by focus group participants was reluctance to test and accessing health services for fear of encountering racist perception of HIV as affecting only Black/African people, and the general perception that African or Caribbean people are carriers of HIV and other diseases (Lawson et al., 2006). Another study found similar experiences by African and Caribbean population in Toronto where focus group participants expressed fear of approaching health services due to being afraid of encountering racist attitudes and the pathologizing of Black bodies as repositories of HIV and other diseases (Gardezi et al., 2008).

Raymond & McFarland (2009) conducted a study on HIV risk among men who have sex with men (MSM) and found racial and ethnic disparities to be causes of stigma, irrespective of sexual orientation. In order to investigate sexual partner selection, the researchers used a cross-sectional survey of men who have sex with men (MSM) and found that Black MSM were reported as the least preferred as sexual partners because they were perceived to be at higher risk of being HIV-positive compared to other ethnicities. As a result, this belief, led men from other races to avoid black men as sexual partners. Furthermore, the study found that Black MSM were counted less often among friends and perceived as less welcome at common gay venues. These findings suggest that the attitudes and beliefs of non-black MSM, relating to race and ethnicity, can separate and isolate Black MSM from other men.

Another well documented source of HIV-related stigma within ACB communities revolves around sexual orientation and homophobic attitudes. Homophobic attitudes persist within African and Caribbean communities and have
resulted in people preferring not to be seen with men whom they perceive to be gay (Lawson et al., 2006). Gardezi et al. (2008) found that people from the African and Caribbean population have the belief that HIV is a “gay disease” and that gay men are to be blamed if they become infected. In a recent national survey, 11 percent of Canadians felt that people who become infected with HIV have only themselves to blame (Calzavara et al., 2012). Similar results were found in another survey where over 50 percent of HIV-negative gay Latino men believed HIV-positive gay men were personally responsible for their HIV status (Courtenay-Quirk, Wolitski, Parsons, & Gomez, 2006).

Tackling HIV-related stigma and homophobic attitudes within the ACB communities is critical for improving the health of HIV-positive ACB men. In 2010, the Ontario Black Gay Men’s Summit highlighted the most pervasive obstacle to the health of gay and bisexual, trans and queer (GBTQ) ACB men was political oppression in conjunction with institutionalized racism. Moreover, studies have shown that HIV-positive Black gay men are more likely to suffer from mental health problems than the general population due to stigmatization as well as the fear of being blamed for their HIV status (King et al., 2003; Smit et al., 2012).

Evidently, consequences of HIV-related stigma have a profound impact on the well-being of ACB men as it may create obstacles in seeking timely and appropriate care and increase the risk for HIV infection (Gardezi et al., 2008). The need for HIV organizations and community leaders to join together to identify and speak about HIV issues within the ACB communities is necessary in changing HIV-related stigma towards HIV-positive ACB men. Furthermore, creating support groups for ACB men to talk about personal experiences regarding stigma and express issues within the ACB
communities (Lawson et al., 2006) could help reduce risk taking behaviors and change perceptions and attitudes towards seeking treatment.

Cultural and Religious Beliefs and Norms

Access to HIV testing and treatment as well as engaging in preventive behaviors can be deterred among those who belong to conservative religious groups and follow austere cultural norms. According Lawson and colleagues (2006), African and Caribbean individuals who are more religious often view health and illness from a spiritual perspective and less from a medical view. For instance, in a study conducted by Zou et al. (2009), more than half of the respondents believed that HIV is a punishment from God and those who are HIV-infected have not followed the “Word of God”. These findings were similar to another study which indicated African participants holding strong beliefs that everything, including HIV, comes from God and it is only God who knows when individuals will die (Lawson et al., 2006). Specifically, participants felt “individuals should live their life naturally” and avoid following any medical instructions since they can be misleading.

Topics involving sex, sexuality, physical and/or psychological health (Gardezi et al., 2008), and safer sex practices are rarely discussed among African, Caribbean, and Black men (Baidoobonso, Bauer, Speechley, & Lawson, 2013). Cultural norms and beliefs dictate ACB men to be “tough” and discourage communication or disclosure regarding health information (Gardezi et al., 2008). Furthermore, ACB men are expected to be knowledgeable about everything and are often prohibited to disclose any information regarding their health within their community (Baidoobonso, Bauer, Speechley, & Lawson, 2013). In turn, many ACB men delay seeking medical attention
until their illnesses have advanced (Lawson et al., 2006). Thus, such cultural norms impede ACB men from access to information regarding HIV and preventive practices and create obstacles in receiving timely appropriate care.

Despite the importance of religion for many ACB individuals, several studies have shown that ACB participants are reluctant, and often do not feel safe, disclosing their HIV status to their religious community. According to Ngozi and colleagues (2009), this unwillingness is slightly more prevalent among individuals who attend religious services more frequently in part because they are more afraid of stigmatization and isolation from their faith community. Discriminatory attitudes, regarding individuals HIV status, have also been found within the church and mosque settings (Lawson et al., 2006). For instance, the term “dead and walking” was mentioned in one study to describe community perceptions of HIV-positive individuals (Gardezi et al., 2008).

Religious prohibitions against condom use have similarly been shown to increase the vulnerability of ACB men to HIV. Threats of social exclusion by religious members who oppose condom use may motivate men to not use condoms and, thus, increase their risk of contracting and spreading HIV (Agha, Hutchinson, & Kusanthan, 2006). In a study by Lazarus et al. (2006), Somali HIV-positive men held more negative attitudes towards condom use compared to women. Additionally, Muslim men were more reluctant to use condoms because they held the belief that “condom is for illegal sexual relations” which is not acceptable in the Muslim religion. Some other men believed that HIV does not infect Muslims since premarital sex is prohibited and individuals only have sexual relations with their partner.
Strong religious beliefs around sex and sexuality have become a major obstacle to tackling HIV within the ACB communities. Serial monogamy and lack of condom use have linked HIV-positive men who have sex with men (MSM) to high-risk sexual behaviors. In a study of HIV among ACB gay and bisexual men in Toronto (2008), 17.9% of HIV-positive MSM reported having anal sex with men whom they knew to be HIV positive and 36.6% reported having sex with a man whose HIV status they did not know. More importantly, only half of the participants reported using condoms all the time while engaging in anal sex. Thus, particular consideration needs to be given to how religious affiliations affect the risk of HIV infection among ACB men.

**Masculinity**

Masculinity is defined as “socially constructed set of values and beliefs that guide men’s actions and behaviors” (Harrison et al., 2006, p.710). According to Husbands et al. (2013), heterosexual Black men are more reluctant in accessing HIV services, compared to Black women and White men, due to beliefs around the notion of masculinity. African, Caribbean, and/or Black men are reported to be more likely to contain their vulnerability to HIV and avoid seeking health related services in order to protect their masculine ego (Husbands et al., 2013). Ultimately, these traditional ideologies of masculinity impact ACB men’s ability and willingness to seek services.

Previous researches have shown sexual orientation and race to be correlated with health behaviors with sexual and racial minorities tending to engage in higher risk behaviors (Delva et al., 2006; Mahalik, Burns, & Syzdek, 2007). However, more recent researches have looked at the importance of gender roles and its connection to HIV prevalence. Differences in the construction of gender roles have been found to reflect
differences between men’s and women’s risk behaviors (Harrison et al., 2006). For example, in a study by Mahalik and colleagues (2007), masculinity and perceptions of the normativeness of men’s health practices were found to predict participants’ own health behaviors but perception of women’s health were unrelated to participants’ health behaviors. Specifically, traditional masculine gender socialization and social norms models were more likely to encourage men to engage in more risky behaviors and put their health at risk.

A study that examined health behaviors and masculinity among five hundred forty-six Kenyan and U.S. male college students found masculinity and health promoting behaviors to be negatively correlated. That is, participants who scored higher on Masculinity reported lower frequencies of health promoting behaviors. Further, compared to U.S. participants, Kenyan men were more likely to ignore self-care, believe that fate and/or luck play a big role in how long a person lives, and were less likely to consult a physician when having symptoms as part of their perception of masculinity (Mahalik, Lagan, & Morrison, 2006).

Dominant social norms have yielded complex attitudes surrounding masculinity (Harrison et al., 2006) which often reinforce ACB men to engage in risky behaviors. In sexual relationships, men are more likely to have multiple partners and are not encouraged to act with sexual propriety and remain monogamous (Hunter, 2004). Black heterosexual men, in particular, have been found to engage in high-risk sexual behaviors compared to other men (Mahalik, Lagan, & Morrison, 2006). For example, due to social expectations, Black heterosexual men often engage in sexual relations with multiple
women, often concurrently, and believe this is intrinsic to being a Black heterosexual man (Bowleg et al., 2012).

The link between sexual orientation and masculinity within ACB communities has been studied by many researchers. For instance, Bowleg et al. (2012) found that Black heterosexual men held the perception that Black men should not be gay or bisexual because Black MSM “are not real men”. Furthermore, the authors found that heterosexual Black men demonstrated a variety of stereotypes that bisexual men are vectors of HIV transmission to Black heterosexual communities. Heterosexual men have also been found to be less inclined in using condoms (Malebranche et al., 2010) and more likely to persist in having sex even if they know doing so might increase their risk for HIV (Bowleg et al., 2012).

According to one recent study on health literacy among those who have HIV, the practice implications are clear: “Interventions are needed that extend beyond the many ‘plain language’ programs developed over the past decade that have been a hallmark professional response to the health literacy epidemic. These methods have resulted in only minimal improvements in knowledge outcome among individuals with low literacy skills, and usually do not lead to improvements in health behaviors. Instead, comprehensive interventions are needed that target both patient understand and self-efficacy through empowering approaches to care” (Wolf et al., 2007, p. 258). This research project is an attempt to develop that comprehensive program envisioned by these authors in a culturally competent and empowerment-centered context to address the specific need of immigrant, refugee, and non-status men from the African, Caribbean, and Black communities.
The Present Study

The central premise of this research is that the health of HIV-positive men can be enhanced by increasing their HIV health literacy. Thus, this study sought to explore and address specific needs of Immigrant, refugee, and non-status HIV-positive men from the African, Caribbean, and Black communities regarding gaps in current HIV health literacy initiatives.

Methods

The methods section that follows will begin by delineating the rationale for why qualitative methods were selected for this research study. The section will then explain participant recruitment and inclusion criteria, and sampling procedure. It will conclude by explaining the study’s data collection process and data analysis.

Qualitative Research Design

Qualitative research is a method of inquiry used by many researchers in different academic disciplines. The aim of this method is to gather an in-depth understanding of human experiences, behaviors, and attitudes, as well as to explore what individuals think about specific topics and the rationale for their thinking (Denzin, Norman, & Yvonna, 2005). Furthermore, qualitative study provides researchers with the opportunity to delve deeper into aspects of human life which could not be otherwise studied by quantitative research (Polkinghome, 2005). For example, a qualitative method can investigate people’s experiences in relation to accessing health care and understand how such experiences affect individuals’ health care behaviors. Thus, whereas in quantitative research, participants are forced to choose from predetermined responses, qualitative
research offers the opportunity to gather detailed accounts from individuals that may otherwise be missed via response options such as multiple choice or rating scales.

The present study used a qualitative approach to understand the experiences of African, Caribbean, and Black men living with HIV/AIDS. Specifically, the researcher used focus groups in which participants were asked to discuss their experiences regarding HIV and health seeking behaviors. The reason for using qualitative methods was because it allowed the research to gather information about a breadth of experiences encountered by ACB men and look for patterns and areas in which generalizations could be made (Baidoobonso et al., 2013). Furthermore, the researcher was able to capture the subjective experiences and beliefs of individuals regarding gaps in current HIV health literacy initiatives and incorporate these experiences into data collection. The sections that follow will explain in further detail the types of topic discussed during the focus group.

Participants

A total of 8 HIV-positive men participated in one focus group. Participants responded to a flyer describing the study as one that was interested in talking about the types of health and psychological resources available to African, Caribbean, and/or Black communities. Participants were screened by phone and if eligible, they were contacted to determine the date of the focus group. To be eligible, participants had to meet the following criteria: a) to be over sixteen years of age, b) to identify as immigrant, refugee, or non-status, and c) to be a member of the African, Caribbean, and/or Black community. Once accepted, participants signed consent forms, explaining that data would be collected.
using audio recordings, and participants were compensated by receiving a $20 honorarium.

Of the 8 individuals who participated in the study, four (50%) were of African origin, two (25%) were of Caribbean origin, and two (25%) were of Jamaican origin. Half of the sample, four (50%), identified themselves as men who have sex with men (MSM), three (37.5%) identified themselves as men who have sex with women (MSW), and one did not specify his sexual orientation. The average age in the sample was 39.5 years (range= 26 to 61 years). Four (50%) of the individuals had completed post-secondary education, and four (50%) had a high school diploma. Over half of the participants (75%) had been in Canada for 11 years or less and two (25%) had been living in Canada over 28 years.

**Sampling Procedures**

The study used a number of different recruitment strategies to reach ACB men living with HIV. Information about the study was given to potential participants in the form of a research information flyer that was posted in approved locations of different HIV/AIDS organizations. Information flyers were also sent electronically to different HIV/AIDS listserv. Additionally, recruitment was conducted utilizing snowball methods via the community and work connections with different HIV/AIDS organizations. Finally, direct contact with service providers was used to assist with the recruitment process.

**Ethics.** This research was approved by the Research Ethics Boards at the University of Toronto. A complete detail of the research was explained to all research participants both verbally and in writing through a detailed consent form prior to the
The consent form explained the study’s purpose, procedure, risks, and benefits. Additionally, limits of confidentiality were discussed with all participants before and after the focus group. Participants were also informed of the voluntary nature of the focus group and that they may decline to answer any questions and terminate their participation at any time. All participants were required to sign a consent form and were provided with an additional copy for their personal records.

**Data Collection**

The focus group was approximately 2.5 hours in length. Topics discussed included participants’ experiences in regards to HIV/AIDS and seeking information regarding their health; experiences of primary health care, HIV specialized care and mental health services; barriers to obtaining health related information; and personal thoughts about an intervention on HIV/AIDS health literacy for ACB men. Probes and follow-up questions were used to find out about gaps in current HIV health literacy initiatives.

**Data Analysis**

The focus group was audio recorded and transcribed in full by a professional transcriber. The data collected was analyzed utilizing a hybrid thematic analysis approach where emerging themes were considered important for describing the phenomenon (Daly, Kellehear, & Gliksman, 1997). This process involved the identification of themes and patterns within the data, which became categories for analysis (Fereday & Muir-Cochrane, 2006). The researcher first focused on participants’ responses in order to identify distinct concepts and develop some initial categories (Lyons & Coyle, 2007). These categories were further reassembled as the examiner developed and related
categories (Lyons & Coyle, 2007) to confirm that each category accurately represented participants’ responses. Finally, the categories were further refined and a core category was selected (Lyons & Coyle, 2007). This research combined a data driven (Boyatzis, 1998) and a deductive (Crabtree & Miller, 1999) approach, where the participants' accounts were treated as “reflections” of their perceptions and/or lived experiences, offering cogent insights into their experiences and opinions of what an optimized HIV health literacy model should integrate. Key themes of responses were identified and all responses were then coded into these themes. In addition to this inductive approach, the research process also used a template approach which involved defining a codebook before initiating the in-depth analysis of the data. This codebook was based on a preliminary scanning of the research texts, the research objectives, and the theoretical framework. Exemplar quotes from participants' focus group transcripts were extracted and used to illustrate each theme. The resulting organization of the findings were verified and modified by referring back to the existing literature on HIV/AIDS health literacy.

Results

Perception of HIV in African, Caribbean, and Black Communities in Canada

During the focus group participants discussed their personal experiences with HIV health literacy initiatives and spoke about the importance of HIV within their community. They discussed their thoughts and provided reasons why their community was at a greater risk for infection. For instance, a Swazi man spoke about lack of mandatory testing and use of illicit drugs and alcohol as factors that make people vulnerable to HIV.

Look into drugs, into drugs, especially for those people that are HIV-negative. HIV-negative because they don’t know their status. They are drinking, they are...
taking drugs. By the time they are out high, anything can happen. (Swazi origin, heterosexual, 61 years old)

Insufficient knowledge and information in terms of navigating the health care system in Canada made it difficult for people to access medical care and diagnosis. A Trinidadian man discussed the difficulties IRN individuals face in accessing health care once they arrive in Canada.

Because most of us come to this place [Canada], some obtain success; some obtain nothing because some of us, we didn’t know the right resources and the right places to go to get many things. (Trinidadian origin, gay, 32 years old)

Participants also suggested lack of respect from agency staffs as a contributing factor in deterring some members of their community from going and receiving help from certain organizations. A Jamaican man, for example, discussed not being treated with respect and feeling that he was being taken for granted.

I just find that they [agency staffs] don’t treat you as a fellow kind of community member, with the kind of respect deserving of you. They take you for granted. If a meeting has changed, nobody thinks it’s right to call and inform the people – to inform people, whatever. I just find that I’m taken for granted. (Jamaican origin, gay, 57 years old)

Another man, from Trinidad, stated not being treated equally in organizations where staffs were predominantly white.

Sometimes you’re going to some white agency. You’re waiting, you’re waiting, and you’re waiting. You wait, especially if there’s white gay man, geez, you will wait. (Trinidadian origin, gay, 32 years old)
Participants also discussed lack of HIV programs and insufficient HIV knowledge, within the ACB communities, as factors influencing individuals’ susceptibility to HIV. Some participants recounted instances of being involved in programs to educate and train people about HIV. For example, a Swazi man described being involved in an outreach program that focused on educating and training people in shelters but unfortunately the program was unsuccessful.

We were actually trying this program of outreach program, outreach program whereby you do education and training of HIV to the shelters, people coming into the shelters, to hospitals, so forth, and all of that stuff, but that program went down again. I don’t know how, who killed it, but it went down. I feel those are some of the programs of action that we need to put back up. (Swazi origin, heterosexual, 61 years old)

Participants continued to discuss a number of issues, from which the researcher identified several key themes discussed in the next section.

Key Themes

1) Canada Vs. “Back Home”

A major theme discussed during the focus group was the health care system in Canada compared to “back home”. Most of the participants had encountered many positive experiences with the healthcare system in Canada and in general felt that the system was much better than “back home”. In the words of one Jamaican man who was HIV-positive:

The healthcare system here in Canada, I have nothing but good things to say about it, nothing but good things. There’s no comparison. Well, Jamaica’s off the
map when it comes to that. Canada, I have nothing but good things to say about it, and I only come with a large sense of gratitude. (Jamaican origin, gay, 57 years old)

In particular, participants who faced additional chronic conditions spoke more positively about the healthcare system in Canada. For instance, a Jamaican man discussed his experience with receiving health care in Canada and compared it to the experiences of his relatives and friends in the United States.

And I’m not only talking about as it [healthcare system in Canada] relates to my HIV. I have failed kidneys; I am on dialysis, and even with that whole process nowhere can be compared. My sister who lives in Philadelphia, she always says to me, ‘kiss the ground Canada walks on because there’s nothing like that in the US’. And even my best friend who lives in New York, he echoes the same thing, and he’s HIV-positive as well. (Jamaican origin, gay, 57 years old)

Participants also stated that by taking initiative and responsibility, people can determine the quality of care they receive. For example, a Jamaican man indicated that if people clearly state their needs to healthcare providers then they would be able to receive better health care. Appointment times to see specialists and wait time at the doctor’s office were not seen as challenges for most men in the group.

I don’t have any challenges. No, as long as I do my part. They [healthcare staffs] give me a certain time, and I come there at that time, and, to me, my healthcare thing is a two way street. Depending on what I ask, will determine what I’m getting back. That’s how I look at it. (Jamaican origin, gay, 57 years old)
Devoting time and effort, by doctors, to explain medical concepts to their patients was also seen as something new and different than “back home”.

My doctor explains everything to me – everything – ‘cause I ask questions, so there is a lot covered. (Barbadian origin, gay, 34 years old)

Availability and access to medication in Canada were seen as major advantages of the healthcare system. Participants stated that economic disadvantages back home prevented their community from accessing proper medications, thus, putting their community at a higher risk for infection. For example, a Swazi man, who was HIV-positive, talked about migrating to Canada because he was not able to get the correct medications “back home”.

My coming to Canada was that I couldn’t get the correct medication back home. I couldn’t because this thing [HIV] was persisting and persisting and persisting, although I had just been diagnosed, but realistically, I knew my days were numbered, my days were just numbered. (Swazi origin, heterosexual, 61 years old)

The participants continued to state:

Drugs? You can’t get drugs that day; they might say they don’t have drugs, don’t have funds, but in Canada it’s nothing like that. As long as you enter a hospital, you get what you want. As I said before, there’s no place like Canada in terms of medication and healthcare. (Swazi origin, heterosexual, 61 years old)

Most participants articulated that health insurance plans, such as OHIP, and availability of government funding were much better in Canada compared to “back home”. A Jamaican man and a Barbadian man stated that such financial aids are nonexistent in their country.
The healthcare system back in our country, it’s not good; it’s worse. The reason why I say that too is because some of us that come here [Canada], you know, we should be thankful to be here and to have this because some of us come here and some of us we’re complaining that, oh, Canada is that, Canada is that, but what we don’t realize is, man, that we have it really good. If you go back home now, you don’t have it good. You have to pay a lot of money for this, for that. It’s not the same. (Jamaican origin, heterosexual, 39 years old)

The concept of having access to a general practitioner, in Canada, was perceived to be extremely beneficial in people’s health status. Some participants expressed that “back home” people do not have a family doctor and are often left waiting in clinics for hours with hundreds of other people who also need medical attention. Due to the high demand, many patients may not be able to seek medical attention that same day and, thus, have to return the next day.

My experience is back home, you don’t have family doctor. You just go to a clinic, being attended to with 100 people, 200 people, to maybe [be] attended [to] or not be attended [to]. (Swazi origin, heterosexual, 61 years old)

2) **Further Training**

Although most participants agreed that Canada’s healthcare system is adequate, some shared negative experiences and difficulties in negotiating the healthcare system. Many participants felt that medical doctors, particularly, immigration doctors, need to be better trained.

We need a lot of training here [Canada]. I mean, the top guys need a lot of training, educational training. (Swazi origin, heterosexual, 61 years old)
Assumptions made by immigration doctors in terms of people’s level of knowledge about HIV were an issue for some participants. Participants felt that service providers do not follow comprehensive guidelines on disclosure of HIV positive status since many fail to take patient’s emotional and mental wellbeing into consideration. One participant, who was a community worker and chose to speak about other people’s experiences rather than his own personal experiences, stated:

What made you [immigration doctors] assume that I have so much knowledge around HIV and AIDS, and you’re breaking such news [HIV status] to me for the very first time. I mean, anything could happen. I could jump at you right on your desk; I could tear the whole place apart. (Nigerian man recounting another individual’s experience, gay, 26 years old)

Technical language used by doctors was also discussed to be an issue, particularly for those who were new to the country. Some participants stated that language barriers between service providers and patients resulted in lack of understanding of certain medical terms.

Discussing further about this person who went to meet his doctor and one of the things he – I remember he mentioned was about language – the kind of technical language they used, you know, the doctor used with him. And that got him to start doing a whole bunch of other research to find out, what does this word mean? What does that mean? What does that mean? What does that mean? (Nigerian man recounting another individual’s experience, gay, 26 years old)

Lack of pre-and/or post HIV counseling made it difficult for people to cope with their diagnosis, especially for those who were distant from family and did not have any family
support. Moreover, lack of counseling made it challenging for new comers to navigate through the healthcare system on their own since most do not have the skills needed to negotiate through the system.

There was not a pre or post counseling before disclosing an HIV result or status to them, and, so then, as a new comer coming into a city whereby they’re still trying to navigate through the process as well as the healthcare system as well, so that seems to be a very heartbreaking situation for them. (Nigerian man recounting another individual’s experience, gay, 26 years old)

3) Immigration

Participants living with HIV reported a range of difficulties related to immigration laws and policies. Gaining legal status and having access to healthcare were seen to be difficult for some participants. Some participants spoke about their experiences of being denied medication and healthcare because they did not have proper refugee documents.

Because the medicine got finished, and then the immigration had told me to wait for one month for them to give me the paper [Refugee documents], so I could not go to any doctor, so I had to just wait. (Swazi origin, heterosexual, 61 years old)

Some participants were uncertain about immigration laws regarding HIV and whether they differed for men and women. In the meantime, some participants went without any type of health care and were not eligible to renew and have access to medications. For instance, a Kenyan man, who was a refugee claimant, spoke about his experiences in Canada:

I’m new here [Toronto], not more than four months, but I can say that it’s a bit difficult. I don’t know why, but I can give you an example. We came here, I
came here with my wife, who is also HIV positive, and our kids. Like, for me now, my medicine got finished and maybe I will start getting my medicine on Monday. But my wife too was the same, the medicine got finished. She went [through] the same procedure, but now she is okay. She has her medicine. That’s why I say I don’t know is it because I’m a man? Like, now I have [gone] two weeks without the medicine because I don’t have that [refugee documents] and that’s bad. (Kenyan origin, heterosexual, 37 years old)

Changes in immigration laws and policies put additional stresses on new immigrants as most participants articulated not having the financial resources to support their families. Most participants described difficulty in terms of applying and claiming refugee status in Canada. Attempting to gain access to financial assistance, such as “Welfare”, was also described to be difficult. Furthermore, participants who had been living in Canada for a number of years commented on the types of stresses new immigration laws brought to newcomers and their families.

Now, when newcomers come in, before you get any medication in this country [Canada], you have to have the documents. The law is being changed, very drastic, that many things you cannot do anymore and many things you cannot get. Before, “Welfare” was for everybody. As you reached the next morning, you could get welfare. Now, they’ve written a new law [that says] you have to be a permanent resident before they give you any kind of “Welfare”, any kind of thing in this country. So nowadays, you cannot get nothing without that piece of you know, that refugee paper. (Trinidadian origin, gay, 32 years old)
There also is the perception that immigration personnel are insensitive to people’s welfare and often hold new comers in holding cells for a number of weeks without proper medical care. Immigration tribunals were also perceived to be unconcerned about peoples’ HIV status and the situations people have to encounter if deported back to their country of origin.

If you don’t have supporting document, they [immigration tribunals] don’t care and they send you home [country of origin]. They don’t really care about some of us. They don’t care nothing if you’re positive, if you’re not positive. As a positive person, they don’t care. They send you to the west end detention or they send you to Broadview. When you reach there one day, two days, three days, then they make you keep begging, begging, begging. The system cares nothing about most of us. (Trinidadian origin, gay, 32 years old)

The amount of time needed for documents and funding to be processed was determined by who was handling the specific case. Interestingly, funding was perceived to be processed more quickly and with less difficulty when they were handled by a white staff worker as opposed to a black staff worker.

I couldn’t get that document, and then I said to myself, ‘Lord God, this belongs to me. It’s funding for me. Why am I being denied of this funding? Where best can I go to?’ And I said, ‘Let me go to [a white skin color support worker]. I told him about my issues, and he said, give me your documents. Without any racism, without anything, they took those documents, went to the city, they applied for me there. Yeah, it’s like a white person is a lion; they can’t touch him – black and white. (Swazi origin, heterosexual, 61 years old)
4) Stigma

Participants discussed stigmatizing attitudes toward HIV positive people within the ACB community. Concerns of whether other people from the community will see and stigmatize them impacted participants’ motivation in seeking services.

Plenty of people wouldn’t [access services] because they believe in the black community, especially people that come from the Caribbean. They would, some of them would never go to some of these organization, never, because they don’t want another black person to see them. (Trinidadian origin, gay, 32 years old)

Some participants commented on the beliefs held by heterosexual individuals, in that HIV is a “gay disease”. Participants also discussed HIV-related stigma faced by ACB community which perceives HIV as a Black disease.

Straight people have a thinking that AIDS is for black people, for the faggots, and AIDS is only for gay men. That’s the thinking. So, they could do anything. But, the thing is, this disease, it infiltrates gay, lesbian, dog, cat, whoever it is and they catch it, you will get it. (Trinidadian origin, gay, 32 years old)

MSM participants described reluctance in disclosing HIV-status to other gay men, prior to sexual contact, for fear of encountering HIV-related stigma. Particularly, HIV-positive participants spoke about fear of being stigmatized, judged and rejected within their community.

You see, gay people, if I go to disclose, I must say that I’m HIV positive and if he is not, but the time [he] will leave my apartment, the whole black community know, gay community know that [I] have the virus, and it’s on the internet, up and down you’re shamed. You can’t come out [of] your own house because the black
people and them. They will strip you alive. You can’t even come back down in
the village. I see it happen many times with black gay people. They strip you.
You have to move out of Toronto because when they damage your name,
especially if they don’t like you too. (Trinidadian origin, gay, 32 years old)

5) Gossip

Experiences of fear of gossips regarding individual’s HIV-positive status were discussed
by most participants. Participants described extreme fear regarding the social
consequences of being seen by someone in their community.

When I know I was positive, I would never go to a black agency. I don’t want
nobody to see me because you’re living in this denial, not really denial, but you
don’t want nobody to know that this is going on with you because you believe
they are going to make some kind of issue out about it. (Trinidadian origin, gay,
32 years old)

Issues around confidentiality also played a role in people’s willingness in seeking
services. Participants felt that lack of confidentiality within their community acted as a
barrier in seeking resources from agencies as well as participating in research focus
groups.

Sometimes we know one another, and we don’t even know what is going on with
each other because we don’t know, but when we meet in certain groups like this
here, you feel like, oh my God, you feel how ashamed that you feel so bad
because I might say, ‘Oh my God, I know this man very well, Lord have mercy,’
and I feel so ashamed because I can’t say, ‘Oh, we have the same thing’ because
we know none of us have a label right on our back. So, sometimes when we
meet, and to avoid some of these things, some people just don’t go and don’t access any services. (Trinidadian origin, gay, 32 years old)

6) Masculinity

Individual’s sexual orientation was perceived to impact health seeking behaviors. In general, participants held the perception that MSM were more knowledgeable about HIV and were more likely to seek services.

But gay men, they’re always, some of them, most of the black gay men, they always go for the health. They will seek it. With straight men, they don’t want to be seen in some of these things. (Trinidadian origin, gay, 32 years old)

Participants also discussed how heterosexual men’s behaviors and notions of masculinity contribute to greater risk taking behaviors and less seeking of services.

Straight men, they don’t want to seek services because of their masculinity. The only sign that they’re really coming to go and see a doctor is when they really fall sick, and when it’s half full blown. Like when they catch full blown and they end up in the hospital, that is the only time most straight men decide to sit back and catch their self and think. (Trinidadian origin, gay, 32 years old)

7) Community Resources

Participants spoke about their experiences regarding access to services from HIV agencies within their communities. There were difference in views in terms of how well ethnic HIV organizations supported members from the ACB community.

I have had very few good experiences with ethnic support organizations. The organizations I can say I have good experiences in my opinion are the mainstream ones. There are so few of them, you kinda know which ones to go to. But for the
others, I have nothing; I have nothing good to say about them. They don’t treat with you respect. They take your for granted because you’re black; they assume that you will take any kinda service. (Jamaican origin, gay, 57 years old)

In contrast, participants who had experience and were well connected with a range of HIV agencies spoke well of ethnic organizations. More importantly, participants talked about the struggles that ethnic organizations had to face in trying to give Black people access to services.

you have to be grateful to the same black ones [organizations] that try to open some of the way for some of you to come in here, because you didn’t get in by your own. You have to be considerate of others, considerate. Put yourself in a position, if I am working in a black organization, back in the days, and it been a struggle to see people come through, black people come up. It’s only changed now, only because they have a black manager now in there. Because of changing of management, black people now could go in there and get the services. (Trinidadian origin, gay, 32 years old)

There also is the perception that being connected to an agency and knowing the “right” people is important in the type of services individuals receive.

I would not be getting any satisfaction if I had not divert myself into an agency. Some agencies battle so much for me to get accommodation. Taking into account that I’m HIV positive, they extracted me from that place, from the shelter, and said ‘This one is HIV positive; he must leave this lifestyle.’ They gave a mandate to particular person that he must get me accommodation there. That’s how the
whole thing started. I met the right people at the right time. So, from the shelter I
never went anywhere. (Swazi origin, heterosexual, 61 years old)

The level of compassion and care seen from agency staffs were also suggested to play a
crucial role in individual’s HIV status.

Whether you like it or you don’t like it, they’re [agency staffs] gonna knock at
your door and say ‘meds, meds, meds, meds!’ Whether you like it, you’ll wake
up and take your meds. Whether you like it, you’ve got to take your meds. Today,
I’m non-detected? Why? Because of the professionalism of those people looking
after me every day. ‘How do you eat? Look at this food. No, it is junk food,
don’t eat it. This is junk food.’ They make sure that I get the right food, the right
treatment. (Swazi origin, heterosexual, 61 years old)

8) Interventions

Participants suggested a number of factors to help increase HIV-prevention efforts and
access to treatment and care within the ACB community. Mandatory HIV testing for
every individual in Canada was perceived to be a critical component of HIV prevention.

What I’m actually trying to get into is that it’s not a matter of tracking into the
HIV positive people and HIV negative people. Everybody coming to Canada, for
every thirty days must go for a blood test, everyone. Because you can pick up this
issue [HIV] anywhere. It can be in Canada, it can be anywhere. It’s not to say
you are from Africa, you’re from Asia, you’re from Japan, wherever; it can come
up where you are. (Swazi origin, heterosexual, 61 years old)

Mandatory testing was also seen as an important step of HIV care continuum.
I see there are a lot of guys out there with HIV, but no one knows, nobody cares about it, but know about it – that one is HIV, that one is HIV positive – but that has not been detected. (Swazi origin, heterosexual, 61 years old)

Focus group participants also emphasized the need for a “leader”, such as someone from the community, to motivate men to get out more frequently and participate in group meetings.

Within this community, you have to canvas within these black places and find the people and them because most men never come out, and for them to do something, you have to have some kind of push, or they’ll always want to gain something for it. (Trinidadian origin, gay, 32 years old)

Participants also compared men and women’s level of motivation in terms of forming and attending weekly support meetings. In general, women were perceived to be more motivated to participate in weekly gatherings and seeking support.

As men you can be invited to this meeting. You come or don’t come to the meeting and they usually don’t come to the meeting. Now, women are so much quickly to do things here in Toronto; very, very quick. They meet maybe twice or three times a month, women only. (Swazi origin, heterosexual, 61 years old)

Other participants also held similar views.

Women they always make their self available to find or to get resources to something. Men have to say ‘Ah, I’m not coming out my house today. I’m not going down there. They’re no food, no money, I’m not coming out’. (Trinidadian origin, gay, 32 years old)
Women were also seen to be more motivated in terms of pursuing education and attempting to find better jobs.

Plenty of ladies will say ‘I want to go back to school and get an education and do something, and make something.’ The men, they say ‘Oh, I’m gonna go and work in a factory’. They [men] just come and think, like, this is it, and this is what I’m getting and this is what I’m going to take. (Trinidadian origin, gay, 32 years old)

Most of the participants indicated that a lack of unity between ACB men prevents individuals from finding the right resources. In general, participants emphasized the need for ACB men to join together to draw attention to HIV in their communities as well as focus on community development measures.

I would say that, you know, we have to come together, men, we have to come together, work hard of it. You know, we have to push ourselves, make that effort. I say let’s come together and work as black men. You know, to build a group and at least make the effort to come out and try, pushing to make things happen. If we just sit back and we don’t push and try to make things happen, things are not gonna happen. We have to do it. (Barbadian origin, gay, 34 years old)

Another participant stated similar beliefs:

Most of the time we [men] are always home, we have nothing to do. But if we come together as people, as black – black people are very powerful and mighty because we have sense, and if we put our minds together, we will move many mountains and make up, uplift men and succeed, and all of we can say that, you know. (Trinidadian origin, gay, 32 years old)
There also is the perception that frequent meetings would enable men to educate and update one another regarding current HIV events. Participants stressed the point that many of the men have good connections and, thus, by coming together individuals can use each other’s connections to ease the stress of navigating the healthcare system.

The thing is that many of us have good connection. You have a connection in an agency; you have a bigger connection in another agency. I have a big connection in plenty agencies, that I know plenty big, big doctors. We black people, we can make differences, but this is sometime when there is a group. Like I sit there and I listen to your view, your view, your view, and sometime within these five different views, I pull out one and make one proper view, and we go with that. Because, you know what, we come together for an understanding that something could be work out. Back in the days, when people started up different organizations, nobody was the boss, nobody was the ED. It was just a set of people [who] came together to help one another. It was based on honesty and trust and loyalty, and with black people, we don’t have that. We don’t have loyalty to one another at all. A group doesn’t have to be a million people to make a success, you know. It just has to have the four devoted or five devoted persons. The word is DEVOTED to this aim, and the aim will be successful. (Trinidadian origin, gay, 32 years old)

Participants also indicated that information regarding HIV is not reaching their community, perhaps because most men do not take the time to stop and read HIV related information posted on the walls of hospitals or agencies. Participants stated that lack of
reading and writing ability, prevented most men from accessing adequate health related information.

Sometime, in the hospitals, you’re there and sometime you’re confused because most black people don’t like reading. They will see something that’s stuck on a wall and they would not read what it is. That sometimes it must be that, when you go to some of these places, they [staff] must hand this [brochure] and let you know this is something for you to read, then they might try it, but plenty of black people, most of them do not know how to read, so it’s a challenge. (Trinidadian origin, gay, 32 years old)

Discussion

The data collected for this study provided critical insight about gaps in current HIV health literacy models and interventions. The conclusions that were drawn were based solely on participants’ personal experiences regarding gaps in current HIV health literacy initiatives.

Previous research on stigma and discrimination has found HIV-related stigma to have a profound effect on individuals’ willingness to access treatment and seek out support services (Gardezi, et al., 2008). Specifically, men from African, Caribbean, and Black communities often avoid engaging in prevention practices due to fear of stigmatization (ACCHO, 2013). Additionally, MSM within the ACB communities are found to face additional layers of stigma due to beliefs that HIV is a “gay disease” and that they should be blamed if they become infected.

In accordance to previous literature, the current study found similar types of stigma faced by African, Caribbean, and Black men that negatively influenced their
ability to seek and access proper services. More importantly, the study found immigrant, refugee, and non-status individuals from the ACB communities living with HIV faced greater settlement-related stress linked to experiences of discrimination and social isolation. These findings are important for AIDS service organizations to implement effective strategies to raise awareness about stigma and discrimination affecting IRN-ACB men.

Effective strategies could involve engaging men from the African, Caribbean, and Black communities to design and lead interventions, and facilitate the contact between ACB men living with HIV and the general public to reduce misconception about HIV transmission (Stangl, 2010). Furthermore, interventions could use media campaigns and cultural mediums (e.g. songs) as a means to reduce HIV-related stigma and empower ACB men to advocate for their rights.

In contrast to previous literature, participants spoke highly about the healthcare system in Canada and described it to be much better compared to “back home”. Availability and access to proper medication and health insurance plan were perceived to positively impact individuals’ health status. Furthermore, access to a general practitioner was perceived to have a positive impact on HIV-prevention efforts and increase individuals’ HIV knowledge. These findings are important indicators about the health care system in Canada in that it is beginning to better serve individuals with chronic diseases and ensuring that more people have access to high-quality primary care.

Some participants described discriminatory attitudes from service providers as a contributing factor in preventing ACB men from seeking proper medical care. Inadequate training of immigration doctors and language barriers, between healthcare
providers and patients, were also perceived to deter men’s access to health and social services. Participants also described lack of HIV counseling services and proper guidelines regarding HIV status disclosure made it challenging for people to cope with the diagnosis. Thus, distributing HIV-related information to healthcare providers and clinics and providing cultural competence, anti-oppression training for healthcare professionals is essential in making sure ACB men are in fact seeking out proper services (ACCHO, 2013).

African, Caribbean, and Black men reported that immigration laws and policies limited their access to medical care and proper medication. Insensitivity on the part of immigration personnel and amount of time needed to receive proper documentations to gain legal status were also perceived to negatively affect the health of ACB men. Furthermore, changes in immigration legislations brought new challenges for people to access financial assistance, therefore, leaving many unable to support and care for their families.

Although African, Caribbean, and Black men living with HIV encountered many challenges in their daily life, they were able to suggest a number of factors to help increase HIV-prevention efforts and access to treatment. Factors such as mandatory HIV testing for all people and frequent weekly support meetings were viewed to play a critical role in HIV-prevention efforts among ACB men. More importantly, participants voiced their concerns regarding lack of unity between ACB men and suggested that, in order for a change to occur, men need to join together and form groups to support one another.
This qualitative study sought to respond to current gaps in knowledge in relation to effective, evidence-based interventions focusing on the context-specific health literacy needs of ACB men living with HIV/AIDS. Issues around stigma, community gossip, lack of training of healthcare providers, comparison of HIV in the context of Canada versus “back home”, gender issues, community resource, and immigration were described to have a great impact on ACB men’s daily experiences with HIV.

This study suggests the need for more resources to focus on examining the unique and often neglected factors related to ACB men and their HIV health literacy, such as cultural and religious values, immigration acculturation, trauma, and related psychological and psychosocial factors. Efforts are needed to counter the social exclusion and unfair treatment encountered by IRN individuals within the ACB communities. Service providers also need to take more steps to ensure members of the ACB communities are comfortable with navigating the health care system in Toronto. For instance, AIDS service organizations could offer training for newcomers to help them understand how the healthcare system in Ontario operates and provide mental health and social supports to help them cope with the disease (ACCHO, 2013).

The findings indicate the need for greater involvement on the part of HIV organizations to form weekly support groups for ACB men. Participants indicated reinforcement from service providers and community leaders would aid in motivating men to attend and seek services. Furthermore, the developing interventions to elucidate the relationship between high risk behaviors and concept of masculinity would be an important tool for HIV prevention research.
The findings also captured the connection between gender role norms and ACB men’s sexual risk and preventive behaviors. Some of the findings, however, echoed expected association between sexual orientation and increased risk behaviors. The findings that ACB heterosexual men are more reluctant in accessing HIV services and are more prone to engage in sexual risk behaviors, appears to fit with previous research on stereotyped views of masculinity (Harrison, 2006). Thus, engaging ACB community and AIDS service organization to discuss about gender role norms as well as developing and implementing provincial-level awareness campaigns to reduce such differences is an important step in tackling societal norms of masculinity.

The data gathered for this study indicates that differences between men and women’s motivation levels are predictors of how well they seek health related information. The findings that men are less inclined to seek out health related services suggest that success in promoting practical and lasting improvements in health behaviors among ACB HIV-positive men depends on more than just increasing their understanding of their specific health conditions. It also requires collaboratively promoting personal self-esteem, assertiveness, and self-efficacy in managing their own health care.

The results of this study can be useful in the design of an evidence-based HIV health literacy psychoeducational and skills-based intervention tailored to the needs of ACB men living with HIV. Perhaps, most importantly, these findings suggest the need to look more deeply at the specific need of ACB men living with HIV and determine types of interventions that would facilitate self-empowerment and advocacy for ACB men living with HIV.
Limitations

A main limitation of the current study was the relatively small sample size which may have impacted the outcome of the study. With such a small sample size, the data may not be broadly generalized to other African, Caribbean, and Black men. In addition, since heterosexual men and MSM encounter different challenges, it would have been helpful to separate the two into different groups in order to capture similarity and differences between each group of men. Further studies will need to examine such groups separately and elucidate similarities and differences.

Future Research Directions

HIV health literacy is fundamental to African, Caribbean, and Black men’s health as it requires individuals to be active participant in health related decision makings. Although the sample size was small, this study represents a beginning of an examination of the gaps in current HIV health literacy models. In order to gain a better understanding of the specific needs of ACB men living with HIV, a replication of this study is needed, using larger sample size. Future research should also consider dividing heterosexual men and MSM into separate groups in order to encapsulate the types of challenges each group faces.
References


Canadian Public Health Association. *Health Literacy Interventions, July 2006*

Centre for AIDS prevention Studies. *What are heterosexual men’s HIV prevention needs*, 2001


HIV in Canada: A primer for service providers. *Canada’s source for HIV and Hepatitis C information*, 2014.


Hughes NE. Adapting Health Canada’s tobacco package warnings to less literate Canadians. Session: Building Healthy Public Policy, oral presentation. Second Canadian Conference on literacy and Health, Ottawa, ON, Oct. 17-19. 2004


Appendices

Appendix A: Focus Group Participant Consent Form

Title of Research Study:
HIV Health Literacy for African, Caribbean, and Black Men

Principal Investigator:
Angela Palangi
Ontario Institute for Studies in Education, University of Toronto

Supervisor:
J. Roy Gillis, Ph.D.
Ontario Institute for Studies in Education, University of Toronto

Introduction:
You are being asked to participate in a research study titled “HIV Health Literacy for African, Caribbean, and Black Men.” This study is being done by Angela Palangi of the University of Toronto under the direction of Dr. Roy Gillis of the University of Toronto in fulfillment of the requirements for her Master’s thesis. Before agreeing to participate in this research study, it is important that you read and understand this form. This form provides all the information we think you will need to know in order to decide to take part in the study or not. If you have any questions after you read through this form, you can ask the study staff. You should not sign this form until you are sure you understand everything on this form.

Purpose of Research:
The goal of this research is to find out what the health care experiences and challenges are for African, Caribbean, and Black men who are currently living with HIV/AIDS. We will be asking questions about your experiences with HIV/AIDS and how you get information about your health. We will also ask about your experiences with your doctor and other health professionals, and how these services could be improved.

Study Procedure, Length of Involvement, and Compensation:
You will be involved in a 2-3 hour long focus group (a type of research group where people are asked about their beliefs and opinions about a topic) with approximately 8-10 other men. You will be asked to answer questions about your
experiences with HIV/AIDS, how you get information about your health, your
experiences with your doctor and other health professionals, and how these
services could be improved. The focus group will be audio recorded and later
written out to make sure your responses are recorded accurately. You will be
paid $20.00 for your time and transportation costs, and this money will be yours
to keep even if you quit the study at some point.

Confidentiality of Responses, Limits of Confidentiality, and Storage of Data:
You will choose another name to call yourself in the research, and your personal
identity will be protected and remain confidential. Research results will not be
reported in a way that could identify you. Your experiences, responses and
comments and any other personal identifiable characteristics will not be reported
in such a way that it could identify you. Audio recordings will be put away
securely and will be erased when the transcription process is completed.
Transcripts (written copies) of tapes/audio recordings will not include any
identifying information that you might mention, for example, a name or an
employer. Audio recordings and transcripts will be kept with an ID number which
cannot be traced back to your name or any other identifying information. The
research team will be the only people who will have access to any digital files,
transcriptions, research notes, or personal information for the research. The
transcriptions, digital files, and notes for the research will be kept in a locked
cabinet in paper form and on a computer protected by a password in the
research office. Transcripts, questionnaires, and any notes will be destroyed after
the data has been published. The investigators however, cannot guarantee that
other men in the focus group will keep what you have said confidential.

Voluntary Participation and Study Withdrawal:

Participation in the research is voluntary. You do not have to do it. You can
choose not to answer any questions and you can end your participation at any
time. This will not affect your current and/or future care at any agency where you
are receiving services. If you choose to stop participating in the study and want
your data not to be part of the final analysis, then the research team will take
action to make this happen. There will be no financial penalty for withdrawing
from the study.

Potential risks and benefits of participating in this research:
You may find it difficult to talk about your experiences or to listen to the stories of
other people in the group. If you have strong feelings such as these, please let
the focus group leader know, and they will meet with you privately to talk about a
way to help you cope. During the group session, the group leader will “check-in” with people to see how they are doing. All group members will receive a copy of a list of HIV/AIDS agencies that provide information and counseling services for people.

It is also possible that you could benefit from participating in the research. Many people find it helpful to share their success dealing with difficult experiences with others.

Publication of Research Results and Procedure for Obtaining Summary of the Research Results:

The research team will collect and look to find categories, patterns and common themes from the focus group data. The results of the research might be presented at scientific meetings and published in academic journals. However, your name and any identifying details about you will not appear in any presentation or publication. If you would like a copy of a summary of the first findings by e-mail, please let us know by filling out the contact form below.

How To Get Questions About This Research Answered:

I understand that if I have any questions or concerns about this study that have not yet been answered, I may contact the Principal Investigator for the research project by telephone at: 416-978-7140 or by e-mail at: healthlitmen@utoronto.ca. Furthermore, if after speaking with Angela Palangi, I still have questions or concerns about the research, I can contact Dr. Roy Gillis. If I am not satisfied with Dr. Roy Gillis’s response, I can then contact the Office of Research Ethics at the University of Toronto via e-mail at: ethics.review@utoronto.ca or via telephone at: 416-946-3273.

By signing this consent form below, I am giving my informed consent to participate in this study, and have had any questions answered about my participation in this research to my satisfaction. I have also been given a copy of this consent form.

_________________________    __________________   _____________
Participant signature (pseudonym)  Print Name (pseudonym)  Date
(1) I am interested in receiving e-mail copy of preliminary findings of this research?
   ___ Yes   ___ No

   If yes, e-mail address: __________________________________________
Appendix B: Focus Group Questions

1) Introduce and Explain Definitions of Technical Terms

2) Experiences related to HIV/AIDS health literacy. In this section participants will be asked to discuss their experiences in regards to HIV/AIDS and seeking information regarding their health. Some of the following aspects will be explored:

Health and community development HIV health literacy
- Where do you obtain information related to your health care?
- Where do you currently seek services in general and health related in particular?
- What role does your status as immigrant, refugee and/or non-status play in your HIV health literacy needs?
- What role do factors such as age, race/ethnicity/country of origin, socioeconomic status, education, family composition, language(s) spoken, disabilities-commorbidities (chronic conditions), immigration status, length of time in Canada, religion/religious affiliation, sexual orientation play in your HIV health literacy needs?
- Do you think there are different societal pressures on men vs. women? If so, how do you think this difference affects how men access HIV/AIDS services?
- Do you think your race and/or class affects your health-seeking behaviours? If so, in what ways?
- What are some of the main factors that influence men’s health-seeking behaviours?
- Do you think your sexual orientation impacts your health seeking behavior?
- Do you think your sexual orientation affects how health care workers provide healthcare services?

Health literacy information
- Reasons for seeking health related information
- How and where do you seek health related information? I.e. internet, newspapers, etc.
- Barriers to obtaining health related information
- What information have you obtained regarding HIV disclosure?
- What kind of information do you wish they had available/they lack in relation to your health care needs?
- The info they get, do they put it into practice?
- Do you have up to date information?
• When you participate in research, do you get information back?
• What role does research play in your health care?
• What formats do you want the information to be in? What works for them?

Experiences of primary health care, HIV specialized care and mental health services

• How would you define health? What impacts your health?
• Who takes care of your health care needs?
• What are some of your experiences accessing physicians (primary health care and specialists), quality of services, barriers to obtaining/understanding/using information provided, comfort level during visits, good and challenging experiences?
• What things are explained/not explained properly when visiting health care providers?
• Are you able to disclose your HIV status and needs to service providers?
• Do you initiate dialogue regarding HIV specific needs?
• What medications are you currently taking? Are you experiencing side effects? Do you understand what the medication is doing? What does the medication mean for you?
• Are you taking your medication regularly? Do you miss any doses, if so, why?
• Do you understand the impact of taking breaks?
• Do you know your viral load? How frequently do you have blood work done?
• How would you define mental health?
• How do you take care of your mental health needs? Who takes care of your mental health care needs?
• Where do you seek mental health services? What are some of the barriers you experience?
• What type of support services do you have in relation to your HIV positive status?
• What kind of support systems do you have in place? How have these helped you build self-determination?
• Give an example of a time when you felt that you advocated for yourself? What did you do? What helped?

3) Thinking of designing an intervention on HIV/AIDS health literacy for ACB men.

• What do you need in order to become more effective in advocacy and self-empowerment in relation to living with HIV/AIDS?
• What should be included in an HIV/AIDS health literacy intervention/initiative for ACB/IRN (immigrant, refugee and non-status) men? What formats should be included? Who should participate and how?

• What should the role of GIPA/MIPA (guidelines that suggest people with HIV/AIDS should have greater control over what is done to them in research and health settings) in HIV/AIDS health literacy for ACB/IRN men be?
Appendix C: Demographic Questionnaire

ID CODE: __________

1) Pseudonym chosen for the focus group: ________
2) Age: ________
3) How would you describe your sexual orientation? ________
4) How would you describe your gender identity? ________
   (e.g. Male, female, transgender)
5) What is your country of origin? ________
6) What is your current immigration status or immigration process? ________
7) What is the highest education level you have completed?
   __ High school diploma or equivalency
   __ Vocational degree/license
   __ Bachelor’s degree
   __ Master’s degree
   __ Doctorate, Professional (MD, JD, DDS)
   __ None of the above, please specify other: ________
8) What language(s) can you speak? ________
9) Do you have any chronic conditions? ________
    If yes, please specify: ________
10) How long have you been living in Canada? ________
11) Have you been tested for HIV? Yes ______ No ______ Unsure ______
    If yes, what was the result? _____ HIV-positive _____ HIV-negative ______
         HIV-unsure
12) Are you affiliated with any religious organizations? ________
13) What was your family income for your household for the past 12 months? ______
14) What is your current marital status?
    (a) Unmarried
    (b) Married
    (c) Divorced
(d) Widowed
(e) Separated
(f) Remarried

15) Do you have any children? __________
    If yes, how many? _______
HIV HEALTH LITERACY STUDY FOR MEN LIVING WITH HIV/AIDS

Are you interested in talking about your experiences about health and psychological services for men living with HIV/AIDS?

Are you a member of the African, Caribbean, and/or Black community?

We are looking for men to talk about what health and psychological resources are available for immigrant, refugee, and non-status men, from the African, Caribbean, and/or Black communities, living with HIV/AIDS and what are the challenges they experience with these services.

$20 for participating in the research

2-3 hours of time required

IF YOU ARE INTERESTED and want more information:

Please CALL (number) or EMAIL (address)
Appendix E: List of Support Resources for Participants

St Michael's Hospital Health Centre at 410
Office phone: 416-867-3728 Fax: 416-867-3726
Web site: www.stmichaelshospital.com
Address: 410 Sherbourne St, 4th Fl, Toronto, ON, M4X 1K2

South Riverdale Community Health Centre
Office phone: 416-461-1925; Medical floor 416-461-2493 Fax: 416-461-8245
Email: srchc@srchc.com Web site: www.srchc.com
Address: 955 Queen St E, Toronto, ON, M4M 3P3

Teresa Group Child and Family Aid
Office phone: 416-596-7703 Fax 416-596-7910
Email: theteresagroup@on.aibn.com
Web site: www.teresagroup.ca
Address: 124 Merton St, Ste 300, Toronto, ON, M4S 2Z2

Toronto People With AIDS Foundation
Office phone 416-506-1400 Fax: 416-506-1404
Email: info@pwatoronto.org
Web site: www.pwatoronto.org
Address: 200 Gerrard St E, 2nd Fl, Toronto, ON, M5A 2E6

Warden Woods Community Centre Health and Seniors Services
Office phone: 416-694-1138 ext 172 Fax: 416-694-1960
Email: samanthab@wardenwoods.com
Web site: www.wardenwoods.com
Address: 63 Mack Ave, Toronto, ON, M1L 1M5

Toronto Public Health
Office phone: Toronto Health Connection 416-338-7600
After hours emergency 416-690-2142
TTY phone: 416-392-0658 Fax: 416-392-0715
Email: publichealth@toronto.ca
Web site www.toronto.ca/health
Address: 277 Victoria St, 5th Fl, Toronto, ON, M5B 1W2

YouthLink-YouthLink Inner City
Office phone: 416-703-3361 Fax: 416-703-3359
Email: innercity@youthlink.ca
Web site: www.youthlink.ca
Address: 7 Vanauley St, Toronto, ON, M5T 2V9

Black Coalition for AIDS Prevention
Office phone: 416-977-9955 Fax: 416-977-7664
Email: info@black-cap.com
Web site: www.blackcap.ca
Address: 20 Victoria St, 4th Fl, Toronto, ON, M5C 2N8

519 Church Street Community Centre
Office phone: 416-392-6874 Fax: 416-392-0519
Email: info@the519.org
Web site: www.the519.org
Address: 519 Church St, Toronto, ON, M4Y 2C9

AIDS Committee of Toronto
Office phone: 416-340-2437 Fax: 416-340-8224
Email: ask@actoronto.org
Web site www.actoronto.org
Address: 399 Church St, 4th Fl, Toronto, ON, M5B 2J6

Alliance for South Asian AIDS Prevention
Office phone: 416-599-2727 Fax: 416-599-6011
Email: info@asaap.ca
Web site: www.asaap.ca
Address: 120 Carlton Street, Suite 315, Toronto, Ontario, M5A 4K3

Family Service Toronto
Office phone: 416-595-9230; Service Access Unit 416-595-9618 Fax: 416-595-0242
Email: sau@familyservicetoronto.org
Web site: www.familyservicetoronto.org
Address: 355 Church St, Toronto, ON, M5B 1Z8

HIV & AIDS Legal Clinic Ontario
Email: talklaw@halco.org Web site: www.halco.org
Address: 65 Wellesley St E, Ste 400, Toronto, ON, M4Y 1G7

Sherbourne Health Centre
Office phone: 416-324-4180 Fax: 416-324-4181
Email: info@sherbourne.on.ca
Web site: www.sherbourne.on.ca
Address: 333 Sherbourne St, Toronto, ON, M5A 2S5

Positive Youth Outreach
Web site: http://www.actoronto.org/home.nsf/pages/positivelyouthoutreach
Address: 399 Church Street, 4th floor, Toronto, ON. M5B 2J6 (located at the south-east corner of Church & Carlton Streets).

Hassle-Free Clinic
Office phone: 416-922-0566 Fax: 416-922-2018
Web site: http://www.hasslefreeclinic.org/
Address: 66 Gerrard Street East, 2nd Floor, Toronto, ON, M5B 1G3

Black Coalition For AIDS Prevention
Office phone: 416-977-9955 Fax: 416-977-7664
Email: info@black-cap.com
Web site: www.blackcap.ca
Address: 20 Victoria St. 4th floor, Toronto, Ontario M5C 2N8