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The Migratory Experiences, Access to Health Care and Employment of Immigrant and Refugee Latinos and Latinas Living with HIV in Toronto

Angel A. Serrano Sanchez
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**The Migratory Experiences, Access to Health Care and Employment of Immigrant
and Refugee Latinos and Latinas Living with HIV in Toronto**

By

Angel Serrano Sánchez.

**A Dissertation
Submitted to the Faculty of Graduate Studies
through the Department of Sociology, Anthropology and Criminology
in Partial Fulfillment of the Requirements for
the Degree of Doctor of Philosophy
at the University of Windsor**

Windsor, Ontario, Canada

2013

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Refugee Latinos and Latinas Living with HIV in Toronto

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DECLARATION OF ORIGINALITY

I hereby certify that I am the sole author of this thesis and that no part of this thesis has been published or submitted for publication.

I certify that, to the best of my knowledge, my thesis does not infringe upon anyone's copyright nor violate any proprietary rights and that any ideas, techniques, quotations, or any other material from the work of other people included in my thesis, published or otherwise, are fully acknowledged in accordance with the standard referencing practices. Furthermore, to the extent that I have included copyrighted material that surpasses the bounds of fair dealing within the meaning of the Canada Copyright Act, I certify that I have obtained a written permission from the copyright owner(s) to include such material(s) in my thesis and have included copies of such copyright clearances to my appendix.

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ABSTRACT

The present study documents and analyzes the everyday experiences of immigrant and refugee Latinos and Latinas living with HIV in Canada, particularly in Toronto. The main objective is to understand the issues that the Latino HIV positive community encounters during the migration process, the barriers accessing health care and employment in Canada, and strategies to counterbalance the negative effects of such barriers. Participants' relationships with relatives, friends and partners are also analyzed as a means to understand better processes of discrimination and marginalization in the context of living with HIV. The study is carried out using a qualitative methodology, which allows deeper comprehension of social contexts and individuals' perceptions and meanings. Thirty face to face interviews were conducted with HIV positive men and women originally from Latin America, representing a wide range of diversity in national origin, age, gender, and sexual orientation. The study contributes to the research done on the areas of migration, the experience of living with HIV/AIDS and links of migration and sexuality. It also attempts to be useful in the construction of a culture of coping strategies, and practical knowledge for managing the disease, which can be of direct interest for seropositive people themselves. Studies that explore the experiences of Latinos and Latinas living with HIV are particularly relevant at a time when in Canada the HIV/AIDS epidemic is growing fast in this community.

DEDICATION

Para Bibiana, mi madre, quien siempre me ha dado su cariño incondicional. Para mi padre, ejemplo de perseverancia.

Para Alejandro, mi primo y amigo constante, pequeño hermano siempre dispuesto a compartir alegrías y tristezas sin importar la distancia.

A la memoria de mi amigo Francisco, porque tu historia de vida fue mi primera motivación a emprender esta aventura.

For the people of this world who have ever experienced the suffering of being far away from home.

For the people of this world whose lives have been affected by the HIV/AIDS epidemic.

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LIST OF ABBREVIATIONS

ACT	AIDS Committee of Toronto
AIDS	Acquired Immune Deficiency Syndrome
ASOs	AIDS Service Organizations
CAAT	Committee for Accessible AIDS Treatment
CHC	Community Health Clinic
CSSP	Centre for Spanish Speaking Peoples
HAART	Highly Active Antiretroviral Therapy
HALCO	HIV and AIDS Legal Clinic of Ontario
HIV	Human Immunodeficiency Virus
IFHP	Interim Federal Health Program
IRB	Immigration and Refugee Board
LAO	Legal Aid Ontario
LGBT	Lesbian Gay Bisexual and Transsexual
ODB	Ontario Drug Benefit program
ODSP	Ontario Disability Support Program
OHIP	Ontario Health Insurance Plan
OHTN	Ontario HIV Treatment Network
OW	Ontario Works
PHA	Person/People living with HIV/AIDS
PIF	Personal Information Form
PWA	People With AIDS Foundation

EXECUTIVE SUMMARY

Issues during migration and settlement process in Canada

- Language barriers
- Lack of information during the refugee claim process
- Difficulties finding appropriate legal representation
- Lengthy wait times to receive the result of refugee claim applications
- Generalized perception of loss of control
- Arbitrary and inconsistent Canadian IRB policies and practices, such as the determination of refugee claimants' sexual orientation, and the evaluation of claims based on stereotypes and racial profiling.
- Experiences of detention during the migration process based on race, sexual and gender identities
- Constant re-appearance of structural and multiple traumas during the refugee claimant process.
- Receiving an HIV positive diagnosis during the migration process

Barriers in the access to health care services

- Lack of legal status
- Language differences and cultural misunderstandings with service providers
- Difficulties to understand the health care system in Canada and how to negotiate the access the services
- Existence of power imbalances in the relationship among health care professionals and patients, and lack of accountability from physicians to patients
- Gender, racial discrimination and transphobia in the health care system
- Lengthy wait times to access specialized medical services
- Stigma and discrimination in the Latino community and the Canadian society, and internalized stigma
- Confidentiality concerns in the access to services
- Deficiencies in mental health services for Spanish speaking people living with HIV/AIDS
- PHAs' lack of coverage of health related products (vitamins, proteins, etcetera) and services

Strategies

- Self-education in regards to how the health care system works in Canada and search for information
- Changing physicians
- Importance of understanding that their own health is more important than stigma in access to health care services
- Accessing products and services which are not covered by health and disability

coverage through AIDS Service Organizations (ASOs) such as People Living with AIDS Foundation (PWA), AIDS Committee of Toronto (ACT) and community clinics

Barriers in the access to employment

- Lack of legal status
- Low English proficiency
- Lack of work related Canadian experience
- Anti-immigrant feelings and racism
- Age related discrimination
- Homophobia
- Concerns related with disclosure at the workplace
- HIV related stigma and discrimination at the workplace
- Difficulties negotiating HIV related accommodations at the workplace
- Misunderstandings about the status of HIV as a disability among HIV positive and HIV negative coworkers
- Issues with agency staff when PHAs have committed to projects and for health or personal reasons have to stop or leave the project
- Long periods of poor health caused by HIV related illnesses, or due to side effects of medications
- Long gaps in job histories related to periods of poor health
- Lack of updated job skills

Strategies

- Not disclosing HIV status to employers and coworkers
- Volunteer work
- Working under the table

Strategies to counterbalance economical constraint

- Use of food banks
- Participating in research projects to get compensation
- Cutting off expenses related to home services (home phone, TV cable)
- Avoidance of public transportation
- Buying clothes out of season
- Preparation of food to sell among friends and acquaintances
- Relying on friends, family and partners to obtain goods
- Attending community kitchens to make meals
- Avoidance of recreational and social activities

Strategies to avoid stigma and discrimination in relationships with family, friends and

potential partners

- Not disclosing HIV serostatus to relatives, friends, and casual partners
- Process of evaluation before disclosing serostatus
- Family members, friends, and partners as sources of support, and care
- Educating family, friends, and other persons around them about the experience of living with HIV
- Compartmentalization of social networks
- Incorporating serostatus as one more aspect of identity
- Considering HIV infection as something normal
- Considering HIV infection as less damaging than other chronic conditions
- Forgetting positive serostatus during matters of everyday life
- Religiosity and nurturing of a spiritual life
- Re-evaluating the experience of living with HIV as positive
- Early disclosure of serostatus to potential romantic and sexual partners
- Dating other HIV positive individuals
- Searching for casual and anonymous sex

CHAPTER 1: Introduction

The present study documents and analyzes the everyday experiences of immigrant and refugee Latinos and Latinas living with HIV/AIDS in Toronto, Ontario. The research particularly focuses on the study of their migratory stories and barriers in access to health care and employment that Latinos and Latinas living with HIV/AIDS confront in Canada. The purpose of this analysis is to understand social inequalities and processes of marginalization that this group of immigrants and refugees encounter in the Canadian society. To understand better the different forms of discrimination that this group faces, I analyze their relationships with family, friends and partners.

The relationship of the experience of living with HIV/AIDS with migration and sexuality is of particular interest. I will try to show the complex linkages among these three different aspects, and how they influence each other in the lives of HIV positive immigrant and refugee Latinos and Latinas.

On the other hand, the analysis of the everyday experiences of immigrant and refugee Latinos/as living with HIV also aims to show their strategies coping with discrimination and marginalization, their experiences of resilience and strengths as related to living with HIV/AIDS (Emlet, Tozay and Raveis, 2011). It is recognized now that the study of resilience has become central to discussions on health inequalities (Aranda, Zeeman, Scholes and Santa-María, 2012).

There exists research evidence that shows that both immigrant/refugee and HIV/AIDS status are characterized by discrimination and inequality. Among newcomers, discrimination and structural inequality have been associated with high levels of underemployment, unemployment, poverty and lack of health services (Wong,

Kanagaratnam, Yee and Fung, 2004). In addition, other research has also found that HIV/AIDS related discrimination exists at work, health care settings, at school, and in other places (Weitz, 1990; Herek, 1999).

In Ontario, HIV positive individuals, who at the same time are immigrants, refugees or lack a documented status, are a fast growing population that faces significant levels of vulnerability (Li, 2007: 1). For instance, Li (2007: 1) comments that, for 2005, 668 immigrant/refugee applicants tested HIV positive through their application process to regularize their migration status, representing 15.7% of Canadian HIV positive tests reported that year. For many immigrant, refugee and non-status individuals living with HIV/AIDS, HIV related stigma, racism, sexism, homophobia, trauma and loss throughout their migration process are a reality. HIV positive individuals without a regular status encounter significant barriers accessing treatment and care, jeopardizing their physical and mental health (Li, 2007:1-2).

Also in Ontario, the Committee for Accessible AIDS Treatment (CAAT) found that a significant number of people living with HIV/AIDS (PHAs) face difficulties for everyday survival, a declining of their health status and a general perception of social exclusion and loss of quality of life. In addition to these common stressors that affect PHAs in general, HIV positive immigrants and refugees experience negative aspects related to immigration and settlement processes, racism, social exclusion, poverty, under-housing, and barriers to social services (Chen, 2007; CAAT, 2008).

Research on immigrants and refugees living with HIV/AIDS is extremely limited, in spite of the harsh conditions that this population encounters. There exist a few studies that focus on screening, prevention and behavioral risks related to gender, cultural issues

and other social aspects. However, current research does not reflect on the multiple and intersecting dimensions of immigrants and refugees living with HIV/AIDS lives. Studies have been conducted on HIV and sexual orientation, HIV and gender, or HIV and race, but there exist scant studies addressing multiple dimensions, such as gender, race, class, socioeconomic status, sexuality, physical and mental health status, among others (Wong et al., 2004).

Research Questions and Objectives

The research questions that guide the present study are:

- What are the barriers that immigrant and refugee Latinos and Latinas living with HIV face during migration and in the access to health care and employment?
- What are the strategies that allow subjects to counterbalance the barriers in the access to health care and employment?
- How do the experiences of migration, living with HIV and sexuality relate and interact in the lives of immigrant and refugee Latinos/as living with HIV in Canada?

Objectives:

- Analyze the experiences of immigrant and refugee Latinos/as living with HIV regarding migration, health care and employment with the purpose of understanding the issues and barriers in the access to such services, and therefore, the processes of discrimination and marginalization that they have to face.
- Document the existence of strategies that allow the subjects to respond to discrimination and live more satisfactory lives.
- Document and analyze the interaction among migration, the experience of living

with HIV, and sexuality in the lives of immigrant and refugee Latinos/as living with HIV in Canada.

The study aims to contribute to the scarce Canadian research on immigrants and refugees living with HIV (Wong et al., 2004). To the best of my knowledge this is the first study in Canada that particularly focuses in the experiences of immigrant and refugee Latinos and Latinas living with HIV. As such, it is a contribution to both the HIV/AIDS literature from the social sciences and the migration literature, especially in the intersection of migration and sexuality, which is an aspect of migration scarcely explored (Carrillo, 2004; González-López, 2005). In addition, the study will attempt to understand HIV related stigma and discrimination within the Latino community, a topic little explored so far in the United States or elsewhere (Varas, Serrano and Toro, 2005).

Finally, following the line of research on living and experiencing HIV/AIDS, this work can be useful in the construction of what Adam and Sears (1996: xi) call a culture of coping strategies, and practical knowledge for managing the disease, which can be of direct interest for seropositive people themselves.

The construction of a Latino Identity

In the United States, Massey and Sanchez (2006) consider Latino identity to be a product of the globalization process that transcends cultures and national boundaries. When new immigrants from Latin America arrive in the U.S., they do not perceive themselves as Latinos, but as Mexican, Colombians, and so on. A shared sense of marginalization from the dominant social group and a pervasive labeling that immigrants experienced in their encounters with non-Hispanic whites are the principal factors that give place to the formation of a Latino identity. The formation of this new identity helps immigrants to

overcome the negative effects of the labeling and marginalization that affect their lives. The formation of a US based Latino identity implies the reliance on sentiments or symbols that are commonly shared across national borders, such as strong family and community ties, religious traditions, food, music and crafts, among others.

However, other authors warn not to take Latino identity for granted because new communication and travel technologies permit the maintenance of strong connections with communities of origin (Courtney, 2006), and therefore, national identities can persist. For instance, for first generation Mexican immigrants, national origin persists as a means for the formation of collective identity, more than the US-based constructs of Latinidad or Hispanidad (Fox, 2006).

Does a Latino community exist in Canada? If Latino identity and Latino community are still contested constructs in the United States where Latino American immigration has a long history and is charged with socio-economic, cultural and political meanings, then it is highly likely that Latino identity in Canada will be even more diffuse. Immigration from Latin America to Canada is a more recent phenomenon, and it does not occur in the same proportion as migration to the United States.

On the other hand, the multicultural scene of Toronto shows signs which can be deemed to be proof of a nascent Latin community in the city. In addition to forming groups with people from the same country, Latin Americans also build community institutions that are pan-ethnic¹, for all Latin Americans and/or Spanish speakers, beyond nationality (Goldring, Landolt and Barriga, 2006). The Centre for Spanish Speaking Peoples and Latinos Positivos are examples of pan-ethnic organizations.

¹ The study of Ricourt and Danta (2003) is an example of the formation of a pan-ethnic Latino identity in the United States.

In this study, the concept of Latinos and Latinas is used to represent those individuals coming from a Latin American country and whose main language is Spanish. However, it is necessary to keep in mind the ongoing discussion about Latino identity and community and recognize that probably not all the individuals coming from a Spanish speaking country consider themselves as part of a Latino community, and that, as any other identity construct, Latino identity is fluid, charged with diverse meanings and open to different interpretations.

Immigration to Canada

Currently, Canada relies on immigration as a means to rejuvenate an aging society; it provides both skilled and unskilled labor and helps to ensure competitiveness in the global economy. For 2011, the country admitted 248,748 new permanent settlers (Citizenship and Immigration Canada, 2012). This way, two-thirds of the country's population growth is now fuelled by immigration (Cohen, 2012a).

The composition of the immigrant population has changed drastically from early times. Up to the early 1960s, admission based on the country of origin formed the core of immigration policy (Green and Green, 2004). There was a prevailing notion of the fittest citizen-to-be as white, Anglo-Saxon and Protestant, meaning of British or American origin (Brown and Cook, 1974).

A new regulation in 1962 removed national origin as a criterion of admission. Additional regulations enacted in 1967 confirmed the norm of not considering national origin as a selection criterion. The points system, which assigns points based on the applicant's age, education, language skills and economic characteristics, was created. With the implementation of these policy changes, immigration to Canada of persons born

outside the traditional immigrant sending countries, Europe and the United States, started to increase (Boyd and Vickers, 2000).

A new principle of admission based on humanitarian grounds was incorporated in 1978. Previous to that year, refugee admissions had been controlled through special regulations (Boyd and Vickers, 2000). This new regulation allowed the systematic migration of family members and refugees, giving them a special priority during the migration process (Green and Green, 2004).

The new immigration policies based on principles of family reunification and the potential contribution of newcomers to the labor market of the country brought significant changes to the composition of the immigrant population. Applicants could be admitted if they met the required criteria, regardless of the nation of origin. The establishment of these new criteria of admission allowed the entry of migrants from non-European countries. In this way, from 1966, newcomers arrived from many different nations, bringing with them more diverse cultural backgrounds than former immigrants. The diversification process of the immigrant population was also accompanied with a declining percentage of individuals coming from Europe, the United Kingdom and the United States (Boyd and Vickers, 2000).

The changes in migratory patterns have brought into existence a visible minority population in the country. The term *visible minority* refers to people who are, because of their race or color, in a group that is different from the majority population in Canada. In 1986, members of visible minorities formed 6.3% of Canada's population; by 1996 visible minorities comprised 11.2% of the population (Li, 2003). By 2006, 16.3% of the population belonged to a visible minority group, and based on current demographic

trends, it is expected that, by 2031, they will represent the 30.6% of Canada's population (Statistics Canada, 2012). The growth of visible minorities and their settlement in metropolitan areas created the impression that there has been proliferation of cultural diversity in the Canadian population, even though it still consists principally of people with an origin in the UK, France or other European nation (Li, 2003).

Although the increasing of racial and cultural diversity in Canada is a reality, social differentiation and hierarchization with embedded inequalities of power, status, wealth and prestige, are part of the experiences of non-white immigrants (Juteau, 2003). Many individuals and groups in Canada continue attributing an unequal social value to groups with a different cultural and racial origin. Research in the area has found that Canadians still consider non-white minorities as socially less desirable than groups of European descent and that racial traits still are meaningful to many people as a means to understand their everyday experiences (Li, 2003). For instance, a survey conducted by Leger Marketing group in 2006-2007 for *Le Journal de Montréal*, showed that 47% of Canadians were willing to admit that they were slightly, moderately, or extremely racist. In Quebec, that proportion was placed at 59% (The Gazette, 2007). Among members of visible minorities who participated in an ethnic diversity survey, 35% reported experiences of discrimination. Experiences of perceived vulnerability are reported by 37.3% of members of visible minorities (Reitz and Banerjee, 2009).

Historically speaking, it is possible to say that immigration in Canada is profoundly marked by examples of racism and discrimination, such as the first federal Chinese Exclusion Act in 1885, restricting the entrance of Chinese immigrants. The “continues passage rule” of 1908, which had the effect of excluding from immigration

applicants who were not able to make a direct journey to Canada from their countries of origin, limiting this way the migration of Indians. During the Second World War, Canadian immigration rules sought actively to impede the entrance of Jews into the country; as a result, the record of Jewish admission is one of the worst in the Western world. In the 20th century immigration of Africans was actively discouraged as well through medical tests, among other means (Canadian Council for Refugees, 2000).

The changes on immigration policies prior to the 1960s were a significant measure against overt forms of racism and discrimination. However, more subtle forms of racism still exist (Canadian Council for Refugees, 2000). The existence of persistent expressions of xenophobia and racial discrimination speaks of a continuing political and cultural attachment to the history of Canada as a white, settler society. Canada's visible minorities continue to confront racial discrimination in the labor force and the workplace, overrepresentation in low-paying occupations, unemployment, substandard housing, neighborhood segregation, and low health status, giving place to a severe dynamic of social exclusion and racialization of poverty (Galabuzi, 2006).

Latinos and Latinas in Canada

The Latino community is a new immigrant group in Canada. In his analysis of the main factors involved in the relatively recent movement of immigrants and refugees from Latin America to Canada, Simmons (1993) points out that this migration process was possible thanks to changes in the 1960s and 1970s of the immigration law.

The widespread economic and socio-political crisis throughout Latin America in the 1970s and 1980s provided a general background for population exodus. Certain groups, particularly professional and skilled workers moved internationally largely for

economic reasons. Nonetheless, the economic factor by itself accounted for extremely little of Latin American migration to Canada, although it undoubtedly accounts for a good deal of Latin American migration to the United States.

Large flows of Latin American workers and peasants to Canada emerged primarily from countries where civil war and repression were taking a substantial toll on life and freedom. In such cases, the relative advantages of Canada with regard to jobs, income, and social services became influential supporting features in directing the initial migration flow to Canada, and in sustaining a later trailing flow of relatives and other migrants. However, the most decisive attraction of the country was its independent policy with respect to refugees: those fleeing right-wing dictatorships in Chile, El Salvador, and other Latin American countries found a relatively welcoming environment in Canada. This way, while opportunities to the United States were restricted, opportunities to migrate to Canada were expanding.

Information on Canada as a possible destination flowed back to Latin America from those who originally came and led to the movement of relatives and other migrants, including those from other Latin American countries who had not yet established a migration path to Canada. Migrant networks in the region as elsewhere are facilitated by the greater ease and declining costs of travel and telecommunications.

Taking into account all these factors, the migration flow from Latin America to Canada arose on the foundation of a combination of exceptional circumstances: violence in sending countries; variable barriers to migrant entry to the United States; an independent Canadian immigration and refugee policy; and relatively high income and employment opportunities in Canada (Simmons, 1993).

Latin American migration to Canada has been characterized by waves of migration. The most important of these waves have been the arrival of political refugees, first from South America, principally from Chile, in the mid-1970s, and the movement of refugees from Central America, mainly from El Salvador, in the 1980s. A new wave of newcomers has arrived to the country since the mid-1990s, this time consisting particularly of professionals, individuals seeking to reunite with their families, and refugee claimants from all over Latin America (Veronis, 2007).

In spite of being a relatively new group of immigrants in Canada, the Latino community is quite diverse with individuals coming from over twenty North, Central and South American nations. In 2007, there were approximately 520 000 Latinos/as in Canada. Contrary to the United States where specific national groups dominate in some cities, regions and/or states of the country, in Canada, similar to the other immigrant groups, the Latino community locates itself principally in the three largest urban areas: Montreal, Toronto and Vancouver, with an important representation of most Latin American nationalities. The metropolitan area of Toronto has the largest concentration of Latino population, with around 150 000 individuals for 2007. This represented 3.2% of the total population of the metropolitan area of the city (Veronis, 2007).

Like other newcomers, Latinos and Latinas occupy a socially, economically and politically marginalized position in the nation when compared to white European immigrants several generations ago, and Canadians in general. The Latino community's rates of income and homeownership are lower than Toronto averages. In addition, the incidence of poverty in the city is higher among Latinos and Latinas: in 1996, median incomes were \$15,000 for Latina workers, and \$20,000 for Latino workers, compared

with \$22,000 and \$27,600 for other female and male workers respectively. Regarding homeownership for 1996, 57.9 % of Toronto families were homeowners while only 25% of Latin families did own their homes (Ornstein, 2000). Similar to many other newcomer groups, Latinos and Latinas are underrepresented in the decision-making circles in the country (Siemiatycky and Saloojee, 2002).

Similar to other immigrant and racial/ethnic communities in Canada, there is scant research on any aspect of the Latino community in the country. However, some studies have been conducted on citizenship and political participation among Latino/a immigrants in Toronto and Montreal (Armony, Barriga and Schugurensky, 2004), transnational Latin families (Bernhard, Landolt and Goldring, 2008), and the political incorporation of Latinos/as in Toronto (Landolt and Goldring, 2009).

In the area of sexuality and HIV risk in the immigrant Latino community, there is a significant lack of knowledge regarding the changes that immigrants' sexual behavior experiments as a result of migration, and what happens with the immigrant's sexuality and sexual behavior during their back and forth movement between home and host countries (Carrillo, 2004). Studies of sexuality and sexual behavior among the Latino population are particularly beneficial in a time when the HIV epidemic is growing fast in this community. In 2010, the Centers for Disease Control and Prevention, in the United States, found that new infections among the Latino community were 2.8 times higher than for White individuals (Centers for Disease Control and Prevention, 2012). This is consistent with findings in Ontario which show that among the studied ethno-cultural groups (Black, South Asian, Latin American, Asian, Arab/West Asian, Aboriginal) in the province, Latino gay and other men who have sex with men (MSM) have a higher rate in

HIV diagnoses. Latino gay men and other MSM account for the largest proportion of HIV diagnoses among ethno-cultural groups in 2004, and continuing a faster increase than the MSM average through 2006 (Remis & Liu, 2006). Also, it is known that in Canada, for the period of 2009-2011, new HIV diagnoses are over-represented among the Black and Latin American ethnicities; 72% of new infections among the Latino community were diagnosed in Toronto (Sullivan, 2011).

Thesis format

The second chapter presents the literature review of research done in the major areas that form part of this project: the experience of living with HIV/AIDS, sexuality in the context of migration and their links to risk of HIV infection and transmission, barriers in access to health care for immigrants and refugees living with HIV/AIDS, and employment and HIV. In the third chapter, the theoretical concepts that help to understand the experiences of migration and living with HIV are analyzed. The models that have been used to explain immigrants' health status are briefly discussed, likewise the social determinants of health perspective. Chapter four presents the methodology employed in the study, explaining the nature of the qualitative methodological perspective and the characteristics of qualitative interviews. In the next three chapters, the empirical results of the study are presented.

Chapter five focuses in the migratory experiences of the Latinos and Latinas who participated in the study, principally their motivations to migrate and the barriers and difficulties that they experienced during the migration and settlement processes. In chapter six, health care services and barriers in access are discussed. In chapter seven, I discuss the main barriers that HIV positive Latinos and Latinas encounter in Toronto to

find and maintain a job. I argue that they have to cope with barriers related to the experience of living with HIV/AIDS and the difficulties that immigrants in general encounter in Canada.

In chapter eight, participants' experiences regarding family, friendship, couples and sexuality are presented and analyzed, making particular emphasis on aspects of stigma and discrimination in individuals' relationships, and the importance of these relations in their lives. Finally, the conclusions of the study and recommendations for future research are presented. The coping strategies and other aspects of resilience that participants have developed to deal with stigma, discrimination and barriers in access to services are presented in each chapter.

CHAPTER 2: Literature Review

The experience of living with HIV/AIDS

Social science research in the field of HIV/AIDS has principally focused on different aspects of prevention, on understanding HIV related high risk behaviors and why some individuals engage more frequently in these so-called behaviors than others. Less research has been devoted to the experiences of people living with HIV/AIDS.

Literature in the area acknowledges that an HIV positive test means a biographical disruption in the personal narrative. It disrupts taken for granted reality and takes the subject away from previously unproblematic accounts of experience and forces reflection and theorizing in order to assert a renewed sense of order (Adam and Sears, 1996). This way, the self-construction of people with HIV is typically centered on the distinction of a before and an after the diagnosis moment. The diagnosis constitutes a, or even the, crucial biographical turning point (Rinken, 2000).

Based on interviews with gay and bisexual men living with AIDS in Arizona, Weitz (1990) reports the highly stigmatizing effects of HIV infection in the middle 1980s, before the existence of antiretroviral therapy. She found striking examples of rejection among PHAs' family, friends, lovers, housemates, coworkers and health care professionals. People living with HIV/AIDS were severely ostracized at the time, when the AIDS epidemic came to reinforce the generalized idea that homosexual behavior should not be tolerated. As strategies to avoid stigmatization, people living with HIV/AIDS had to hide the disease from family, friends, sexual partners and coworkers. Although hiding the condition gave them some protection against rejection, it also meant having to endure the illness alone and in silence, without any support. Other strategies

reported by Weitz (1990) to avoid HIV related stigma are: testing how family and acquaintances are likely to react to their illness; avoiding communication with friends and family member who prove unsupportive; joining support groups for persons who live with HIV/AIDS as a manner of replacing lost social networks, and coming out of the closet in regards to HIV; educating others and speaking on public media helping this way to reduce stigma and discrimination.

Adam and Sears (1996) conducted a study with people living with HIV/AIDS in the binational context of Detroit, Michigan, and Windsor, Ontario. They describe and analyze the effects of HIV infection in PHAs' identities and personal relationships with family, friends and partners, and PHAs' experiences in access to health care and employment. The main objective of the study was to give voice to people living with HIV infection in order to identify the everyday problems associated with the disease and facilitate a culture of coping strategies, success stories, and practical knowledge for managing the disease. The authors found out that even though stigma and discrimination still had a significant presence in the personal relationships of PHAs, in many instances those same relationships were significant sources of support, care and compassion. In regards to sexuality, Adam and Sears (1996) expected to encounter substantially different styles of negotiating sexual and affectional relationships between gay men and heterosexual women and men, but surprisingly they found strong parallel experiences between all groups. Many of the dilemmas and ways of working them out demonstrate similar experiences among people regardless of race, social class, or sexual orientation.

Wilton (1996) explores the geographical dimensions of the experience of living with HIV/AIDS. Interviewing HIV positive men in Los Angeles, California, he found

that, during the course of everyday life, his interviewees drew on diverse resources, which allowed these men to cope with significant challenges associated with HIV/AIDS. These resources go beyond medical care, and include material and emotional support from service agencies, which form a vital part of their formal social networks, and family members and friends who are part of valuable informal networks. In addition, respondents counted among their resources their own physical and psychological reserves. Wilton (1996) found that, during certain circumstances, the impact of HIV/AIDS can be highly overwhelming, forcing these men to change and even sometimes to relinquish some aspects of their daily routines. However, most of them worked to overcome these restrictions on their daily activities. This way, even though it is true that participants' worlds had been diminished to some extent and in some aspects, the truth is also that they spent much of their time living with, and not dying from HIV/AIDS.

In the literature, there are also some examples of migration and the experience of living with HIV/AIDS. In his study of new migrants from non-English speaking countries who are diagnosed HIV positive during the process of settlement in Australia, Körner (2007) affirms that HIV positive newcomers face two significant life disruptions. Such life disruptions represent at the same time outstanding uncertainties: the arrival to a new and unfamiliar country, and the process of adjustment to living with HIV, which is a highly stigmatized condition, and depending on multiple factors, has the potential of being terminal. Legal status has powerful effects on immigrants' everyday lives, and their possibilities of planning for the future. The lack of permanent residency in the new country means uncertainty and fear of deportation, and therefore, represents a critical

barrier to access health care services, including HIV testing, and disclosing of an HIV positive status.

Living with HIV, on the other hand, represents uncertainties about health, treatment success, and the future. Therefore, when migration and HIV intersect, compounded effects are present, generating negative results in the migration process and on the person's health status. Körner (2007) contends that to provide effective care and support for individuals going through such harsh conditions language, cultural, and financial barriers to health and support services should be removed or at least controlled. In addition, ethnic and racial communities in the host countries must evaluate their attitudes and perceptions in regards to HIV and PHAs in general, with the goal of fighting stigma and discrimination and facilitating in this way the process for HIV positive newcomers of building new social networks.

Doyal, Anderson and Papparini (2009) explore the experiences of black African immigrant men who were receiving health care for HIV in London. Through focus groups and semi-structured interviews they explore aspects of employment, parenthood, access to health care, disclosure and sexuality. The researchers encountered high rates of unemployment and poverty among participants, even though on average they had higher education than the general population in London. In addition, they found that most of the participants disclose their serostatus to very few persons due to fear of being rejected, as well as a loss of interest in sex related to illness, medication, doubts about their physical aspect and attractiveness, and stressful events in their everyday lives. In such an uncertain context, marked by insecurity, isolation and fears about the future, sex as an expression of love was difficult to achieve.

Most of the participants were on antiretroviral drugs; they recognized that the treatment made them dependent on others and sometimes left them with a feeling of being trapped in a country far from home. Some of the interviewees spoke about the possibility of returning to their countries of origin if HIV medication were available. However, the difficulties of obtaining the drugs back home are a real concern for many of them. As a strategy to cope with adverse events, many of the men referred to religion and the cultivation of a spiritual life as sources of strength. Testing HIV positive provoked some of the participants to turn initially against God, but after adjusting to this new condition, many of them returned to religious faith as a source of consolation.

In their research of the experiences of Caribbean immigrants living with HIV/AIDS in the Bronx, New York, Pivnick, Jacobson, Blank and Villegas (2010) recount a series of structural issues that constrain participants' lives. As in other studies, the importance of the migratory status as a determinant in the lives of immigrants was found. Participants without regular status reflected on the impact of lack of authorization to access health care, employment, and family separations. They affirm that seeking HIV primary care depends on the resolution of non-medical needs before engaging in medical care. Regarding disclosure of HIV status, respondents consider it difficult to communicate their condition to family and friends because of fear of rejection, social isolation, and retaliation against relatives and themselves, including family members and children back in their countries of origin. For those participants who receive financial help and support of other relatives living in the U.S. disclosure of HIV status, in addition to disclosure of sexual preference for gay participants, were deemed to jeopardize this valuable support.

Other critical issues are difficulties in traveling to primary care venues, temporary housing and homelessness, HIV related stigma extensively reported in the context of familial and social relations, lack of financial resources as a barrier in access to HIV medical care, and the negative influence of immigration laws in the lives of undocumented immigrants, who do not access health care or other basic services due to fears associated with deportation (Pivnick, Jacobson, Blank and Villegas, 2010).

Literature regarding the experiences of Latino and Latina immigrants living with HIV/AIDS is scarce, with all of the studies conducted in the United States. Most of the research in the area explores the experiences of Latinos and Latinas in relation to their use of HIV related health care and barriers in access to such services.

Martinez, Lemos and Hosek (2012) explore the stressors and sources of support perceived by recently diagnosed Latino youth living with HIV. Initial psychological impact of HIV diagnosis and the stigma associated to the infection; disclosure to family and friends; physical self-image and concerns of changes caused by the virus and antiretroviral drugs; side effects of this medication; the impact of HIV on individuals' plans and life goals, including reproductive health concerns, were the most salient themes emerging from focus groups with HIV positive Latino youth.

In regards to disclosure to family and friends, the authors report that Latino youth face the dilemma of the need for family support, which implies disclosure, and the fear of a negative reaction from family members. Disclosure was a painful decision to take, principally when the respondents considered that the communication of an HIV positive diagnosis would bring suffering to the family. The group of participants also spoke of fear of a negative response from those family members who adhere to strict religious beliefs,

curtailing the possibilities of a much needed emotional and psychological support. Those participants who did not disclose to family described the difficult situation of maintaining the secret and a sense of isolation and 'incompleteness,' while disclosure to friends was even more unlikely due to fear of rejection. This way, stigma was another common theme during the study. Participants described feelings of shame, and the experience of stigma, rejection and acts of malice from peers. In addition, the lack of confidentiality in institutional settings, such as the school, can further exacerbate stigma.

As coping strategies, Martinez, Lemos and Hosek (2012) report an effort for deriving positive effects from a traumatic event, such as gaining a better understanding and appreciation of their life and clarity about what actually matters. Participants also sought ways to live with HIV, rather than living stuck in the negative aspects of HIV infection. Social support was described as an important factor to counteract the negative effects of HIV infection. Service providers, other PHAs, and significant others were cited as sources of support. Finally, there was a strong emphasis on religious or spiritual beliefs, principally among Spanish-speaking Latinos compared to bilingual or English-speaking participants.

In their report of the needs in care and access to health care services of HIV positive Latino immigrants in New York, Shedlin and Shulman (2004) describe the experiences of Latino PHAs as either documented or undocumented immigrants. HIV infection and AIDS play a complex role during the migration process: while some participants affirmed they planned migration with no knowledge of HIV infection and tested positive during immigration related medical tests, others moved out from their countries of origin to escape HIV related stigma, shame and rejection, or to look for care

in the United States. According to participants coming from countries with less experience in the management of the epidemic, severe stigma was a common and recurrent aspect of life.

Disclosure intersects and affects crucial aspects of life, such as migration, employment, care seeking, health status, support and use of medications. Individuals interviewed in this study reported a series of strategies to communicate or keep in secrecy their HIV status. Some openly disclosed to all of their family; others communicated it to certain relatives, usually siblings but not parents while others live in isolation and disclosed only to a friend or no one (Shedlin and Shulman, 2004).

It is possible to see in the literature that research with people living with HIV/AIDS has been conducted from diverse theoretical frameworks, and in spite of this, common themes emerge in regards to the experience of living with HIV/AIDS, independent of race/ethnicity or cultural affiliation. Stigma and discrimination are still extremely attached to an HIV positive diagnosis, hindering disclosure of serostatus to family, friends, partners and health care providers, producing a severe feeling of isolation among individuals dealing with the infection. Immigrants living with HIV/AIDS have to deal with the similar struggles and dilemmas to other PHAs' issues, with the additional burden of settlement in a new country and the stress attached to the process. Besides, migration status will determine to a significant extent the experiences and access to social services of immigrants in the host country, including health care services, among others.

Migration, sexuality and HIV

Human history has always been characterized by relocation. Migration can be defined as “a permanent or semi-permanent change of residence, including permanent settlers or

landed immigrants, temporary workers, guest workers, asylum seekers, students, and undocumented arrivals with the intention of short- or long-term settlement” (Samuel and George, 2002: 33). Movement through national borders is as ancient as the nation in itself, though characteristics such as its volume, direction, causes and effects are always changing. Migration may be caused for multiple reasons and can be related to diverse situations. For instance, the economic relocation of highly skilled and managerial level professionals has little connection with the movement of massive populations originated by violent conflicts and environmental disasters. Nowadays, globalization and its related international economic integration and free movement of capital have brought new chances for mobility for some individuals and groups. For others, globalization has increased economic insecurity and overall powerlessness, with ever increasing barriers to free movement (Burnett, 2002).

Increasing digitalized technology and communication world-wide allow large business corporations to relocate their activities all over the world, beyond frontiers, making use of local force labor, supplies, and the most favorable conditions of the market. The relatively new economic dynamic weakens national boundaries by giving international importance to local markets and facilitating their integration. The integration of the world economy facilitates the free movement of money, materials, resources, other services and finally, people beyond countries. In this way, a larger wave of migration is not only facilitated, but originated by worldwide trade and the expansion of a free market economy.

The global economy creates a degree of freedom of mobility for those associated with its creation and prosperity... Immigrants will be attracted to developed regions of the world because of the material affluence, economy prosperity and the resulting occupational opportunities and financial rewards for individuals... The robustness of the highly developed economies also attracts others to venture to move, including those who are

marginalized and displaced in their own countries as a result of economic globalization, capitalist expansion, and other social and capital forces. For them, the advanced capitalist countries provide an opportunity to improve their livelihood, even though their lack of educational expertise and technical skills is likely to land them only in marginal sectors and in low-paying jobs (Li, 2008: 14-15).

Extensive research has examined many aspects of those individuals who relocate. There is a frequent focus on the study of migration and its links to labor markets, economics, and political activism, and more recently family life, gender relations, and religion. However, the sociology of immigration has remained desexualized, in the sense that it has overlooked immigrants' sex lives and how sexuality changes after migration. The scarce research on the sexuality of Latinos and Latinas in the United States has remained confined within behavioral, public health, and epidemiological sciences (González-López, 2005).

Pioneering research on sexuality and sex lives of U.S. Latinas and Latinos was informed by an acculturation model which perceived the sexuality of Latinas and Latinos as a unidimensional entity that is transformed along a continuum between both a traditional and conservative Hispanic, or Latin American sexuality and a modern and liberal North American sexuality. From this perspective, it is believed that with acculturation Latinos and Latinas begin to take the sexual attitudes and behaviors that are part of mainstream U.S. culture, which differs from traditional Latin culture (González-López, 2005). However, during her research with Mexican immigrant men and women in Los Angeles California, González-López (2005) found that the sexual transformations of their participants were complex, nonlinear, and diverse. Their sexuality transitions involved social processes that had nothing to do with becoming sexually acculturated:

[Immigrants'] sex lives are surrounded and imprinted by social dimensions that include gender processes and socioeconomic segmentation, race, citizenship; their everyday life experience of surviving in a complex capitalistic society; and their residence in immigrant

communities, where women and men actively participate and create cultures of sexuality (González-López, 2005: 27).

In spite of the gray areas, what is clear is that migration has a profound impact on the sexuality of the individuals in movement. For instance, in their study with Mexican female farmworkers in California Castañeda and Zavella (2003) affirm that, after migration, Mexican women are enmeshed in new processes of racialized, gendered sexuality. Constructions of gender and sexuality will be contingent upon Mexicans' placement within the local economy and shaped by political and social forces. This way, women will see the different perceptions and behaviors related to gender and sexuality as originating in new circumstances brought on by transnational migration. In this unstable and contested social climate, these women migrants construct new subjectivities regarding their work sites, their social lives, and their bodies. Other examples of changes that immigration brings to the sexual lives of immigrants are presented in research conducted by Espiritu (2003), Haour-Knipe and Rector (1996), Herdt (1997), Bronfman and López Moreno (1996), and Carrier (1995).

In addition to the study of the impact that migration has on individuals' sexuality, Carrillo (2004) proposes that research in sexuality and migration must also focus on understanding sexuality itself as an important cause of transnational movement. 'Sexual migration' (Cantú, 2009; Parker, 1997) refers to “international migration that is motivated, fully or partially, by the sexuality of those who migrate, including motivations connected to sexual desires and pleasures, the pursuit of romantic relations with foreign partners, the exploration of new self-definitions of sexual identity, the need to distance oneself from experiences of discrimination or oppression caused by sexual difference, or search for greater sexual equality and rights” (Carrillo, 2004: 54).

In their work with immigrant women, Argüelles and Rivero (1993) argue that the transnational migration dynamics and experiences of women have been predominantly examined through political and economic frameworks, with little consideration to the role of gender, sexual abuse and oppression based on sexual orientation as determinants of transnational relocation. Talking with immigrant and refugee Latinas, they found that, for many women, transnational migration represents another strategy to break free from heterosexist oppression, which manifests itself through gender and sexual abuse.

One of the most representative works on sexual migration is Cantú's (2009) study of the migration of Mexican gay men to the United States as a result of their sexual orientation. In his work, Cantú acknowledges the scarcity of research on immigration that has incorporated sexuality as an important aspect of analysis and as a force that determines and organizes processes of migration and the ways how newcomers incorporate in their host societies. The author also contends that scholars of Latina/o sexuality have placed a strong emphasis on cultural explanations for differences between Latin American sexual ideologies and practices and American sexualities. As a result, structural forces influencing sexuality, migration and community formation have been overlooked. Therefore, in order to understand Mexican sexualities, it is necessary to move away from one-dimensional cultural models and instead examine them from a more complex and materialist perspective that recognizes that culture, social relations, and identities are embedded in global processes (Cantú, 2009: 98).

In his work on the topic of immigrants and asylum seekers based on sexual orientation, Luibhéid (2005) explores the dilemmas that queer immigrants face during the migration processes and to fully reach a sense of belonging in First World nations,

particularly in the United States. Migration rarely represents a clear-cut solution to the difficulties that queers face: they must deal with racial, gender, class, cultural, sexual and language barriers that are inextricable from global histories of imperialism and exploitation that link the U.S. to other countries and regions.

Luibhéid (2005) contends that gay, lesbian, and transgender immigrants occupy a position of intersectionality, both in their experiences in the asylum system and in relationship to mainstream gay and lesbian organizations and immigrant rights advocates. GLT people fleeing persecution often face qualitatively unique social and legal barriers to winning asylum in the US; furthermore, their political needs often go unmet. Gay and lesbian human rights organizations too often neglect immigration issues, and immigrant rights organizations neglect gay and lesbian immigrants. Instances of studies that further explore the intersectional experiences of queer immigrants in Canada are the works of Lee and Brotman (2011) about the experiences of sexual minority refugees in Canada, and O'Brien et al. (2006) describing the experiences on mental health issues, homophobia, and social isolation that sexual minority refugee youth encounter in Canada.

The study of the relation of migration and sexuality directly leads to the analysis of the links between migration and HIV. Globalization not only facilitates the flow of capital, technology, and people, it sets in motion sexually transmitted infections as well (Castañeda and Zavella, 2003). Research conducted principally in the African continent has shown that patterns of spread and prevalence of infection are strongly related with human migration patterns. Migration has a determinant role in the susceptibility to HIV, sexually transmitted diseases (STIs) and other infections (Crush, Williams, Gouws and Lurie, 2005). For instance, a study in Uganda found that HIV infection and relocation are

strongly correlated. Therefore, those individuals who migrated within the previous five years had a rate of HIV infection that was times higher than those persons living in the same location for ten years or more (Nunn et al., 1995).

In the same manner, research in Mexico found that migration is a factor that heightens vulnerability to HIV infection among marginalized populations, such as unauthorized migrants located at the Mexico-US border region (Magis-Rodríguez et al., 2004). Decosas et al. (1995) conclude that what determines vulnerability to HIV is the breach of social networks and the disruption of the social life, rather than the points of origin and destination of movement. Thus, they concluded that the fact that migration is close related to the spread of HIV has secondary importance, when considered that the conditions of high vulnerability that some groups face during relocation facilitate the eruption of HIV epidemics.

However, the study of the relation among migration, sexual health and the risk of exposure to HIV is not exempt from contradictory results. Carrillo (2004) contends that, in the research literature of the topic, there is no solid agreement in regards to the levels of HIV risk that new Latino immigrants face and the cultural factors that associate with lower or higher risk. For instance, some studies show that the level of HIV risk among newcomers is lower, concluding that newly arrived migrants, sexually speaking, are more conservative and modest. Therefore, traditional sexual cultures are seen as a protection against mainstream US values. Such values are damaging for immigrants' sexual health because of the sexual permissiveness that a process of acculturation to such values may produce. However, other studies highlight the higher levels of HIV risk among Latin newcomers and less culturally integrated Latinos and Latinas. In those cases, machismo

and traditional sexual cultures are blamed for such results. It is considered from this perspective that more acculturated Latinos/as present lower HIV risk because they are able to subscribe to self-determination, assertiveness, and individuality, all values deemed as highly prevalent among mainstream U.S. social groups.

Carrillo (2004) concludes that the contradictory results in Latino immigrants' health research might be due to the fact that the evaluation of the impact of migration on health, and on sexual health, has not been conducted paying attention to crucial factors. Among such factors we find prevalent conditions in migrants' countries of origin, cultural beliefs and conducts in such countries, and the previous knowledge and experiences of the culture and practices in the United States and other host nations.

In addition to the study of migration and vulnerability to HIV infection, research on the migratory processes of people living with HIV/AIDS is relevant as well. Investigation in the area has established that people living with HIV/AIDS are considerably mobile (Patton, 1989; Ellis, 1996; Berk et al., 2003). Elmore (2006) contends that one way of discussing the aspects that determine and shape personal decisions to relocate is in terms of 'push and pull' factors. Push factors for PHAs can be misconceptions and negative behaviors towards HIV/AIDS in localities of origin, or lack of confidentiality and anonymity. Pull factors than can be mentioned are the belief that there is a more supportive community and better HIV related health care services in particular geographic regions (Elmore, 2006).

PHAs' geographical relocations can occur as a process of step migration, which is a common form of relocation among gay men who initially move from hometowns to larger cities in search of more 'accepting' venues of the gay community. Later, if the

individual tests HIV positive, further relocation may happen from a medium- to a larger urban center with the purpose of accessing better equipped health care and other support services (Elmore, 2006).

In a national probability sample, in the US, Berk et al. (2003) found that individuals living with HIV/AIDS seem to be more mobile than the general population: 17% of PHAs migrated after an HIV positive result. Making a comparison between genders, males are more likely to relocate than females, and white individuals more likely than the black or Latin communities. The most decisive factors for moving are to be near to a caregiver, seeking the sense of belonging to a community with similar interests and needs, the search for HIV care services and moving away from stigma and discrimination.

Models to explain the health of immigrant and refugee populations

Beiser (2005) reviews conflicting models that have been used to explain immigrants' health during the last century: the sick and the health immigrant paradigms. In this section, both models are briefly explained.

In the first half of the 20th century, the idea that new immigrants were sick and that the general population must be protected from newcomers was prevalent in North America. This idea is the central conception of the sick immigrant paradigm. The model proposes that those individuals, who are unhealthy, poorly adjusted, and likely the least competent in their countries of origin, are the same who seek the opportunity to relocate. Under the influence of this conceptual model, newcomers were seen as the dangerous carriers of infectious diseases and mental problems, generating rejection and discourses against immigration even after the Second World War. In addition, this model served as

an ideological justification to refuse entry to Canada of immigrants without British or North European origins, and the exclusion of 'sexual deviants' until the 1970s.

Due to changes in Canadian immigration laws in the 1960s, currently all applicants to migrate to Canada, refugee claimants not included, must undergo a series of medical tests prior to be accepted in the country. As a consequence of this extensive medical screening, newcomers have on average, better health than long term residents in Canada². Accordingly the healthy immigrant paradigm proposes that if healthier immigrants become ill as they relocate in the country, it is due to factors such as convergence and resettlement stress.

The principle of convergence explains that after relocation immigrants are exposed to physical, cultural, and environmental factors which shape and determine immigrants' patterns of morbidity and mortality. Under such influences, newcomers' health status gradually becomes similar to the health standards of the receiving country. As immigrants and native citizens are exposed to the same pollutants, toxins, stress and ageing factors, the shift in health status is passive. However, part of the process is active when newcomers adopt some of the host society habits, such as drinking, smoking or eating low nutrients food.

Leclere, Jensen and Biddlecom (1994) offer alternative hypotheses to explain the convergence of immigrants' and Canadian-born population's health. These authors consider that due to obstacles accessing health services, such as language or cultural barriers, information gaps and lack of experience with the health care system, the health status of recently arrived immigrants gradually worsens. In this way, Leclere, Jensen and

² Interestingly research in the United States has also shown a healthy immigrant effect. Usually, the health status of newcomers from Latin America is better than that of US-born citizens (Carrillo, 2004).

Biddlecom (1994) explain the increasingly poor health of new immigrants as a result of under-use of preventative health services, under-diagnosis and poor consideration and treatment of health issues. In spite of the universal coverage of the Canadian health system, including hospital and other services, due to recent changes in the 1990s, the number of non-covered health care services has increased. The neoliberal changes that the Canadian health system has undergone in the last years has impacted more dramatically on low income and poorly educated segments of the population, who struggle to cope with the system restructuring (Birch and Gafni, 1999), the immigrant community being one of the groups severely affected (Newbold, 2006). Alternatively, to explain convergence in the case of the existence of diagnosed conditions, it is likely that immigrants' access to and use of health services improve gradually, and health issues before undiagnosed are detected at some point, generating the perception that immigrants' health is worsening over time.

The resettlement stress principle considers that the processes of migration and resettlement increase the probability of experiencing unemployment, poverty and difficulties accessing diverse services. It is not uncommon that in the period of ten years after arrival, immigrants live in poorer conditions than their native-born counterparts. Poverty may have multiple negative effects on health, such as an increased exposure to disease related factors, and it imposes greater difficulties accessing treatment. Similarly, during difficult situations, immigrants have not only fewer economical, but also fewer social resources than the native-born population.

The sick and healthy immigrant paradigms might be useful to explain immigrants' health; however, the existence of unexpected and contradictory results of empirical

research shows inadequacies in both models. Therefore, a new paradigm must be developed. Such a paradigm should consider the characteristics of the individuals before migration, the factors that increase stress before and after relocation, and the coping strategies that help individuals, families and the whole society during migration and resettlement. In addition, the study of immigrants' health in general must take into account relevant differences among the immigrant groups, such as the country of birth, status in the new country (immigrants and refugees), health conditions and disease before migration, experience of the western health system back home, the degree of acculturation and cultural retention, all these aspects have a significant effect on health status.

Social determinants of health

Another perspective that proves to be useful to explain the health of immigrants is the social determinants of health framework. The World Health Organization has defined social determinants of health as “the circumstances in which people are born, grow up, live, work and age, and the systems put in place to deal with illness. These circumstances are in turn shaped by a wider set of forces: economics, social policies, and politics” (World Health Organization, 2005: 1).

Based on public health and other social scientific studies, from social determinants of health perspective, populations' and individuals' health status is affected to a greater extent by their social and economic traits, rather than by individual health behaviors, such as smoking, diet and exercise (Hayes and Dunn, 1998). Similarly, research on social inequality and health has shown the existence of a strong relation between social status (income, social class, employment status, and educational level)

and health (mortality, morbidity, etc.). In this way life expectancy, for example, is in direct relation with socio-economic status in most of the wealthy nations worldwide. However, this relationship is not just a difference between wealthy and poor populations. Individuals in the higher levels of income, education and occupation have longer and healthier lives (Hertzman and Weins, 1996). On the other hand, individuals located at the lower levels of the social scale are more vulnerable to diverse health risks (Evans, Barer and Marmor, 1994). The World Health Organization (2005) recognizes that the relationship between social status and health is similar in low, middle and high income nations, confirming the global nature of the phenomenon.

Differences in health status among population groups that are systemic and significant, but also preventable, unfair and unnecessary are known as health inequities. Those health inequities should be of interest to all members of society because greater inequity represents poorer health to all, rich and poor alike. The healthiest societies in the world are those that have the least economic differences among its members, more equity and less relative poverty (Wilkinson and Pickett, 2009).

Regarding immigration and health, it is possible to say that changes in social status – influenced by poor working conditions and language barriers, among other factors – and cultural differences between sending and receiving societies are among the most significant factors related with relocation. Therefore, health impacts are often associated with relocation. Similarly, health inequity presents itself differently amongst immigrant and native born groups (Dunn and Dyck, 2000).

Canadian research on immigrant health is scarce. Some studies describing socio-demographic and socio-economic trends have been conducted on the topic. There are

significant gaps on the knowledge of the impact on health status of immigrants' educational level, work status, economic income, family organization, immigrants' living conditions and differences among immigrants groups (Kinnon, 1998). Research conducted in this area includes examples of the relationship between suicide among immigrants and its links to housing, work, education, integration in the host society and social networks (Chandrasena, Beddage and Fernando, 1991; Noh and Avison, 1996); studies of the impact on health of the immigration experience itself (Beiser and Hyman, 1994); and research that analyses the impact of relocation to a locality where one's own ethnocultural group does not exist on mental health (Ruble and Shaw, 1991; Beiser et al., 1995). The scarce research done in the area makes evident that social determinants of health have a strong impact upon immigrants' health status (Dunn and Dyck, 2000).

Health care and access barriers for immigrants and refugees living with HIV

Another aspect of immigrants' health research where there does not exist a clear agreement is on immigrants' level of use of health care services in comparison with the Canadian born population. Some studies have found that immigrants and non-immigrants have similar patterns of health care services use (Laroche, 2000; Hyman, 2001). This suggests that there are not significant differences in rates of use between immigrants and Canadian-born individuals, or that immigrants' use of basic components of health care approaches their Canadian counterparts' levels of use after 6-8 years in the country (McDonald and Kennedy, 2004).

However, the same studies recognize issues in research procedures, such as the failure to differentiate recent from long-term immigrants, precluding the understanding of what is happening during the first five years of resettlement. There are few Canadian

studies that examine the effect of acculturation on the use of health services, the interactions between different forms of medical care, the changing patterns of use of health services over time, and differences of use within immigrant sub-groups. Overall the research has not captured the difficulties encountered by immigrants in accessing health services, nor the extent of their unmet needs.

Research also documents that health care services, preventive, and treatment services are not appropriate for immigrant communities. Elliot and Gillie (1998) mention that immigrant groups utilize health services less often, medical treatments and the quality of health care they receive are shorter and of poorer quality than those for their native counterparts. In addition, the evaluation of those services is carried out from epidemiological and biomedical perspectives, which pays little attention to the actual health and health care experiences of people accessing such services. Furthermore, in some studies there is a tendency to aggregate ethnic groups to a level that individual differences in health and health perspectives become difficult to understand, privileging sample size over the understanding of personal experience of health care services.

Literature on the topic mentions as the main barriers that immigrants encounter in their access to health care services: cultural and language differences, the experience of racism, discrimination, sexism, fear of Western medicine, and lack of knowledge of the available services. Immigrants particularly from Asia, Africa and Latin America may feel overwhelmed when so much is new, and there is little experience of how the health care system works in Canada (Newbold and Danforth, 2003).

It is also relevant to mention that socioeconomic status and poverty – unfortunately a common condition among new immigrants and refugees – are not only

two of the most fundamental determinants of health but also determinants in the access and use of health services. Poverty, for instance, not only increases the possibility of exposure to risk factors for diseases, but also compromises access to treatment (Beiser, 2005). It has been found that immigrants principally in unprotected and low wage jobs cannot afford the time off to access health services (Hyman, 2001; Jiwani, 2001).

In relation to issues of discrimination and racism, Jiwani's (2001) research on immigrant women of color, domestic violence and health care, indicates that the health care system, like other social institutions, replicates sexism, racism and classism. In this way, the health care system is not exempt from social inequalities, such as a differential of power and privilege accorded to individuals located at different levels of a hierarchical scale. The maintenance of the status quo and the authority of physicians depend on ideological beliefs that consider Western medicine as superior to other, indigenous and therefore inferior, forms of health care (Jiwani, 2001). As a form of maintaining this superiority, physicians tend to stereotype patients according to their cultural background (Cave et al. 1995). Therefore, belonging to a cultural-racial minority will influence the health care a person receives (Beiser, 1998).

Varcoe (1997) studies the existence of racist stereotypes about people of color among health care practitioners. Among nurses, notions of deserving versus non-deserving patients are highly present, non-white, poor women, and women with addictions are usually seen as non-deserving patients. The health care system is organized around powerful discourses of scarcity, deservedness, and violence. Experiences of violence and abuse among women of color are often associated and explained by their culture. The association of violence with particular cultural and racial groups shows the

pervasiveness of racism among Canadian mainstream services.

There is scarcity of Canadian research on the topic of access to health care services for immigrants and refugees living with HIV/AIDS (Wong, Kanagaratnam, Yee and Fung, 2004). Existing studies focus on screening, prevention and behavioral risks related to gender, cultural issues and other social factors, but current research literature in the topic does not reflect the intersectional nature of immigrant and refugee PHAs' everyday lives. There are studies that include the dimension of HIV and sexual orientation, HIV and gender, or HIV and race, but scant research addresses multiple dimensions.

In Ontario, the Committee for Accessible AIDS Treatment (CAAT) has developed significant efforts to implement research in access to social services for immigrants, refugees and non-status people living with HIV/AIDS. In a community based research project with PHAs from Africa, Asia, Latin America, the Caribbean and Western and Eastern Europe, CAAT (2001) found that the lack of legal status is a significant barrier in access to primary care and drugs for the treatment. Fifty five percent of their sample reported that fear of disclosing their HIV status or immigration status and social stigma were also key barriers to accessing health care. Only half of their sample had any form of health care insurance in Canada. PHAs without health coverage may be eligible for care at Community Health Clinics (CHCs), but many do not seek care due to fear of deportation, or because they are unaware of the services.

In a study aimed to explore the needs and barriers in access to mental health services for immigrants, refugees and non-status PHAs from Africa, the Caribbean, South Asia, East and Southeast Asia, and Latin America CAAT (2008) found that the

participants face multiple barriers when seeking formal mental health support. These barriers are sometimes the result of negative attitudes and behaviors from service providers, and sometimes they arise from the structure of health care and social services. The most salient barriers are stigma and discrimination related to HIV status, race, sex, sexual orientation and transphobia; a lack of communication between service providers and PHAs, as the latter often feel neglected by their service providers and decide not to return for support in the future; language barriers and difficulties of finding services in the own language; the manner in which services are organized in Canada that are confusing to immigrant PHAs; differences in the idea of what mental health means; long wait lists and limited service availability.

As mentioned before, research on access to health care services for specific ethno-racial communities in Canada is limited. The Public Health Agency of Canada (2007) in a report about the HIV/AIDS epidemic among immigrants from countries where HIV is endemic, points out that people from countries severely affected by social, economic, and behavioral factors have an increased vulnerability to HIV infection. Racism, homelessness, transience, poverty, lack of employment, settlement and migration status issues, fear and stigma, denial as a coping mechanism, isolation, lack of social support, job loss, fear of deportation, discrimination, power relations, cultural attitudes towards HIV and AIDS, homophobia, and a lower status of women act as barriers to program and services access. Other barriers encountered are a lack of accessible services because of their location, language issues, and depending on migration status, the fact that health care may not be free.

Tharao, Massaquoi and Teclom (2004), conducted research among African and

Caribbean women regarding facilitators of HIV transmission and factors related with the reduction of risk and/or the ability to cope with HIV once infected. They found that African and Caribbean people suffer from high unemployment and underemployment rates, limiting their life opportunities. Under such circumstances, HIV/AIDS information and access to services do not have priority. For HIV positive individuals, dealing with HIV, poverty and struggling for survival, have a negative impact in their capacity of coping with illness.

African and Caribbean communities living in Canada, as many other communities, keep close ties with their cultures of origin. Tharao, Massaquoi and Teclom (2004) consider that some culturally based values, beliefs and practices are related to a higher risk of HIV infection, and have an impact on HIV positive individuals' ability to cope or prevent secondary transmission. The authors cite among those values the existence of multiple sexual partners; lack of discussion and communication around sexual practices and sexuality in general; limited condom use; confidence in relationships; and use of traditional therapies. Among Islamic and fundamentalist Christian followers, religion negatively influences reproductive rights and sexual behavior within marriage. Religion to a substantial extent also determines the discourses concerning how to be a good mother and a good woman. Religious practices and beliefs relate with homophobia directed to men who have sex with men, a factor that pushes them to maintain their relationships underground, and the risk of HIV infection for women involved in relationships with men who have sex with men living undercover may be higher.

The existence of stereotypes based on gender roles, power imbalances in the

relationships, economic and other forms of women's dependency on men, in addition to violence, have a negative effect on women's ability to protect themselves against sexually transmitted infections. For HIV positive women, all these factors diminish their coping abilities against HIV infection. Finally, racism is another decisive factor which determines people's access to services and the type of available services for African and Caribbean communities.

There are no studies so far that specifically analyze the barriers and difficulties in access to health care and other social services for the immigrant and refugee Latino community living with HIV in Canada. Some research on the topic has been conducted in the United States, where the Latino community is the largest and fastest growing ethnic minority (Guzmán, 2001), and one of the most severely affected by the HIV/AIDS epidemic (Mahoney, Khamarko and Goldschmidt, 2008; Martinez, Lemos and Hosek, 2012).

Shedlin and Shulman (2004) report the results of a qualitative research on access to care for immigrant Latinos/as living with HIV in New York. In a series of focus groups, they explored the perceptions, beliefs, experiences, and HIV care knowledge of Mexicans, Dominicans, and other PHAs from Central America. The most significant barriers were factors related to culture, such as gender issues and machismo. Aspects of health care use, such as when, where and what services were used, were strongly influenced by those cultural factors. Experience with the health care system, which is related with acculturation, was another determinant of health care usage. Other barriers accessing services were a concern or shame of being considered homosexual; low language proficiency, which is related with difficulties to communicate properly with

health care providers; lack of migration status and thereby concerns about being deported; difficulties and fear of disclosing HIV status to relatives, coworkers and employers; significant gaps in the information of the available services, their location and lack of time to seek care; low economic status and not having insurance for doctor appointments, and costly medicines and treatments. Some of the participants affirmed that they first saved money prior to seeking health care, due to expectations that the service would be expensive. The researchers also found the existence of, sometimes correct and wrong, ideas regarding the service available for unauthorized immigrants.

Zuñiga, Brennan, Scolari and Strathdee (2008) conducted a quantitative study about barriers to HIV care among Latino PHAs in the border region of the United States and Mexico, where rates of HIV prevalence are increasing. Among their most relevant results, they found that half of the participants faced at least one barrier accessing HIV care services, and one third of them reported two or even more barriers. Stigma was one of the barriers most frequently reported, as well as fears of drug side effects.

In their work with undocumented Latinos living with HIV/AIDS in Houston Texas, Dang, Giordano and Kim (2012) found stigma and rejection from family members and community as barriers in access to health care services. In addition, language barriers represented difficult to overcome obstacles while navigating the health care system. These authors discuss as well experienced and perceived structural barriers related to the undocumented condition, such as exploitative work conditions that delayed accessing health care services, concerns of being deported in case of accessing services, and significant difficulties in obtaining required documents, such as a proper ID, proofs of income and/or employment status. Incorrect judgments regarding deportation risks and

the lack of information awareness about availability of HIV care services were also factors that delayed HIV diagnosis and accessing HIV primary care. Therefore, the authors concluded that Latinos/as without a regular migration status were more likely to access HIV related health care services late in the disease course, frequently in the phase of AIDS.

Literature on the topic points out that structural barriers are the principal obstacles in access to health care services for immigrants and refugees living with HIV/AIDS, independently of their ethnicity, race, or cultural background. There is solid agreement that migratory status will profoundly influence the access to health related services, health status and other crucial aspects of the lives of immigrants and refugees, either HIV negative or living with HIV/AIDS. In addition, for HIV positive immigrants and refugees, HIV related stigma works as another obstacle in access to services, again independently of race/ethnicity or cultural background.

Employment and HIV/AIDS

Most of the studies on people living with HIV/AIDS and their experiences in employment coincide with the fact that the development of highly active antiretroviral therapy (HAART) in the 1990s has meant a dramatic improvement in quality of life for many PHAs (Ferrier and Lavis, 2003; Dyer, Twillman and Sequeira, 2006; Maguire, McNally, Britton, Werth and Borges, 2008). HAART opened the possibility for many of them of remaining employed, or going back to work (Goldman and Bao, 2004; Brooks, Martin, Ortiz and Veniegas, 2004; Martin, Steckart and Arns, 2006).

Employment is deemed as a positive experience for PHAs, giving them the feeling of normality, being productive, higher economic resources (Brooks and Klosinski,

1999), more frequent opportunities of communication with other individuals, and a healthy feeling of meaningful activity and accomplishment (Dyer, Twillman and Sequeira, 2006). It is also considered that being an active member of the labor force reduces health inequalities and makes available life opportunities for the person and his/her family group (Rodger, Brecker, Bhagani, Fernandez, Johnson, Tookman and Bartley, 2010).

In the literature of the experience of living with HIV/AIDS and employment, there are examples of studies from a quantitative perspective (Brooks, Martin, Ortiz and Veniegas, 2004; Burns, Young and Maniss, 2007, Oliva, 2010; Rodger et al., 2010) and examples of research from a qualitative approach (Maticka-Tyndale, Adam and Cohen, 2002; Ferrier and Lavis, 2003; Dyer, Twillman and Sequeira, 2006). In North America, most of the research in this field has been conducted in the United States, and there are some few examples of research done in Canada (Adam and Sears, 1996; Maticka-Tyndale, Adam and Cohen, 2002; Ferrier and Lavis, 2003).

There is a strong emphasis on the identification and analysis of the barriers and difficulties that people living with HIV/AIDS encounter to come back to work and maintain current jobs. Although compelling reasons for at least considering workforce reentry exist, the barriers and obstacles may override any perceived benefits for substantial numbers of disabled people living with HIV/AIDS contemplating workforce reentry (Martin, Steckart and Arns, 2006).

In a qualitative study of the process of workforce reentry for people living with HIV/AIDS, Martin, Steckart and Arns (2006) derived nine composite variables describing barriers to workforce reentry. Those variables help to understand in a more

comprehensive manner the different obstacles that people living with HIV/AIDS encounter in access to employment.

Table 1: Barriers to employment for people living with HIV/AIDS. From Martin, Steckart and Arns (2006)

<p>Physical health issues</p> <ul style="list-style-type: none"> • Non-HIV illness • HIV-related illness • Fatigue/low energy • Medication schedule/side effects • Physical problems • Hospitalization <p>Mental health</p> <ul style="list-style-type: none"> • Depression • Anxiety/panic • Psychosis <p>Job skills deficits</p> <ul style="list-style-type: none"> • Lack of experience • Lack of job skills • Lack of education • Language barrier <p>Lack of resources</p> <ul style="list-style-type: none"> • Lack of transportation • Financial instability • No telephone • Lack of wardrobe 	<p>Motivation/attitude</p> <ul style="list-style-type: none"> • Fear of disability benefits loss • Missed appointments • Lack of focus • Fear of change • Motivational problems • Poor impulse control • Unrealistic goals <p>Social problems</p> <ul style="list-style-type: none"> • Death/loss/bereavement • Relationship/ breakup problems • Lack of social support • Spouse/partner abuse <p>Cognitive deficits</p> <p>Substance abuse relapse</p> <p>Incarceration history</p>
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Most of the research on HIV and employment has encountered similar barriers and difficulties that PHAs face to maintain or find a new job, even though among these studies there exist some divergences in regards to some factors affecting access to employment for people living with HIV/AIDS. For instance, Rodger et al., (2010) in a study with 545 HIV positive patients, did not find an association between employment status and any objective indicator of physical difficulty to work, such as a low CD4 count. They conclude that PHAs' physical condition health is not the most significant barrier to entry the work force. They found instead as factors strongly correlated with not working, poor psychological health, personal perceptions of a 'poor' health status, and being diagnosed as HIV positive for a period of ten years. On the other hand, Martin,

Steckart and Arns (2006) found that precisely the most frequently experienced barrier to workforce reentry was physical health problems. In addition, Burns, Young and Maniss (2007) in a quantitative study with Latinos in the Southwest United States found that while there is a direct relationship between mental health and employment, there is also a relation between CD4 count and being employed.

In a study based on focus groups with clients of an AIDS service organization, Dyer, Twillman and Sequeira (2006) in accordance with the barriers they experienced to return to work, classified participants in two clusters. The first group experienced obstacles of a more motivational nature, and the individuals' doubts about returning to work seemed to deter the process of job search. In the second group, even though the individuals were willing to work, they confront disability and significant health needs. Participants in this cluster presented multiple and interacting illnesses or serious disabilities of physical and mental nature; therefore, they were in need of diverse accommodations. Exploring the labor participation of people living with HIV/AIDS in Spain, Oliva (2010) came to the conclusion that PHAs' employment status is directly related to health status and other personal traits, age, gender, and education included.

Another often cited barrier in access to employment for people living with HIV/AIDS is the fear of stigma and discrimination in the workplace (Braveman et al., 2006; Dyer, Twillman and Sequeira, 2006; Maguire, 2008), and for working individuals, fear of stigma is an impediment to disclose their serostatus (Maticka-Tyndale, Adam and Cohen, 2002). Dyer, Twillman and Sequeira (2006) confirm the existence among their participants of internalized stigma, racism, sexism, homophobia and shame related to an HIV positive status. Rodger et al. (2010) state that there exists a gap between perceptions

and reality of stigma in the workplace: for almost half of their participants out of work stigma and fear of discrimination were a real preoccupation. However, only 11% of those individuals working confirmed the existence of stigma and discrimination. On the other hand, Braveman et al., (2006) state that stigma and discrimination are still real. In their literature review in HIV/AIDS and employment, they found that several studies reported instances of discrimination and stigma in the workplace.

For a long time, loss of income benefits and health insurance have been cited as serious obstacles to return to work for individuals on disability (Hennessey and Muller, 1995; Kutner and Cardenas, 1981), and this concern still continues to be a pivotal issue for people living with HIV/AIDS who contemplate the possibility of going back to work. The loss of entitlements as a main concern for PHAs and therefore a main obstacle to return to work, is an issue widely cited in the literature of employment and HIV/AIDS (Ferrier and Lavis, 2003; Brooks, et al., 2004; Razzano, Hamilton and Perloff, 2006; Maguire, et al., 2008). In Canada, PHAs received government subsidized health care regardless of their employment status; however loss of disability benefits, such as cash grants, drugs and mental health services, were significant concerns for persons living with HIV/AIDS (Braveman et al., 2006). In fact, dependence on government programs to obtain costly drugs and a limited but secure income generates in many PHAs feelings of being 'trapped on disability' (Maticka-Tyndale, Adam and Cohen, 2002), and a sense of powerlessness to influence how the rules are applied (Ferrier and Lavis, 2003).

While most of the studies on access to employment for people living with HIV/AIDS focus on barriers and difficulties in access to employment, Braveman et al., (2006) state that there are fewer instances of research that describe programs and service

interventions, and many fewer reports of the outcomes of successful interventions to assist PHAs in finding and maintaining employment. AIDS service organizations and others involved in providing services to persons living with HIV/AIDS would benefit from publication of additional work on interventions related to HIV/AIDS and employment.

There are other aspects in the area of HIV/AIDS and employment that deserve being studied in more detail, such as the effects of HIV disclosure on work related success, the interaction among internalized stigma, self-efficacy, compatible work venues, and a person's traits that facilitate his/her success at work. The importance of research on the relationship between disclosure and stigma at the workplace can provide helpful strategies for clinical work with PHAs (Dyer, Twillman and Sequeira, 2006).

Conyers (2008) highlights the scarcity of studies that evaluate the impact of an active work life on the health status of HIV positive individuals, and the lack of research on appropriate employment conditions that allow them to keep an active work status. There is also little research to evaluate the degree to which HIV positive individuals have been successful in securing jobs with access to health insurance. Employment leading to a better access to health insurance certainly has positive effects on individuals' health outcomes.

Another gap in research on HIV and employment is a lack of more detailed consideration of race and ethnicity. There are very few studies where being part of a racial, ethnic, or cultural group is taken into account (Razzano, Hamilton and Perloff, 2006; Maguire, 2008), while those studies include Latinos and Latinas among their respondents, the group is a remarkably small proportion of the whole samples. There is

only one quantitative study that focuses specifically in the analysis of different aspects of employment for Latinos/as living with HIV/AIDS (Burns, Young and Maniss, 2007), with no examples of qualitative studies exploring the perspectives and experiences of Latinos and Latinas PHAs in regards to employment. In their work Burns, Young and Maniss (2007) suggest as future areas of research the impact of age on Latin PHAs' employment status, the connection between CD4 and employment as HIV positive Latinos often have lower CD4 and higher susceptibility to opportunistic infections than Caucasians, and the links among employment, physical and mental functioning, and locus of control.

As research moves from PHAs' general experiences at work and employment to individual experiences and intervention studies, it will be necessary to go further in the analysis of racial identities, and ideologies, the concept of disability and its acceptance in different cultural groups, and the effects of heterosexism and HIV related stigma. Research on these areas will be of crucial importance to design intervention programs that positively respond to the needs of diverse HIV positive communities. Therefore, to understand the perceptions and ideas of PHAs of diverse cultural and racial backgrounds, investigation on HIV/AIDS and employment will have to make the analysis of factors such as race, sexual orientation, and gender in research proposals (Conyers, 2008). Consideration of these aspects on the research agenda are of vital importance now that increasingly the HIV positive population is formed by women, persons of diverse racial backgrounds, and individuals with poor social supports, low educational level and scarce economic resources (Braveman et al., 2006).

Another aspect that practically is not considered at all in the research of

HIV/AIDS and employment is the changing nature of the labor market. Only the study of Maticka-Tyndale, Adam and Cohen (2006) gives some consideration to the accelerated changes that mark the 21st century. PHAs and workers in general, confront a labor market characterized by higher levels of stress, with faster paced labor and longer work time. With corporate downsizing and other aspects characteristic of this globalized era, such dramatic changes are likely to come (Seccombe and Livingstone, 2001).

CHAPTER 3: Theoretical framework

In this chapter, I review the principle of social construction of difference and the HIV/AIDS epidemic as a socially constructed phenomenon. The main tenets of the theoretical perspective known as intersectionality are also reviewed. Intersectionality is employed in this study to understand better the complex experiences of immigrants and refugees living with HIV/AIDS, and their access to health care and other social services.

Social construction of difference and social construction of HIV/AIDS

The position of a person in the social hierarchy will determine to a great extent his/her health status and overall wellbeing, but how is the social hierarchy constructed? The conceptual framework known as social construction theory is useful to explain the existence of social categories, and hierarchies that generate an unequal distribution of resources among individuals.

Social construction theory considers that a determined social order is not naturally given, and thus it cannot come from natural laws, rather social organizations are a result of human activity and interaction. Human beings, through interaction, create culture, individuals gradually objectify and internalize those cultural aspects, and finally take them for granted as natural entities (Berger and Luckman, 1966).

Accordingly, social constructionists affirm that the ways of classifying individuals as a kind of person is the product of social events and social institutions (Hacking, 1999). Human beings are not born with natural identities. There are no given meanings to be man, woman or intersexual, a person with a disability, or particular racial/ethnic, sexual or class traits. It is through social contact and interaction that all individuals learn and

experience the social world. The meanings, beliefs and ideas that we all learn will be determined and shaped by our social locations in particular cultures. Although categories like race, sexual orientation, class and gender identities are socially created, not natural features of the individuals, they exert a powerful impact and their consequences are quite real (Ore, 2009).

The construction of social categories occurs in a variety of contexts that we encounter every day; the most significant is the institutional context which includes institutions such as the family, the economy, the state, the media and educational institutions. The process of social categorization is linked to social hierarchization and inequalities of power, status, wealth, prestige and health. It affects the allocation of resources and opportunities, including life chances and group monopolies (Juteau, 2003), creating systems of inequality (Frye, 1983).

Race, class, gender, and sexual orientation constitute regions of hegemony³; they are socially constructed and link social structure and meaning. All these categories, among others, tie socially disadvantaged locations and structural inequity and injustice, to individuals who are connected to them. At a political level, there is not a clear demarcation among the forms of oppression produced by racial, class, gender and sexual orientation; such forms of oppression intersect and overlap in many ways. Therefore, political conflicts will be based on some, or all of these themes simultaneously, and their multiple intersections (Omi and Winant, 1994). Systems of race, class, gender and sexual

³ For Gramsci, hegemony implies those conditions that in a society are necessary conditions for the implementation of domination. Frequently, domination is reached by force, but it is close to impossible to secure and maintain domination through force. Therefore, a part of consent must come into play for the maintenance of domination. In order to consolidate their hegemonic power, dominant groups create popular systems of ideas and practices and disseminate them through educational, religious, and media institutions. Gramsci called those systems of ideas and practices common sense. Therefore, when social groups adhere and reproduce this common sense they tacitly consent to the way in which society is ruled and controlled (Omi and Winant, 1994: 66-67).

orientation are present in every aspect of people's world, operating at all times and in all places, determining how we see and understand every aspect of our lives (Weber, 2010).

In the same way that gender, race, class and sexual orientation are socially constructed; illness is defined and conferred meaning. The real and concrete effects of any disease are understood through social interaction, in particular social contexts (Adam and Sears, 1996). Therefore, it is possible to say “there are no illnesses or diseases in nature” (Sedwick, 1982: 32).

Susan Sontag (1990) affirms that society historically has made sense of feared diseases, first tuberculosis and now cancer and AIDS, through metaphors, stereotypes and myths that complicate the understanding of such conditions. Considering the origin of a disease as a punishment has been a chronic idea. In this way, contracting HIV, principally through sexual contact, is considered a tragedy that the person has brought to him/herself (Sontag, 1990).

HIV positive people bear the stigma of being considered responsible for their own disease since the moment they choose to engage in “deviant behaviors,” such as homosexual sex and drug use. In this way, even HIV positive individuals who do not practice drug use or homosexuality will be inevitably linked to stigmatized groups and practices. When a member of these stigmatized groups contracts HIV, the stigma attached to it will be layered upon existing homophobia, negative conceptions of drug use and deviance in general. For people of other social excluded groups, such as people of color and the poor, stigma will be even more severe (Green and Sobo, 2002).

[Being seropositive] remains one of the most stigmatized and stigmatizing health conditions known. The negative valuation of AIDS and its negative symbolic connotations are to a large extent the result of cultural processes whereby boundaries are drawn between the “healthy self” and the “unhealthy other” who is imagined as contagious, sexually deviant and addicted (Green and Sobo, 2002: 17).

Since the identification of the virus, multiple actors, from diverse social positions, have proposed different, and sometimes contradictory, meanings and understandings of the disease; showing the socially constructed character of the disease. The health threatening nature of HIV infection guarantees a crucial role to medical-scientific technologies in the definition of the disease and people living with HIV. Such technologies are responsible of the generation of discourses that, once appropriated by social groups, are used to exacerbate discrimination and stigma against HIV positive individuals, as a reason of being considered “deviants,” “promiscuous,” “guilty,” or “victims.” As an example of such medical-scientific technologies, epidemiologists, in conjunction with other health professionals, defined the category “high risk groups” to determine the groups of the population that are at greater risk of HIV (Shoveller and Johnson, 2006). Since the outset of the epidemic, in North America and Europe, the concept of “risk groups” has been used to hold diverse minorities responsible for spreading the virus, such as gay men, Africans, and Haitians. The use of this concept has caused the segregation of “diseased” and “unhealthy” others from a “healthy” majority that have been released of any responsibility for the transmission of the virus (Holland, Ramazanoglu and Scott, 1990).

Governments all over the world, attempting to reduce transmission, have negatively affected the human rights and freedom of people living with HIV. In many nations, norms that regulate PHAs' behaviors and freedom of movement have been implemented, frequently affecting HIV negative people considered as part of “high risk groups.” Such regulations are based on ideologies that deem HIV positive individuals as potential contaminators that must be controlled. In addition to the fear of transmission, economic considerations, such as the costs of health care services, have reinforced

repressive measures to control the spread of the virus (Holland, Ramazanoglu and Scott, 1990).

Mass media have also played a decisive role in the social definition of HIV/AIDS. Since the outbreak of HIV/AIDS, mass media, connecting with public conceptions of the disease, have reinforced homophobia and racism. They contributed to the early identification of members of “high risk groups” as morally tainted and practitioners of “dangerous behaviors,” therefore directly responsible for the epidemic, and a threat to normality and health (Holland, Ramazanoglu and Scott, 1990).

In the story of the construction of HIV/AIDS as a social phenomenon, there exist also examples of resistance against the imposition of damaging ideologies and identities from above. In the United States, in the middle of a context of severe discrimination, arose a social movement formed by communities and individuals affected by HIV/AIDS: gays, lesbians, hemophiliacs, injection drugs users and members of ethnic and racial communities. One of the goals of the AIDS movement was an active challenging of the negative meanings and attributes assigned to HIV positive people, fighting for more accepting and positive representations of people living with AIDS (Epstein, 1996).

The existence of the AIDS movement and its challenge to oppressing categories speak of HIV positive individuals' agency to improve their lives. As a matter of fact, the emergence of the category “People living with HIV/AIDS” is a direct outcome of such movement:

PWA (person with AIDS) is an identity label developed by people who were suffering from complications of AIDS to destigmatize two of the metaphors used to characterized AIDS, the metaphors of death and punishment, which found their way into everyday discourse in terms such as “AIDS victim,” “invariably fatal,” “promiscuous,” “AIDS patient,” and “innocent victim.” This redefinition process was a means by which an emphasis could be put on processes of living and dying, with dignity and without blame, and on a person's ability to take control of his or her life (Huber and Schneider, 1992:

182).

In this way, since the identification of the virus in 1981, a multitude of voices, from governmental organizations, mass media, and civil society, have charged the HIV/AIDS epidemic with a series of powerful social meanings and attributes. This has resulted in the edification of “AIDS” as a social institution, which must be differentiated from AIDS the biological disease (Plummer, 1988).

Intersectionality

In spite of the significant interconnections of the various dimensions of inequality, social scientists have analyzed them by isolating these factors and treating them as if they were independent of one another, forgetting the analysis of historical linkages and systemic interrelationships that reveal the underlying ways any one dimension of inequality is shaped by another. As a result, the experiences of whole groups are ignored, misunderstood and erased. (Thornton and Zambrana, 2009).

Abstract entities are created when social aspects, which form concrete phenomena, organizations and beings, are analyzed and studied separately as if they were naturally independent of each other. Positivist science often analyzes gender, race and class, as if they were separate traits generating unconnected forms of oppression (Marx Ferree, Lorber and Hess, 1999). However, one-dimensional analyses have the unintended consequence of making one form of oppression seem more important, or making one group more victimized. When one group is singled out in this way, the focus of attention moves away from relations of power among dominant and multiply oppressed groups (Weber, 2010).

Kimberlé Williams Crenshaw (1994) was one of the first theorists to propose an

intersectional analysis. She argued that understandings of violence against women would be limited unless one took into consideration the race, ethnicity, immigrant status, and class of women who were targets of violence. Programs that took into consideration only aspects linked to gender were narrow at best, and deeply flawed at worst, because they failed to consider how intersecting power relations of race, class, immigrant status, and gender affected women's options.

Williams Crenshaw (1994) states that women of color are positioned within overlapping systems of subordination. At a political level, this means that women of color are located between at least two subordinated groups, whose agendas quite frequently collide. Gender narratives commonly are based on the experiences of white women from middle class levels, and racial narratives are produced from black men's experiences or racial discrimination. However, Williams Crenshaw asks where do black women's experiences fit? Race identities have been obscured in feminist discourse while gender identities have been overlooked in antiracist discourses. The need to split the political energies of women of color between frequently opposing political agendas produces a sense of disempowerment seldom experienced by men of color and white women. As a result, both feminist and antiracist movements often overlook the location of women of color. In the same way, at a theoretical level, feminist analyses that do not consider the racial dimension will be incomplete and may be used to understand and describe only white women's issues and experiences. Likewise, explanations of racial inequality that do not take gender into account in their analysis will be insufficient for comprehending women of color's lives (Browne and Misra, 2003).

The opening statement of the Forum of the UN Conference on Racism 2001

stated that:

An intersectional approach to discrimination acknowledges that every person, be it man or woman exists in a framework of multiple identities, with factors such as race, class, ethnicity, religion, sexual orientation, gender identity, age, disability, citizenship, national identity, geopolitical context, health, including HIV/AIDS status and any other status are all determinants in one's experiences of racism, racial discrimination, xenophobia, and related intolerances. An intersectional approach highlights the way in which there is a simultaneous interaction of discrimination as a result of multiple identities (Declaration and Program of Action, 2001 in Thornton and Zambrana, 2009: 12)

Intersectionality, which is part of the general social constructionist framework, relies on the principle of social construction of difference. Its purpose is to develop a critical analysis of inequalities based of race, ethnicity, class, age, sexual orientation, ability and gender among other categories of differentiation. The ultimate goal is to challenge monocausal explanations of inequalities with the purpose of promoting interdisciplinary knowledge to change the lives of groups of people who have been and remain in subordinate positions. From this theoretical approach, it is considered that inequalities and oppression are distributed in the population throughout key social divisions, such as race, gender, class, sexuality, nationality, and physical ability. Dimensions of inequality are not readily separable but mutually constituted and social problems, policies, and practices are not only the result of either race, class, or gender alone, but the product of a particular intermeshing of these and other dimensions of inequality. The various combinations of these categories create different results for groups or individuals in specific locations at distinct historical moments (Thornton and Zambrana, 2009).

A matrix of domination will be formed by intersecting and interlocking racial, gender and class systems. Positioned in such a matrix, any individuals, women and men alike, through the combination of their racial, gender and class status, can experience disadvantage and privilege simultaneously (Browne and Misra, 2003). In a hierarchical

society, determined statuses are associated with higher value than others. The privilege or stigma that one status might generate will be affected by the individual's other statuses. Some statuses are so strongly marked by the stigma that they can cancel out the privileges that other valued statuses could provide to the individual (Rosenblum and Travis, 2008).

Intersectional theory aims to locate the lived experiences and struggles of people of color and other marginalized groups – such as diverse ethnic/cultural groups and sexual minorities – as a starting point for the development of theory (Thornton and Zambrana, 2009). The notion of everyday experiences as the starting point for the production of knowledge locates intersectionality close to a feminist standpoint epistemology⁴. Both perspectives regard it as necessary to start social analysis from the position, experiences and activities of those individuals who scarcely are considered during the process of knowledge production, instead of starting research from the abstract constructions derived from scientific disciplines or dominant social institutions (Cantú, 2009). Grounded in people's everyday lives, intersectional knowledge will strive to uncover the diverse effects of disparities based on race and gender, with the goal of eliminating inequality (Thornton and Zambrana, 2009).

Marx, Lorber, and Hess (1999) suggest that to develop an intersectional analysis based on people's experiences as the point of departure, a specific social location, practice, or topic must be selected. The analyst must try to determine the combined

⁴ Proposed as an alternative way of knowing, a feminist or women's standpoint epistemology seeks to start scientific inquiry from women's experiences, rather than from men's experiences. Feminist standpoint epistemology draws on *The German Ideology* in which Marx and Engels assert that life delimits consciousness. This epistemology proposes that inquiry need focus on the world that actually happens and can be observed, spoken of, and returned to check up on the accuracy of an account or whether a given version of it is faithful to how it actually works (Clough, 1994: 62, 72).

effects of race, class, gender, sexual orientation and other salient social categories, instead of considering only one or two of them for analysis. This form of analysis, emphasizing participants' standpoints, can counteract the process of abstraction that characterizes positivist approaches to science.

An intersectional analysis is not only useful to explain individual identities and perspectives; it is useful to explore the influences that racial, class, gender, physical, sexual, religious and national characteristics and their compounded effects have on group identities (Thornton and Zambrana, 2009). From an intersectional approach, the diversity that exists among individuals classified under a single group identity must be considered. For instance, the terms Latino and Latina are in close relationship with various discourses of national and political identities. Homogenizing such diversity under the single category of Latino or Latina brings as a consequence the erasure of intersecting racial/ethnic, and socioeconomic differences (Thornton and Zambrana, 2009).

Another goal that Thornton and Zambrana (2009) attribute to intersectionality is to uncover the ways different regions of hegemony connect and generate inequality and oppression at structural, and interpersonal levels. At the structural level, intersectionality seeks to explain the ways government, the legal system, and educational institutions among others, are organized for the reproduction of subordination. Intersectionality strives to show the origin of the unfair distribution of goods and services, and their concentration at the high social levels through the study of structural inequities. At the interpersonal level, intersectionality focuses in the analysis of racism and sexism in the everyday relationships among individuals, practices that reinforce the reproduction of the status quo.

Intersectionality seeks to explain the connections between broad social institutions, structures and phenomena and how such aspects of social life are experienced and interpreted by individuals placed in different social positions. Studying such connections will help to understand the role of race, class, gender and sexuality as determinants of social structures and identities (Weber, 2010).

In this way, intersectionality seeks to provide a theoretical base to understand how multiple identity categories overlay and intersect at different social levels – structural, ideological and interpersonal – taking into account historical and geographical contexts (Thornton and Zambrana, 2009).

Examples of intersectional research

The intersectional framework has focused on the study of the social problems of those groups and individuals most harmed by inequalities. Poverty, education, barriers in health care, inadequate housing, and violence have been analyzed considering the multiple intersections of race, class and gender (Thornton and Zambrana, 2009). This approach has been applied principally in the context of the United States, but its applicability to other geographical locations where inequalities based on race and ethnicity, class, gender and sexuality are present must not be minimized. The next are a few examples of research, either empirical or theoretical, conducted from an intersectional approach.

One of the first studies that consider the intersectional nature of violence against women was conducted by Williams Crenshaw in 1994. Working with women victims of abuse in minority communities in Los Angeles, she confirmed that economic aspects such as access to employment, housing, and wealth, have a crucial role in shaping women's of color experience of domestic violence. Being poor will be strongly related with being a

woman of color, thus showing that racial, gender and class traits intersect. Immigration status is another aspect of women's lives where power structures intersect. For migrant women, their status as immigrants leaves them in a vulnerable position that is not reducible to economic class.

Other of the pioneers of the intersectional theory is the feminist Patricia Hill Collins. With an intersectional perspective, Hill Collins (1999) critiques scientific methodologies and looks at the intersection of gender and race in the construction of science and scientific knowledge. Gender and race operate within science less as parallel dimensions in constructing scientific knowledge than as intersecting dimensions of social organization where knowledge and power are intimately linked. Feminist analyzes show how science is not only gendered, but also remains profoundly shaped by race categories. Positivist understandings of science as an objective activity allow the maintenance of gender subordination under conditions of modernity. Therefore, in Hill Collins' analysis, notions of science, race, gender, and modernity are integrally linked.

Cotter, Hermsen and Vanneman (1999) investigate the existence of gender based wage inequalities, considering various racial/ethnic groups – white, African American, Hispanic, and Asian – in metropolitan areas of the United States, from 1965 until 1990. Their results show a substantial uniformity of gender differences across all four racial/ethnic groups and at each earning level. Another work which considers wage inequalities is Browne's and Misra's (2003). Seeking evidence of intersectionality in three central domains on labor market inequality – wage inequality, discrimination and stereotyping, and immigration and domestic labor – the authors find that race and gender intersect in the labor market under certain conditions. Like William Crenshaw, they

consider that immigration and citizenship add greater complexity to the race/class/gender nexus. Differences in the labor market position are not only based on gender, ethnicity, place of residence, and citizenship status, but opportunities and modes of incorporation also vary within immigrant groups depending on their birth cohort and year of arrival. Finally, Browne and Misra (2003) suggest the necessity of further elaboration of theories from a multiracial and multiethnic perspective because much of the intersectional research currently focuses on white and Black men and women, without considering the wide array of other ethnic groups whose changing labor market experiences might shed greater light on the complexity of labor market inequalities.

Dworkin (2005), exploring contemporary epidemiological classifications in the HIV/AIDS epidemic, considers the usefulness of applying an intersectional analysis. Individuals do not have singular identities or experiences within social structures, but rather, intersecting ones. Dworkin contends that the literature on HIV and heterosexual transmission is based on two main assumptions. First, heterosexual women are usually deemed as categorically oppressed and vulnerable while heterosexual men are considered powerful and invulnerable. In addition, notions of masculinity and femininity have been naturalized. The author affirms that ideas that deem women and men as unified or homogeneous are flawed.

Adequate gender analyses in HIV/AIDS studies must take into consideration male and female simultaneous privileges and inequalities, and the existence of diverse groups of women and men, including dominant, subordinated, marginalized, racialized, classed, and sexualized men. Although HIV transmission and infection are close connected to social and economic relations of inequality, surveillance categories do not consider the

existence of intersecting identities and behaviors, generating a flawed analysis of the contextual factors that shape risk. Dworking proposes the examination of intersecting dimensions of race, class, and shifting gender relations for women and men.

Collins, von Unger and Armbrister (2008) report the accounts of 24 Latina women living with severe mental illness in New York City. The multiple stigmatized identities of inner city women with severe mental illness, such as being a member of an ethnic minority group, immigrant, poor, and a woman who does not live up to the gendered expectations guarantee the use of intersectionality. The study relies on an intersectional analysis to understand how these multiple identities influence women's sexuality and HIV risk. Participants' stories show mental illness aggravates existing power inequalities based on gender, race/ethnicity and class and weakens women's status within their families and relationships. Collins, von Unger and Armbrister (2008) suggest the importance of interventions that acknowledge women's multiply layers of individual and structural vulnerability, and facilitate women's empowerment in and beyond their sexuality.

In her work Weber (2010) applies an intersectional framework to study the educational system in the United States. She contends that, in the educational system, race, class, gender, and sexuality hierarchies are generated and maintained by segregating and isolating groups through differential treatment. Understanding educational segregation processes is crucial to unraveling the dynamics of race, class, gender, and sexuality.

Weber (2010) conducted analyses of the history of the modern school system, current macro institutional dynamics (power relations in the economic, political, and

ideological realms and their role in education), and micro individual dynamics (power relations based on race, class, gender, and sexuality in school settings, from kindergarten through twelfth grade). She concludes that, in spite of the ideology of equal opportunity, racial, class, gender and sexual differences play a determinant role in the schooling people receive throughout the history of the United States. Disadvantaged individuals in the educational system – poor and working-class students, students of color, girls, and GLBT students – have few economic, political, and ideological resources to generate changes.

In the field of migration studies, Cantú (2009) makes a compelling contribution to the growing literature of gender, race, and sexuality in analyses of migration. While migration studies have a long history and have produced a large number of classic studies, few works have incorporated an intersectional approach and sexuality as a significant dimension of analysis. In 'The Sexuality of Migration,' he analyses the experiences of Mexican gay migrants, and the relationship between economic and political processes and national and sexual identities.

Patricia Pessar's (1999) review of research in migration that incorporates gender as a central organizing principle, highlights the importance of considering multiple identity's variables to understand fully the lives of immigrant women and men. Pessar contends that to understand the ways women challenge patriarchal domination and exploitation at the family level it is necessary to theorize the compounding class, racial, legal, and gender oppressions that characterize immigrant women's lives. Therefore, it is crucial to abandon the notion that gender oppression is the most significant form of oppression for immigrant women. It is vital to examine the multiple and intersecting

structures of oppression based on gender, class, race, ethnicity, and immigration status.

As we can see, there is a wide variety of themes that can be analyzed from an intersectional perspective: violence against women of color, feminist critiques of science, wage and labor market inequalities, epidemiological categories and the HIV/AIDS epidemic, mental illness and AIDS risk, the educational system, and migration. Other examples of intersectional investigation include the analysis of poverty discourses, working mothers and maternity leave decisions, professions, early school leaving, disparities in political participation and civic engagement, among others (Thornton and Zambrana, 2009).

CHAPTER 4: Methodology

Community based research and the definition of community

One of the reasons for the increasing demand for community-based research (CBR) in the field of HIV/AIDS (Harris, 2006) is that it involves a process of learning from direct experience (Trussler and Marchand, 2005). CBR proposes a more egalitarian and collaborative relationship between members of academia and community members. Therefore, the ultimate goal of this research approach is to develop new and more meaningful partnerships to conduct scientific research between groups that have traditionally been separated during the production of knowledge (Harris, 2006).

Blumenthal (2011) distinguishes between community-based research and community-based participatory research (CBPR), stating that the first one refers to research that takes place in the community as opposed to other settings such as laboratories and clinics. In CBPR, the research team develops a partnership with the community. Community members will have the opportunity of collaborating actively during the whole research process, first participating on the definition of the research topic, questions and objectives; in the phases of planning and executing, during the collection and analysis of data; and finally in the process of result dissemination. More than a method, CBPR is an approach that intends to give authority to the community in the research project, seeking its empowerment (Israel, Schulz, Parker, Becker, 1998).

The present study agrees with the main goals of CBR and CBPR, and acknowledges the importance of striving to share full responsibility of the research process with the community and community members. However, as an international

graduate student there exist significant challenges to conducting a research project following the principles of CBR and CBPR.

As a student, one is accountable to an academic department, which imposes its own requirements and timing restrictions. Academic agendas may enter in open confrontation with the necessary processes to establish a solid CBPR project, such as approaching community members and spending time to build a relationship of trust with the community. Time becomes a limiting factor, especially when a student has limited access to funding and feels the pressure to graduate as fast as possible.

Fortunately, as a manner of balancing the limitations in time and funding, I had the opportunity well in advance of approaching and building trusting relations with the Centre for Spanish Speaking Peoples (CSSP) and Latinos Positivos (Positive Latins), community based organizations with wide experience working with the Spanish speaking community of Toronto. My former participation as a research assistant with the CSSP and other organizations in two projects – the “Mano en Mano” project, the evaluation of a pilot HIV prevention program for Latino gay and MSM newcomers, and the “¡Cuéntame! Conta-me!” research project that explores the experiences of Spanish and Portuguese speaking gay men and MSM (men who have sex with men) in the GTA – allowed me to build valuable connections with members of the community before starting my own research.

Another serious challenge working with communities is defining the community itself, and identifying members who represent it. Communities are not monolithic organizations and volunteers, agency representatives, staff members, and other spokespersons may not represent all members of a community (Blumenthal, 2011). It is

beneficial to recognize that often communities are defined and delimited from researchers' position of privilege, and that definition might leave out of research projects more marginalized subjects and ,therefore, many issues and voices unheard. In the case of the Latino community, it is relevant to question the actual existence of such a community in Canada and consider the potential definition of it by government agencies and researchers, among others.

Alcoff (1991) proposes a different issue when doing research with diverse communities, and it is what she calls the dilemma of speaking for others. The practice of speaking on behalf of researched communities or groups has come under increasing criticism and, in some communities even rejected. The social location and identity of a speaker influence the meaning and sense of the speaker's discourse. No spokesperson should take for granted the possibility of transcending his or her particular social position. Furthermore, some advantaged social locations might be harmful for the communities or groups they represent. Frequently, the practice of individuals on positions of power speaking in the name of disadvantaged people and communities has brought more oppression and disadvantage for those groups. As a possible answer, Alcoff (1991) affirms that an examination of the speaker's location, even though necessary, will not be enough. She considers that before speaking for others, it is crucial to analyze the effects of what is said at the discursive and material levels. An analysis of the speaker's location and the propositional content of the speech must be complemented with a thoughtful understanding of where the speech goes and its effects. Looking exclusively at the content of a discourse, without paying attention to its effects will not give, as a result, a proper or meaningful evaluation of it.

In regards to my social location, I would say that as an international graduate student originally from Mexico, who has been in Canada for around five years and whose main language is Spanish, my life is affected and shaped by the same structural forces that affect participants' lives. Even though my position as a graduate student may imply a privileged position, as any other newcomer, I have encountered the same difficulties and barriers in terms of language proficiency, lack of social networks, and cultural mismatching, during my settlement in Canada. In fact, my current lack of status as a permanent resident might even put me in less privileged circumstances compared with most of the interviewees who already have a permanent status in the country. Although my HIV negative serostatus keeps me away from the HIV related stigma and discrimination that participants very likely encounter in their everyday lives, I think it is fair to say that, as a man who experiences same-sex emotional and sexual interests, I am at risk of HIV infection.

This research project and its written presentation have been carried out with the purpose of obtaining a doctoral degree at University of Windsor, and in that sense, it is intended for an academic public. However, I have the expectation that the study will be worthwhile for community organizations that provide services for Spanish speaking immigrants and refugees who live with HIV. I expect the study will be worthwhile for other individuals living with HIV as well, and that the experiences and strategies to cope with stigma and discrimination collected here can be an invitation for them to reflect in their own experiences.

Beyond its academic purpose, following the principles of public ethnography proposed by Adler and Adler (2008), the study seeks to reach a non-academic public and

engage individuals out of scholarly activities in a dialogue about social matters. With the purpose of communicating research findings and sociological analyses to an intelligent population of lay persons, it is crucial to keep in mind standards of reflexivity, relevance, and accessibility. This allows the pursuit of change that needs to be done at different levels to eliminate discrimination and marginalization against immigrant, refugee and non-status people from Latin America and other immigrant groups living with HIV/AIDS. Seeking to reach this extra-academic audience, study results will be returned to the Latino community through the Center for Spanish Speaking Peoples and Latinos Positivos with the purpose of disseminating the study among the Latino community and principally among Latinos and other individuals living with HIV in Toronto.

Ethical Issues

Ethical research must be conducted having in mind that two different sets of values should be balanced: the pursuit of knowledge and the rights of research participants and other members of society. Social researchers must ponder the impact of potential benefits, such as advancing scientific knowledge, which can be a base for policy making and helping individuals and communities, against potential research harms, participants' loss of dignity, self-esteem, privacy, or deprivation of their human rights. Therefore, ethical research implies that investigators must balance the advantages of advancing knowledge against the individual rights of privacy and noninterference in the personal life (Neuman, 2004).

In their work in ethics and HIV/AIDS research, Loue and Pike (2007) discuss a series of ethical obligations that researchers must consider in regards to participants in HIV/AIDS research. Among such obligations researchers are obliged to protect

participants' confidentiality, but to go further, the former must support research participants to disclose and maintain their privacy in accordance with the individuals' interests, simultaneously considering participants' community and cultural contexts. Researchers must keep in mind that the danger of disclosing an HIV positive status in particular situations is quite real for some research participants, and that a breach of confidentiality and anonymity can occur from the smallest incident. Therefore, all possibilities must be mindfully pondered; investigators have an obligation to maintain protective measures, in addition to discuss in detail with participants potential risks and the ways of prevent them.

This investigation raises a potential risk of losing confidentiality as a result of sharing personal information in a research setting. The risk can be deemed significant if we consider that personal information, such as sexual orientation, migratory status, and HIV status is discussed and shared with the researcher during the study. A mismanagement of this information can put participants at greater risk of stigma and discrimination. As a measure of protecting participants' confidentiality, I agreed to strict management of all the information produced during the research process and to sign a consent form which assures the maintenance of confidentiality of all the data. Moreover, participants were informed of confidentiality policies regarding information that is disclosed during the study.

In addition, there was the possibility that the interview process could raise issues that may be troublesome to some participants; for those cases we counted on the support of the CSSP and Latinos Positivos, where the participants could be referred for counseling services if the need arose. Fortunately issues of distress did not arise among

the participants during the interview. The project obtained ethical clearance through the University of Windsor Research Ethics Board (REB).

Qualitative methodology and the use of narratives

A qualitative methodological perspective informs the present study. Qualitative methods emphasize the study and analysis of the qualities of processes, and meanings. Such processes are not evaluated experimentally or in terms of quantity, intensity, or frequency. From the point of view of this perspective, it is vital to explain processes of creation and assignation of meaning to social experiences. Therefore, there is an emphasis on the study of the social construction of reality, the relationship among researchers and participants of research, and the ways that context shapes inquiry (Denzin and Lincoln, 2003). With the use of qualitative methodologies, more fluid and flexible images emerge of what it is like, from the point of view of the person concerned, to live, for instance, with a chronic disease (Flick, von Kardorff and Steinke, 2004).

As part of a qualitative approach, experiential data are the starting point of the study, and through interviews we get access to participants' lives and the ways those lives are constrained (Campbell, 2006). Van Den Hoonaard (2012) defines the qualitative interview as a regulated conversation that brings to light participants' points of view in regards to their own experiences, perceptions and feelings. A relatively informal style characterizes the interview process, in which the interviewer encourages people to describe their world in their own terms. Interviews, however, diverge from conversations in that the interviewer has the task of bringing the discussion back to the topic of the interview when it veers off track. Usually the discussion during the interview is lopsided because the interviewer says much less than the participant says. However, the former can

never engage in passive listening: he or she must listen intently with the purpose of identifying ideas or potentially useful concepts to ask about in subsequent questions.

An active process of interpretation is inherent to all interviews; practices of meaning creation on the part of interviewer and interviewee take place. The analysis of how this process of creation happens is as valuable as the same content of the interview (Holstein and Gubrium, 1995:4).

The stories produced during the interview process communicate the central meanings of the experiences that are of interest for research. Such stories represent narratives that organize chronologically events and assign meaning to story teller's experiences and feelings. Narratives give an explanation of the speaker's and others' conducts; they represent us before others in the way in which we want to be deemed. Therefore, narratives help to make sense of the social world and create identities (Stephens, 2011).

Hydén (1997) affirms that narrative accounts are one of the most powerful and effective forms to communicate experiences of pain and suffering. Thus, social researchers interested in biomedicine, suffering and disease rely frequently on the study of narratives. The experience of illness disrupts a person's ongoing life and identity. Chronic conditions alter the relationship between the individual's body, self and everyday experience of the world, shattering his/her personal biography and questioning his/her moral location (Bury, 1982; Stephens, 2011). The use of narratives in the sociological analysis of medicine has shown that illness has been conceptualized principally as a medical construction, at the cost of ignoring the perceptions of the person who is suffering and his/her social context (Stephens, 2011). Loue and Pike (2007: 64) state

clearly that the use of narratives in the study of illness and health can benefit both researchers and participants, “The solicitation of narrative that is broader and deeper than standard clinical histories will enable researchers to contextualize disease and research involvement in the lives of research participants, and will assist participants in the process of voicing their realities, concerns, expectations, and hopes.”

In this study, Plummer's (1994) point of view regarding stories will be taken up, considering that stories or narratives are not simply 'languages' or 'texts' or even 'discourses,' but they are charged with dense, empirical human life. Thus, from a sociological standpoint, narratives “must be seen as socially produced in social contexts by embodied concrete people experiencing the thoughts and feelings of everyday life... If they are 'texts,' then they are texts embodied by breathing passionate people in the full stream of social life.” (Plummer, 1994: 16).

According to Riessman (2008), narrative analysis interprets oral, written and visual texts, offering, as a result, not a final version of people's perspectives but interpretations of their experiences. Therefore, there is no a definitive narrative but diverse possible narratives which are influenced and shape by multiple factors, principally by the interaction that occurs between the person who narrates and the person who listens (Hydén, 1997). Regarding those listeners, they are not a passive audience during the process, but they participate actively in the narrative construction, rejecting and questioning what is told (DeFina and Georgakopolou, 2008). Accordingly, in research settings the listener is represented by the interviewer, and with any other narrative account, the result will be a construction shaped by both, the interviewer and the respondent (Mishler, 1986). Therefore, it is beneficial not to ignore or minimize

interviewers' participation during the construction of narrative accounts (Stephens, 2011).

Smith and Sparkes (2009) propose two general standpoints of doing narrative analysis: the story analyst and the storyteller. Both approaches have some similarities, and according to the research's goals, investigators may shift from one approach to the other. The analysis in this study is more along the line of the story analyst standpoint; this approach is a method that carries out an analysis of stories (Polkinghorne, 1995).

Narratives represent the crucial data to be systematically studied. Researchers make use of diverse procedures and techniques to analyze and explain the stories of interest.

Narratives will also be studied from a particular theoretical perspective in order to link theory and empirical data, allowing participants' own voices to be heard as part of a context. The results of this analysis are full and rich in detail descriptions of participants' psychological and social worlds.

Summarizing, “story analysis refers to an analytic process that initially collects stories for its data, turns these stories told into stories to be formally analysed, extrapolates theoretical propositions and categories from them, and then represents the results from all this by telling them in the form of a realist tale” (Smith and Sparkes, 2009: 282).

Recruitment of participants and data collection

The interview guide for the present study consisted of a series of open questions organized in seven main sections: life in the country of origin, stories of migration, access to health services, access to employment and employment services, relationships with family, friends and partners, sexuality and a brief final section of demographic information.

The interview guide was elaborated by taking into account the project's research questions and available literature about the life of Latinos and other immigrant groups living with HIV in the Greater Toronto Area (GTA). Later, the interview guide was reviewed by an academic committee at the University of Windsor. It was also reviewed by two staff members of the Centre for Spanish Speaking Peoples (CSSP), who have ample experience working with the Spanish speaking community in the field of HIV prevention. Finally, a person who is HIV positive himself and part of the Latin community in Toronto also reviewed and made valuable suggestions to the interview guide. Recommendations from all these sources were incorporated to obtain a final version (appendix 1).

Interviews were carried out with immigrant, refugee, and non-status, Latino men and women living with HIV/AIDS in Toronto. A non-probability sample was chosen, and the basic inclusion criteria were being a Spanish speaking individual, or having an origin in a Spanish speaking country, and living with HIV/AIDS in Canada, more specifically in Ontario. A wide range of diversity in national origin, age, gender, and sexual orientation was considered. The individuals were invited to participate in an in-depth interview where they were asked about their experiences with migration, employment, housing, and health care, and the barriers they have faced in access to all these services. The interview also touched the topics of relationships with family, friends and partners with the purpose of better understanding processes of stigma and discrimination, and the strategies and resilience that participants have developed against these processes.

The project counted on the recruitment of participants with the collaboration and support of community based organizations that have significant experience working with

Spanish speaking communities, and groups of HIV positive people in the field of HIV prevention, and the experience of living with HIV/AIDS.

The Centre for Spanish Speaking Peoples (CSSP) is a community based organization which offers services for Spanish speaking newcomers in the areas of settlement, legal aid, women and youth programs. This organization also delivers an AIDS program which promotes healthy sexual practices through education, counseling and support groups, and informs and educates the Spanish speaking community in the various methods of preventing the transmission of HIV. The CSSP is a valuable source of information regarding the issues and main barriers in access to services which affect to immigrant, refugee and non-status Latinos/as living with HIV/AIDS in Toronto.

Latinos Positivos is an organization of Latinos and Latinas living with HIV/AIDS in Toronto. It provides a space to identify the needs of the Latin community living with HIV/AIDS, considering the barriers in the efficient access to services and the stigma and discrimination suffered by Latinos/as as a result of a positive HIV status. Both organizations, Latinos Positivos and the CSSP represented a safe and confidential environment for the presentation of the project to potential participants and for the conduction of interviews.

Participants were contacted principally through Latinos Positivos. They were contacted over the phone by a staff member of the organization who gave them general information of the project and invited the subjects to participate. Individuals were also contacted through the social network of a staff member of the CSSP; former HIV positive participants of other CSSP's projects were invited as well. Finally, participants themselves asked HIV positive friends and acquaintances whether they were interested in

participating. Those individuals interested in participating were later contacted by the researcher to answer further questions and arrange an appointment for the interview.

During the appointment, previous to the interview, participants were informed about the objectives of research, and their rights to remain in the project without answering any questions they feel uncomfortable with, and the possibility of withdrawal at any moment with no further consequences. Signed consent forms with relevant information and contact information were distributed among participants (see appendix 2). With the purpose of protecting individuals' anonymity, personal names were not kept at any time. Consent forms, interviews, and transcripts contain only identification numbers.

All the interviews were carried out from September to December of 2011. Some of them were conducted at the office of Latinos Positivos or the satellite office of the CSSP, or in accord with the request of some participants, the interview took place at individuals' home, or even in public places such as coffee shops, the street or parking lots. Interviews in public places were conducted at venues where the participants could feel more comfortable, and where they considered there were minimum risk of being recognized by some else. As a form of maintaining the confidentiality, before starting the interview, both participant and interviewer verified as best as possible that nobody else around was a Spanish speaker. During the interview process, the interview guide was used in a flexible manner allowing the participants to explain in more depth what they considered essential in their accounts. Following Van Den Hoonaard's (2012) suggestion, interviews were finished explicitly inviting the participants to add anything they considered noteworthy that was not asked in the interview. Interviews were audio

recorded for later transcription and lasted from one to two hours.

As a manner of showing appreciation for their interest in participating in the project and the time taken for doing so, participants were compensated with \$30 dollars after the interview. 30 interviews were carried out with Latinos and Latinas living with HIV in the GTA. 29 out of the 30 are in Spanish and one in English at the participant's request.

Berg et.al. (2004) affirm that during the interview process, some demographic traits of the interviewer, principally age and gender, may have a decisive effect on the participants' responses and in the generation of rapport. Despite training and/or experience in the interview process, studies demonstrate that interviewers' most visible characteristics may affect how respondents answer questions. As the sole interviewer in this project, I can tell that differences based on gender generated a different dynamic during the interview. As a male interviewer, it was more difficult for me to discuss openly sexuality and sexual practices with female participants than with male participants, regardless of the sexual orientation of the interviewee. Likewise, female participants discussed and elaborated their sexuality and sexual practices to a lesser extent than male participants, probably because they also felt less comfortable openly discussing intimate topics with a man that they just met.

Analysis of interviews

Ryan and Bernard (2003) distinguish for the management and analysis of qualitative data between two different ways of analysis. The linguistic school approaches texts as the object of analysis while the sociological approach considers texts as the window that allows insight into human experience.

For this study, texts were obtained from the transcription of the recorded interviews. General themes and codes were induced from the reading of the interviews, taking into account the research questions and objectives and following the suggestion of Spradley (1979) of approaching the texts searching for traces of conflict, contradictions, the strategies that individuals develop to manage their personal relations, acquire and maintain status, and the diverse manners of problem solving. Themes and their respective codes were organized in a codebook; later on, new codes were added during the process of codification. The transcripts were coded with the software NVivo 9. The advantage of code-and-retrieve programs is that they allow the attachment of codes to texts organized in lines, sentences, or full paragraphs. In addition, this software allows the linking of various codes to a segment of information (Neuman, 2004).

Finally, data and codes were scanned selectively looking for cases that illustrate broader themes and to allow for comparisons of information. Ryan and Bernard (2003: 278) affirm that the models emerging from the codification process “are simplifications of reality. They can be made more or less complicated and may capture all or only a portion of the variance in a given set of data. It is up to the investigator and his or her peers to decide how much a model is supposed to describe.”

They also suggest that a commonly used technique to describe broad themes and topics of interest is the presentation of respondents' direct quotes. Such quotes are useful to exemplify concepts, theories and negative cases. Therefore, the direct words of research participants facilitate the understanding of themes and topics that probably took the investigator a good deal of time to grasp (Ryan and Bernard, 2003).

As a manner of maintaining the anonymity of the participants, quotes in this study

do not keep personal identifiers. In addition, it is necessary to mention that as most of the interviews were conducted in Spanish, the quotes presented here were translated to English. Words originally said in English during the interview are marked in italics.

Dissemination of results

In addition to the regular means for the dissemination of results such as the writing of a dissertation work, articles published in specialized journals, and presentations in specialized conferences, the results will be returned to the Latino community through the Centre for Spanish Speaking Peoples and Latinos Positivos. Both organizations work directly with the Latin population living with HIV/AIDS in Toronto, and the investigation results can inform future HIV/AIDS prevention programs delivered by these community organizations. In the same way, the investigation has the potential of being useful for policy makers who can in turn propose policies which benefit the Latin community as a whole, and particularly Latinos/as living with HIV. The research can be useful principally for the Latino immigrant community, especially for those individuals living with HIV in Canada and for other immigrant communities affected by the epidemic. The study and its results will be a valuable source of information and dissemination of the issues and dilemmas that HIV positive immigrants have to face in access to social services and coping strategies against stigma and discrimination in Canada.

Description of the sample

Thirty Latinos and Latinas, originally from twelve different countries in Latin America now living in Toronto, were interviewed. Seven participants come from North America

and the Caribbean region⁵ (23.3%), seven from Central America (23.3%), 15 from South America (50%), and there is no information regarding country of origin of one individual (3.3%). Their ages range from the twenties to the sixties. Two are in the range of 18-29, 5 in 30-39, 17 in 40-49, 5 in 50-59 and one participant in 60-69. The sample consists of 26 men, three women and one trans-woman. Twenty-one men identified as gay, 2 as bisexual, 2 as heterosexual and 1 as two spirits. Two women identified as heterosexual, and there is no information in regards to sexual orientation of one more. The trans-woman participant identified as heterosexual.

The sample is quite diverse in regards to the time residing in Canada. At the time of the interview 10 participants had been in the country for 5 years or less, 6 between 6-10 years, 3 between 11-15 years, 3 between 16-20 years, 5 between 21-25 years, and 3 more than 26 years living in Canada. Twenty four of the participants made a refugee claim application to obtain legal status in Canada. Two individuals came as permanent residents sponsored by a family member living previously in the country, two more came as sponsored children when their parents applied for permanent residency in their countries of origin, one more arrived as a student and later applied for permanent residence, and there is no information regarding the migration status of one respondent. For most of the participants, the migratory process is being solved in a satisfactory way, and most of them have been granted legal status. 15 have obtained citizenship and 12 permanent residency. Three participants are still in the middle of the refugee determination process.

⁵ Spanish speaking countries by region, North America and the Caribbean: Mexico, Cuba, Dominican Republic, Puerto Rico. Central America: Guatemala, Honduras, El Salvador, Nicaragua, Costa Rica, Panama. South America: Venezuela, Colombia, Ecuador, Peru, Bolivia, Paraguay, Chile, Argentina, Uruguay.

Regarding the time and place of the diagnosis, 20 participants received it after arriving in Canada, either in Toronto or Montreal, 9 tested positive in their countries of origin, and one while he was living in the United States. Four received the diagnosis between 3 to 5 years ago, 11 in the range of 6-10 years, 10 between 11-15 years ago, and 5 between 16-20 years ago. Other demographic characteristics of the sample are shown in table 2.

Table 2: Demographic characteristics of participants

		Total
Gender	Male	26
	Female	3
	Trans MTF	1
Sexual Orientation	Gay/homosexual	21
	Heterosexual	6
	Bisexual	2
	2 spirits	1
Marital Status	Single	16
	Married	3
	In a relationship with a man	3
	Divorced/ separated	6
	In multiple relationships	1
	No information	1
Education	No formal education	1
	Secondary	5
	High school	4
	Started College or university	6
	College/university graduated	14
Work Status	Disability	14
	Unemployed	4
	Part time	6
	Full time	5

	Retired/pensioned	1
Income/ year	- \$10 000	3
	10-19,999	17
	20-29,999	5
	40-49,999	2
	60-69,999	1
	No information	2

CHAPTER 5: Migration experiences of Latinos and Latinas living with HIV

In this chapter, participants' experiences during their immigration processes are presented. The chapter focuses on the reasons why respondents left their countries of origin, the main motivations to come to Canada, the barriers to settle in the country, and the relationship between the migration process and being HIV positive. The majority of participants in this study, 24 out of 30, obtained legal status in the country through refugee applications. For that reason, the chapter starts with a brief introduction to the refugee process in Canada.

Applying as a refugee in Canada

The changes in 1978 of immigration norms have permitted the entry of individuals from all over the world seeking refuge in Canada. The country offers protection to persons who for several reasons are persecuted in their countries of origin, and whose deportation may cause them to suffer torture, cruel treatment or punishment, or any other risk to their lives. There are two mechanisms of application to obtain a refugee status. The person may submit their application immediately at the port of entry, usually an airport, seaport or a Canada-United States frontier. Another option is, once in the country, to apply at any office of Citizenship and Immigration Canada.

In either way, officials receive refugee claims and are responsible for the first assessment of each case's eligibility. Those cases considered as eligible will be referred to the Refugee Protection Division of the Immigration and Refugee Board of Canada (IRB). At this point, the applicant or refugee claimant must submit a Personal Information Form (CIC, 2012).

The Personal Information Form (PIF) is a crucial document during the refugee process; it is the first document that the decision-maker will read, thus affecting the final decision. The PIF is formed of two sections. The first part contains basic personal data information, such as applicant's birth date, citizenship, family information, former countries or residence, employment, identity and travel documents, and an account regarding how the individual arrived to Canada. In the second section, the refugee claimant must give a detailed account of the circumstances that forced him/her to seek protection in the country, and all the attempts the claimant pursued to obtain protection from the state (Legal Aid Ontario, 2003).

After the required documents have been properly submitted, the applicant must wait and prepare for a hearing, where he/she will defend their case and must answer in detailed further questions. Finally, if the IRB accepts the claim, the refugee claimant is granted the status of “protected person,” and allowed to live in Canada and become a permanent resident. However, if the case is rejected the applicant might appeal to the Federal Court of Canada for a formal review of the IRB decision (CIC, 2012).

During the refuge process, Legal Aid Ontario (LAO) provides eligible individuals with diverse services, which include representation by a lawyer through the certificate program. This program gives the opportunity to low-income Ontarians and refugee claimants to be legally represented by a lawyer. To be eligible for the certificate program the refugee claim must be considered as legitimate and the applicant as a low-income person, having an annual income of \$10,800 dollars or less (Legal Aid Ontario, 2012).

Reasons to migrate

From the perspective of academic and policy fields on labor migration, it is considered

that economic reasons are the main motivators of migration, dictating the decisions and strategies of those individuals who relocate. From a neoclassical economic point of view, rational subjects will consider and invest in relocation if they can expect future gains, often such gains will be only considered in economic terms (Broughton, 2008). However, economic and social demographic analyses most of the time do not consider the multiple ways how migrants understand the migratory process, and their strategies to deal with economic constraint, which go beyond instrumental calculations. Scholars from various other disciplines argue that other factors should be considered in the equation (Broughton, 2008).

For instance, it is clear for some academics that other factors, such as gender, play a central role in migration processes. Going further, some have changed feminist conceptualizations that only look at gender hierarchies for more encompassing and complete frameworks. Such models map the intersection of gender, racial/ethnic, class and migration statuses, and their influences on the daily experiences of male and female migrants and native-born individuals (Pessar, 1999). Some scholars (Carrillo, 2004; González-López, 2005; Cantú, 2009) add sexuality as an important factor that determines and shapes migration.

In some participants' narratives, it is possible to see that economic reasons were a powerful motivation that impelled their desires to leave their countries of origin:

The economic situation over there was not good anymore. Jobs practically were very scarce, and at my workplace they were cutting people off. Besides we were getting paid like in parts or sort of little by little. Payment was coming late, four or five months. We got let's say less than 50% and the next week they completed the monthly payment, and that was going on. There was like a bad administration, and then there was no money to buy the chemical products to manufacture the medicine that the laboratory produced. My job was to sell the products, and there was nothing to sell. There was no income for the laboratory, and therefore, there was no money to pay the workers (30-39 years old, gay male).

Well, honestly I left [country of origin] because of work and economy related issues because once I finished working for the government, for instance, which was my last job, those jobs are temporary above all, because if one knows anybody, when the job is over you have to wait until a friend of yours gets a position to see if you can get a job. [Getting a] job in private companies, which is where I worked most of the time, is through interviews, exams and that is the usual procedure, but when you reach a certain age in [country of origin], well you know, it is difficult that they even look at your resume. Then I was going through a situation. I lost my job in the local government (40-49, gay male).

However, in our sample, it is clear that issues around sexuality and sexual orientation, particularly in the case of those individuals with a different sexual orientation from the normative heterosexual, were a strong consideration to migrate from the country of origin to Canada:

(I: What was the main reason to leave your country?) The discrimination against gay people, the freedom of expression. There was too much homophobia, and for a person who has the profession that I had in [country of origin], that was not well regarded either. My family always said that the arts are for gay people and what a coincidence, I like arts and, I am gay. A bit discriminated (40-49, gay male).

In fact in many cases, the levels of violence related to sexual orientation were so severe that individuals' lives and basic human rights were placed at risk, generating the urgent need to flee their countries:

My story is quite true. I was fired from the center where I worked at the university. That is why I had to work in the arts afterwards; that was just because of being homosexual. That is why they dumped me off. The police kicked me; they hurt me, because of being in gay parties and all that, and that was the reason, my political reason, and due to belonging to a certain social group that made me stay in Canada (40-49, gay male).

(I: Why did you leave your country of origin? Why did you leave the country?) First at all because of the discrimination. People told us that they will burn us alive to all those having gay sexual orientation (Int 40-49, gay male).

What made me flee [country of origin] was when a friend of mine was murdered. I was with him when the police beat us up. In [country of origin] police officers use a thing called the bolillo, which is a thick wood stick and they beat you up with that, but it seems that because that guy was small, short, then they beat him up badly, and they killed him. He died right there. The police of course did not believe me because the police officers who bashed us ran away when they saw him on the floor, then I started to scream like crazy. In [country of origin] there are as well small streets that you use to go through without going around the whole block, alley, that was in an alley. I went out to the main

street, started to scream and a cab driver stopped. I told him that I had been beaten all over my back, the clothes all torn, I had blood stains, I got bruises and all that, started to scream. The man grabbed his radio and called to his cab station, and the police came. They asked me who had done it; I said the police. The man laughed, and told me, “No, no, no, give me the plate number.” I said, “and you think that I said, hold on, stop beating me I am going to write down your plate number and then continue beating me up?” My friend died, and the next day it came up in the newspaper, a little thing this small, “Homosexual died in very odd circumstances.” Nothing was ever done. Immediately I decided that it was not a time for me to live any longer in [country of origin], and I left, migrated to the United States (50-59, gay male).

For those participants who dared openly disclose their sexual orientation to family members, breaking a tacit understanding of their own homosexuality (Decena, 2011), and putting at risk necessary family bonds, high levels of violence, stigma and discrimination permeated the family group, giving place in many instances to abusive relationships:

(I: Tell me a little bit about why you left your country?) Well because I had acceptance issues with my family. My family did accept me and did not, sort of *border line*, and then I had already gone abroad for a year, to study abroad out of [country of origin], in Brazil, and really the situation got bad with my family because I told them that I was gay very early, at the age of 12, and from 12 to 15 years old, things were worse, and because I was the youngest of the sons, was very *surveyed* [sic], very supervised and my rights were restricted in the sense that I could not call people, could not entertain friends, could not overstay in the street, could not do. A time came that I started to have my friends and started to meet gay friends, and my family realized that I was taking control of my own life, then they told me that if I wanted money I would have to work, because I did not have money, I did not have anything, then I felt very stigmatized... I realized that I did not want to live under that kind of, principally with my brothers who beat me; they abused me, everything (Int 40-49, gay male).

In some cases, the stigma and discrimination based on sexual orientation in the country of origin were so pervasive at the time that some of the participants were practically forced to leave situations of economic comfort and an advantaged social position, contrary to the idea of economic reasons as the main motivation to migrate:

If I speak about my country, I moved out due to the homophobia and for sexual orientation, to a more developed country, where I was more accepted ... In that time, there was much homophobia and much discrimination, then I suffered very much over there. That is why I came here; otherwise I would not have ever come here. I was doing well economically. I had a good social and economic position, a good job. I was good over there, but what made me want to come to Canada was the homophobia, the sexual

orientation, that's why I came! Because there were some beatings... Many friends were taken to jail, the law fell on them. Parents had to send them to study abroad, or they all had to move out because they could not deal with the social pressure (50-59, gay male).

(I: Tell me a bit about why you left your country?) Because, in spite of the fact that I had a life, compared with others, a very good and pleasurable life, I traveled a lot, had a good job, had my apartment. I had everything, but I had no freedom, and between the lack of freedom and in addition the discrimination from many points of view, because of my sexual orientation, etc., then I decided. I used to travel a lot to Canada, saw that there was a chance. It was a very open country, with many opportunities, and above all very open minded. Then for me and for my partner who in the end could never come, I decided to come, I mean not to come back to [country of origin] (50-59, gay male).

Nowadays, the legal conditions in Latin America that allow the persecution and abuse based on a different sexual orientation have changed. With the reformation of the penal code legalizing same-sex relations in Nicaragua and Panama in 2008, all Spanish speaking countries, in addition to Brazil, have fully decriminalized homosexuality, and anti-discrimination laws have been implemented in Brazil, Ecuador, and Peru (Encarnación, 2011). Even though the establishment of legal norms for the protection of sexual minorities represents an advance of democratic efforts in the region, this is more a political victory than a social transformation. Gay rights have been attained in most parts of Latin America without broad popular acceptance of homosexuality, which is demonstrated by the rise of antigay violence in the region in the midst of a gay rights boom⁶ (Encarnación, 2011), and despite possibilities of same-sex marriage in Argentina and Mexico city.

Twenty out of the 24 respondents who gained status in Canada as refugees are males who identify themselves as gay, homosexual or bisexual. The fact of having sexual

⁶ Regarding the level of homophobic violence in Latin America, the numbers speak for themselves: 539 trans people were assassinated in the region in the period 2008-2010 while 50 LGBT activists were assassinated just in 2010. Four hundred crimes against gay men, lesbians and transsexuals occurred in Mexico between 1995 and 2005; and 260 in Brazil in 2010. In the last five years, 171 homicides of LGBT persons happened in Honduras while one LGBT person per week is killed in Peru (SentidoG.com, 2012).

and emotional same-sex interests represented for them a strong motivation to leave their country of birth and come to Canada. This sub-group of participants relates to Manuel Guzman's concept of "sexiles" or sexual migrants (Luibhéid, 2005), who are those queer migrants leaving home and nation as a result of their sexuality. Lee and Brotman (2011) define sexual minority refugees as those individuals fleeing persecution because of their sexual orientation or gender identity.

Following international guidelines, such as the 1951 Convention relating to the status of refugees, Canada offers protection to individuals who fear persecution for being member of a particular group (Patil and Trivedi, 2000). The Supreme Court of Canada, in 1993, defined sexual orientation as a legitimate basis to claim to be a member of a particular social group. In this way, many gay and lesbian individuals have gained regular status in Canada as refugees, claiming that they have faced persecution and violence in their countries of origin or any other nation as members of a particular social group, a sexual minority (La Violette, 2004).

In our sample, not all participants who self-identify as gay, homosexual or bisexual came to Canada as refugees; some applied as skilled workers or were sponsored by a family member. In addition, some gay and bisexual refugees did not apply on the grounds of sexual orientation, rather they applied due to political persecution or personal problems back home. However for most of them, sexual orientation was an influential factor when considering the possibility of migration.

Participants also mentioned other prominent motivations to leave the country of birth, such as war, fleeing personal risky and dangerous situations or leaving as a result of persecution back home:

(I: Tell me, why did you leave your country?) Because my husband, the father of my

kids, I understand, belonged to a guerrilla group... He told me a bit about it, only once then (I: That is why you decided to leave your country?) Yes because afterwards he was assassinated, and I understand as well that the reason was that he wanted to quit (20-29, heterosexual female).

The case of Salvadorians is worth mentioning; many left El Salvador in the 1980s fleeing civil war and a military dictatorship backed and encouraged by the United States government (Simmons, 1993):

(I: Why did you leave your country? What made you flee?) The political situation, the war. I left in the 80s; there was a mass slaughter, I mean one of many, but when I saw that I lost all my neighbors, my friends, all of us were young boys and from participating in the church we were getting killed. Then the Catholic church was considered left wing. Then I decided to leave and see how I could help my family to get out as well (50-59, gay male).

In many instances, there was not just one reason to leave the country of origin. Economic hardship, discrimination, stigma and violence based on sexual orientation, and other difficult personal conditions intersect to different extents producing a more complex picture of individuals' motivations to migrate:

Then, I was going through a situation, I lost my job in the state government, I had cancer, taking chemotherapy. Besides I did not have access to HIV medicine, and was without a job, and with all this I tell you, honestly I was thinking that it was better to die because I did not see where to go. And my family situation, at that moment at home, that also was especially difficult. On top of that, my personal life, then everything came down on my shoulders (40-49, gay male).

(I: Would you ever go back to your country to live permanently?) At this moment I cannot because, first I am HIV [positive] and in [country of origin] there is no medical insurance for people without a job, let alone if one is HIV [positive]. The medicine has to be bought in private clinics. Second, just this year [2011] 800 gay people have been killed up to August in [country of origin]; that is up to August, 800 gay people (40-49, gay male).

It is possible to see in these narratives that intersecting dimensions of sexual orientation, socioeconomic and health statuses compound each other and create a complex set of motivations that forced our participants to relocate. That refugee applicants are forced out of their countries of origin as a result of multiple and complex reasons has been found in

other studies (Lee and Brotman, 2011). Even though refugee applicants come to Canada fleeing situations of discrimination, abuse and violence in their countries of origin, Luibhéid (2005) cautions about the reinforcement of simplistic discourses that construct Canada as a safe nation, in opposition to other homophobic and violent third world countries.

Migration Networks

For the majority of the interviewees, social networks represented a valuable resource before arrival in Canada and during the early stages of settlement. Migration networks are “sets of interpersonal relations that link migrants with relatives, friends or fellow countrymen at home” (Arango, 2000: 291). Networks are a determinant factor of the migration process. Many of the participants, without ever having visited Canada, had ideas and perceptions about what life was like in the country thanks to information received through relatives or friends living in the country already. For instance, one respondent comments that he knew about the good quality of HIV related health care services in Canada thanks to his brother who lived in the country for a longer time:

When I said to my brother that I was [HIV] positive, he told me, and considering the situation over there [in country of origin], he told me, “well if you wish you can come here, I mean I have found out that over here there is treatment, and there are more services for people with HIV” (30-39, gay male).

Extended family networks (Bernhard, Landolt and Goldring, 2008) – which involve the regular circulation of goods, resources, information and individuals across the borders of nation-states – were essential for many of the participants. For some, family members helped them to obtain legal status in the country through family sponsorship:

I wanted to come here. My brother sponsored me. I had a brother in the north of Ontario; then I told him that I wanted to come. I was young and came yes, with no problem. I came as a *landed immigrant* (I: Did you apply before coming?) Yes because my brother

sponsored me. At that time, it was possible to do so... nowadays it is not like that... I came very well; my brother was doing well economically speaking. They had a beautiful condominium. I was part of the family. They did not have their daughter yet (60-69, gay male).

Extended family networks were also important for those participants who, once in the country, filed a refugee claim application. Respondents who did not have relatives in Canada at the time of migration obtained information and received help during the process of settlement through friends originally from the home country:

A friend here in Canada used to call me frequently to the place where I was. I told him that he should stop calling me because I would not be at that place anymore; then he told me "Why don't you come over here?" He invited me to come (I: Is this person Canadian?) He is a Canadian citizen, I mean, Salvadorian but with his documents already. He is a Canadian citizen already... Then my friend told me, "go to the embassy, the Canadian consulate in Costa Rica, ask for the requirements and come to see how it goes." (40-49, gay male).

For some gay and bisexual participants, the help of gay friends was also critical during the migration process. Once in Canada, these social networks, family and friends, were a valuable source of support, providing information, accommodation, food, economic and emotional support to the newcomers.

Once settled in Canada a vast majority of participants has kept frequent communication with family and friends in the country of origin, creating transnational ties (Berhard, Landolt and Goldring, 2008)

Those participants who still have nuclear family (parents, siblings) and extended family (cousins, uncles, aunts) in their countries of birth keep regular communication with family members usually through telephone calls and the Internet. For many of the interviewees the relationship with relatives back home is so meaningful that, in addition to keeping close and frequent contact with them, they send money every time they can afford to do so. Conversely, for those individuals whose family relationships were

characterized by severe abuse, violence and discrimination, the current communication is not open. In some cases, there is practically no communication at all:

I do not have any contact with my family. It has always been very problematic, and when finally I came out of the *closet*, trying to save the relationship, with them having to accept or manage that. They simply ended up excluding me... (30-39, gay male).

Overall, participants' connection with their countries of origin is an example of transnationalism, where immigrants' lives and practices occur in receiving and sending countries (Levin, 2002). This way, individuals separated geographically are connected through economic markets and the dissemination of information and culture (Courtney, 2006).

Barriers during the immigration process

For all immigrants, independently of their migration status, the immigration process represents a singularly stressful time, charged with radical changes in life (Körner, 2007). However, during this process, refugee claimants may encounter a series of obstacles that make migration an especially stressful event (Lee and Brotman, 2011). Participants in this study mention the stressful situation that the refugee application process meant for them because it represented a moment where their life and future were at stake. There is a generalized perception of loss of control of their destiny:

It is not quite comfortable to be living in a country where your documents do not advance that you do not know whether you are going to be granted the documents or not. It is so much stress, really because I work in the field; I can tell you how people suffer. The stress that they have every day, they do not know whether they are going to stay, or they are going to go, whether they are going to be granted with documents or they are going to be deported. I mean, every case is special, each person is different. It does not matter where they come from, from where in the world, it is always the same stress (50-59, gay male).

Barriers that all immigrants have to overcome, such as language difficulties and lack of

information, represent a source of greater concern for refugee applicants, due to the vulnerability of their migration status.

For our interviewees in general, the language barrier was one of the first difficulties encountered. Coming from Latin America, for many of them this was the first time in an English speaking country. For refugee applicants, the language differences may be particularly stressful due to the difficulties in understanding the refugee process:

Everything was so difficult that I do not know what to tell you what was difficult because everything was difficult, everything, the language, the staying, how you are treated, all that was painful because nobody, maybe, because I did not speak the language I felt horrible, I felt in horror, I felt like in a horror movie. I did not know what they were talking about me, what they would do to me, what is going to happen tomorrow, where I am going to go after this room (I: You did not understand, did you?) Nothing, nothing, for me it was horrible from the beginning to the end until I was out (40-49, heterosexual transwoman).

Immigration services have their own translators who help applicants with language interpretation during the application process. To communicate with lawyers and other representatives, the participants relied on lawyers' own translators, volunteers from community organizations and sometimes friends or relatives.

Lack of information is another obstacle that participants faced during their processes. As some of them mentioned, there is a lack of understanding of the refugee process as a whole, its different phases, the relevant information that they must provide to construct a successful case and the available service organizations which provide help. In many cases, they obtained information by themselves, going to service organizations or asking friends that have gone through the process before.

Yes, I think that I had problems with access to information; I think that also it was one of the reasons, I think I did not understand the process with my lawyer because, in fact, I had not gone through a process like this, and I did not have all the information that I would have wanted to have and my lawyer did not provide it to me. He believed that I knew already, or he supposed that I must look for it in another place because it was not his job give me information about the processes, and in part I looked for some information on my side, the process how it goes after, how is the *meeting*, in what

moment to bring the proofs and when not to, what kind of proofs? I looked for that, through friends who went through the process, etcetera. But some sort of official information or that my lawyer provided me with information about the process, no (20-29, gay male).

A difficulty related to the lack of information is when participants did not have proofs or other kind of information to support their Personal Information Form (PIF) because many of them fled their countries without an idea in advance of the refugee process, or even without clear intentions of making a refugee claim once in Canada. One Mexican participant mentioned how he depended on friends and family members back home to obtain the proofs that supported his PIF. They looked for documentation even 20 years old to post from Mexico, a time and resource consuming process.

Another obstacle, which is related to the lack of information, is the difficulty in finding appropriate legal representation. Some of the participants have the perception that the lawyers in charge of representing them were not genuinely interested in their cases, and therefore, were not doing their best to succeed. In those cases, the participants had to change lawyer, adding one more stress to a process that is stressful in itself. In some cases, the imbalance in power relationships between the lawyer and the refugee claimant was so evident that claimants became uncomfortable with the situation. One participant affirms:

With my lawyer, I did not have very good relationships. I think that I was tired of his attitude because he looked a bit arrogant, a bit like I was the refugee and he was the lawyer... He did not treat me like that, but he looked so; indeed his attitude was so (20-29, gay male).

Another participant mentioned how the problems were not with the lawyer, but with a paralegal who tried to take advantage of him in a moment of high vulnerability:

When I arrived they took me to a paralegal, a Chilean woman, and she robbed me so much... As they give us a social insurance number when we request refuge, the social [insurance number] arrived at her office, then she charged 500 dollars just to take you to

migration, and *welfare* and do your application for the number then she said that if I did not pay her the 500 dollars she would not give me the number and I was paying her 100 dollars every time, until I met this Cuban friend and he told me, “She is robbing you” (I: Were you paying that out of your pocket?) Yes, that was when I was receiving help (I: And from the help you received you had to pay her) Yes I paid her, besides I paid the rent with that, then I was left with nothing... (40-49, gay male).

On the other hand, some of the interviewees affirm that their lawyers were supremely professional, reliable and supportive, and that if their cases were successful it was to a considerable extent thanks to them. However, in lengthy cases the maximum number of hours that a lawyer can represent the refugee claimant through legal aid is not enough, and the applicant has to cover the expenses if he or she wants to maintain legal representation, have a successful claim, and finally obtain legal status in the country. In some cases, this expense can represent a significant debt. One participant who does not have clear information in regards to his own application, mentioned that he was informed that legal aid had finished, and due to the fact that he cannot afford to pay a lawyer out of his pocket his situation becomes more complicated and the case seems to be at a dead end:

The lawyer tells me; it is a lawyer that I took; she calls me and says that she can help me, but she says that the case of migration finished already, then she wants to say that she is going to work, but the government will not pay her anymore, then I would have to pay, do you understand? That's what she told me the first time that I needed money to make the process advance. (I: Do you know how much money...) No because I never talked of money, because I did not have money; I was just looking for help for my problem... (30-39, heterosexual male).

Most of the participants who filed a refugee claim agree that lengthy wait times are one of the most significant and stressful difficulties they encountered during their processes. One participant reported that her whole process, since the moment she applied until she was granted with the status of refugee, was around eight months, which is the shortest time mentioned for participants in our sample. However, she affirms that it may have been a short process, but because of her intersectional identity – being a feminine gay

male at that time, coming from Latin America – the process was tremendously stressful. The regular wait time for most of the participants was from one to six years. The most stressful of this situation is not having access to any concrete information about the processes, which creates a perception of living in limbo and a lack of certainty about their future, restraining individuals from making long term plans:

Well, it was solved [the refugee process] only two weeks ago; almost five years I was in limbo. Very stressful... They did not reply to me at all, I thought that my file was lost, my *file*, everything, I said, “What happens with me?” My lawyer said, “Everything is in order. What is happening is that it is still not your turn. Wait” (I: Two weeks ago was the *hearing*?) No, two weeks ago they resolved it. The *hearing* was like three years ago... the hardest was the pressure of not knowing what was going to happen with me. I believe that was the most difficult that I had... (30-39, gay male).

Regarding the wait times, the Immigration and Refugee Board of Canada (IRB) affirms that numerous cases must be processed, and to honor fairness and efficiency such claims are not studied on a “first come, first serve” basis. According to the organization, many factors are involved in the time that is necessary to process particular cases; for instance, the type and complexity of the claim, more complex cases will require more time for investigation and preparation. Others aspects involved include that proper decision-makers, legal counsels and interpreters are available (Immigration and Refugee Board of Canada, 2012).

The difficulties during the migration process related to a different sexual orientation are particularly problematic. The Canadian refugee regime is bound by practices of heteronormativity, which have consequences for sexual minority refugees (Lee and Brotman, 2011). Participants' narratives show instances of the strong impact that such practices had in the individuals going through the refuge determination process.

Several Canadian IRB policies and practices have been identified as arbitrary and inconsistent. For instance, the fact that sexual minorities must prove their sexual

orientation before IRB adjudicators, and frequently the latter evaluates if the claimant truly belongs to a sexual minority group based on their own beliefs and common sense (Miller, 2005). Such common sense frequently is based on stereotypes and profoundly homophobic. Because of inconsistencies at the decision-making level, the probability that a refugee claim is accepted will depend on how the IRB adjudicator interprets and understands the case and evaluates evidences, rather than on the norms of the Convention refugee guidelines (Lee and Brotman, 2011). Evidence of this fact is found in one of the participant's experiences that shows how preconceptions and stereotypes about what is gay and what is not, permeate the whole system of the refugee determination process:

Not even the lawyer believed me [that I was gay] because at that time I used to wear a mustache... She said to me that, for the *hearing*, I must look as feminine as possible, and when she saw me she was surprised, she told me, "Wow! Is this you? I told you to look feminine but not so much." (I: How did you go?) Well I went very feminine; I had longer hair, to here [shoulders], I had it dyed, longer hair, I had long nails, I was a bit chubbier because I was on treatment and I had my three meals... (40-49, gay male).

Other evidence of the inconsistencies that characterized the refugee determination process is when refugee claimants from particular nations or regions are evaluated on the basis of stereotypes based on national origin. For instance, Lee and Brotman (2011) found that immigration officials respond in particular ways to Mexican refugee claimants. There is a disbelief in the legitimacy of Mexican sexual minority refugees due to the fact of coming from Mexico⁷. A participant from South America mentions the existence of such stereotypes during the determination process:

What I have seen at the *Immigration and Refugee Board* is that it is a lottery. There are judges that take the time to study the case. I even met a judge; he was a judge but now he

⁷ Citizenship and Immigration Canada affirms that from 2005 to 2008, the number of refugee claims of individuals from Mexico almost tripled from about 3,400 to up to 9,400. For 2008, Mexican cases formed 25% of the claims in the country. For the same year, the proportion of acceptance of Mexican refugee claims was just 11% (CIC, 2012). In 2011, 83% of Mexican claims were rejected. These numbers have been used to qualify Mexican applicants, among applicants from other nations, as false refugee claimants who just want to use Canadian health care services (Cohen, 2012b).

is retired, he told me that yes ...that indeed they did not read the documents, mainly from Mexico, that is how it is. If someone comes from Mexico they are going to reject him because he is from Mexico, without studying the case... (30-39, gay male).

The interviewee, despite not coming from Mexico, had difficult times during his application. He affirms that the IRB adjudicator did not study his refugee claim and, did not read it at all. The only way to solve his claim was when his legal representative requested a change of the adjudicator on the grounds of the former being biased:

The biggest problem is that this judge was working to put me out then, or he did not read the documents. At some time, he tried to insinuate that I was here to take advantage of the system, to obtain the papers for free... That was a battle, from one hearing it went to eight or nine sessions. It was three years; every two months hearing the absurd questions try to find contradictions. His strategy was obvious, *dismiss this case*, arguing that it was not true, but he never could and what happened at the end was that my lawyer was able to show that he was biased, and the judge was changed and with a new judge in less than two hours I was granted refuge; it was a very particular thing... (30-39, gay male).

The violence of the refugee determination process is evidenced during the detention experience (Lee and Brotman, 2011) that some of the refugee claimants encounter during their processes. The intersection of stereotypes based on national origin with a non-normative sexual orientation may generate problems during border crossing and the refugee claim process. Some sexual minority refugees are deemed as a security risk. In our sample, one participant mentions being detained when she arrived in Canada. Her detention seems to be based on her nationality, being accompanied by an American citizen, and her sexual and gender orientation:

I came alone with my partner. At that time, he was an American, but they thought that we would do something here. Then they arrested me, and wanted to deport me. If they deported me it would be very difficult for me, I would be treated very badly. I was, I was very afraid, I was nervous. Then I had to apply for refugee status, and I was detained for three months in immigration (40-49, heterosexual transwoman).

Another important aspect of the sexual minority refugee experience is the constant re-appearance of the structural trauma suffered by applicants. During the process, they are forced to re-tell their stories of persecution, along with the frequent questioning of the

credibility of their arguments. This systematic re-telling of violent stories can trigger horrific after-effects by re-traumatizing refugees and possibly causing long term psychological damage (Lee and Brotman, 2011). For example, when one of the participants was asked about what represented the most difficult thing during his refugee claim, he commented, “ [the most difficult was] recalling all that the prosecutor made me recall, all that I had gone through in my country. I even cried.” (40-49, gay male).

Many participants speak of multiple traumatic experiences related to the immigration process and violence, abuse, stigma and discrimination in their countries of birth. Traumatizing events take a toll on individuals' mental health: depression, sadness, fear and suicidal thoughts were not uncommon feelings among our participants at some point of their lives, either once arriving in Canada, or when still living in the country of birth. “Yes at the moment the pressure, the stress was so strong that I had to deal with all the post-trauma issues. Yes, sometimes I collapsed, and I could not stop crying and at some point I even thought about killing myself” (30-39, gay male). “Many things passed through my mind, at some point I had the idea of committing suicide because I was completely overwhelmed, sad” (40-49, gay male).

A particular traumatic experience is when refugee applicants receive an HIV positive test result during the medical examination required to settle legally in Canada. Individuals in such a situation will have to adjust at the same time to life in a new nation with an unknown culture, and to deal with a highly stigmatized and health threatening condition. Both conditions, being an immigrant/refugee and being recently diagnosed HIV positive, will influence each other. The difficulties related to relocation will be more severe due to live with HIV; while the struggle against the infection will be more

stressful as a reason of relocation in a new nation with unfamiliar culture and lack of supportive networks (Körner, 2007). Participants' narratives show the traumatic situation of receiving an HIV positive diagnosis during the immigration process:

I started the immigration process, thank God things went well, but when I took the medical test I was diagnosed [HIV positive] here. It was very hard because I did not have a support network; I did not know the health system, I did not know, basically I was newly arrived, the part of not having enough information was very hard because, in addition, I did not have any kind of education in that regard, I did know the social side, and that was very clear for me, but I did not have the basic education on HIV, for me it was death and I came with a trauma, and passed to other kind of trauma and I went in *shock* and when I entered in *shock* it was more difficult because I had to do it by myself (40-49, gay male).

Adding to the uncertainty of the immigration process, an HIV positive status makes the option of going back to the country of origin, if denied legal status in the receiving country, more unlikely because of HIV related stigma, lack of health care, and other forms of social and political unrest (Körner, 2007).

For many of the participants who were already living with HIV/AIDS back in the country of origin, HIV related stigma and discrimination, and the lack of appropriate HIV related health care services must be added to the list of prominent determinants of migration:

In regards to medicine in my country, we are very bad. We live with the help of Brazil. We do not have medicine in the country, and it was stated that for only two more years would we receive help. Afterwards, we have to see what we can do if the government will be in charge of that. Who will take responsibility in regards to medicine? And the government did not want to know anything about people living with HIV that they did not have funds to help the people, that they cannot take charge of providing medicine. I used to say, "This year that is going to finish, because I came in August, and one more year and afterwards what is going to happen with me? If I do not take the medication what am I going to do?, then it was said that here there were medicines and all that, that they provide, then I decided to stay. At least I am going to have more life, I am going to have medicine, but I did not know anything about immigration, anything about that (30-39, Heterosexual female).

(I: Tell me a bit about the first time you left your country and went to the United States, why did you leave?) Because of HIV. Well, I got infected with HIV by a partner that I had in [country of origin] and over there, there was no treatment. Now there is but it is still almost the same problem, and in the United States there was treatment already at that time, I saw the chance of going, and I did, ... (I: At some point would you come back permanently to your country of birth?) No, I do not think so because the same situation in

regards to the medication has always stopped me from living in [country of origin]. I love my country, being with my family, my friends, but I cannot (30-39, gay male).

In spite of the trauma of receiving an HIV positive diagnosis during the migration or refugee process, it is necessary to recognize that living with HIV seems to generate not only disadvantages, at least for some refugee claimants. It could be expected that HIV infection would make migration more difficult in all the cases, adding one more complication to a process already charged with difficulties. However, the relationship between living with HIV and the immigration process is complex and not always negative.

The Immigration and Refugee Protection Act affirms that foreign nationals may be not admitted in the country if there are considered medically inadmissible based on their health status. Individuals who are considered a potential danger to public health or public safety⁸ or can cause high demand on costly health services might be denied entry in Canada (Canadian HIV/AIDS Legal Network, 2011). Although refugee claimants have undergone a medical examination, including an HIV test, as part of the refugee process, an HIV positive result is not an automatic barrier to admission in Canada. Refugee claimants are exempt from the excessive demand provisions of the Immigration and Refugee Protection Act, which ultimately means that refugee claims are not evaluated in terms of health status.

In this way, many of the respondents who came to Canada as refugees affirm that their HIV positive status was not an impediment to staying in the country. In fact, for

⁸ Since 1991, according to Canadian policy PHAs, based on their HIV status, do not represent a danger to public health or safety. Therefore, PHAs are not accepted in the country only if it is expected that they generate an “excessive demand” on health and other social services funded publicly (Canadian HIV/AIDS Legal Network, 2011).

some of them, legal status was granted on the grounds of being a person living with HIV. An HIV positive refugee applicant who is not admitted in the country during the refugee claim still has the opportunity of gaining residence through Humanitarian and Compassionate grounds. This type of request may be accepted if the person is able to demonstrate that she/he is in danger of severe hardship if she/he goes back to her/his country of birth. Severe hardship might be for instance the lack of proper HIV health care (HIV and AIDS Legal Clinic of Ontario, 2012). One participant comments; [Being HIV positive] “was the reason why I could stay here ... of course because in my country there was no treatment” (30-39, gay male).

This is an example of how the addition of another stigmatized category to the intersection of multiple stigmatized identities as stated by intersectional theory, may generate contradictory and unexpected results. Collins, von Hunger and Armbrister (2008) came into a similar conclusion when they found that mental illness reinforces intersecting gender, racial/ethnic and class inequalities and damages women's relationships and position in the family group. However, the contradictory effect of the intersection of mental illness and gender, race/ethnic and class subordinated positions is that, for the women, the illness generates financial stability through government economic and housing support.

The lack of migratory status not only represents a source of stress and creates a perception of being in a limbo, but it creates real disadvantages, such as difficulties in access to good job opportunities, and social services (Magalhaes, Carrasco and Gastaldo, 2010). Fortunately, for most of the participants their legal situation in Canada was already solved; currently, many of them are permanent residents or citizens. However,

others are still in the middle of waiting, hoping that their legal situations will be solved positively while trying to continue their everyday lives in the best possible manner.

Final comments

The migratory stories of the participants are neither an easy and straightforward journey from their countries of origin to Canada, nor a fully rational decision taken in advance. Economic reasons are not the sole motivations to leave the country of origin. The interviewees' narratives show that many of them fled their countries of birth seeking to improve their life well beyond financial conditions, even in some instances, risking their economic stability and social position back home.

In most of the cases, intersecting dimensions of class and sexual orientation create strong motivations to relocate. A harsh economic situation, political turmoil, in addition to homophobia, violence, discrimination and persecution based on sexual orientation, forced the participants to flee their countries of origin.

However, we should be cautious in understanding migration stories as simple narratives of movement from repression to freedom (Luibhéid, 2005). Such narratives reinforce a culturally racist paradigm and presents Canada as a safe heaven, hiding very real forms of homophobia and transphobia present in Canada today. These stories overlook the fact that particular forms of homophobia and transphobia currently present in Latin America and other countries of the third world have their origin during colonialism (Gupta, 2008).

During the migration process, particularly during the refuge claim, participants' intersecting dimensions of identity came into conflict with IRB practices. A non-normative sexual orientation clashes with heteronormative practices of the Canadian

refugee system. As in other studies (Millibank, 2002; Miller, 2005; Fairbairn, 2005; La Violette, 2007; Rehaag, 2008), arbitrary and inconsistent IRB practices impact negatively the cases of sexual minority refugees. Among those practices are the determination of claimants' belonging to a sexual minority group based on IRB adjudicator's folk knowledge and prejudices in regards to gay identities and sexual orientation.

The intersection of a non-normative sexual orientation and particular national identities may negatively influence the refugee claim as well. Certain national origins, likewise sexual orientation, such as the case of Mexican applicants, are associated with stereotypical images that hinder the objective evaluation of concrete refugee claims. Similarly, the negative evaluation of individuals based on intersecting dimensions of sexual and gender identities and national origin is demonstrated by the detention experience that one South American participant with a non-conformity gender identity suffered upon arrival in Canada.

Memories of violence and persecution in the country of origin, and all the difficulties that newcomers, particularly refugees encounter to obtain legal status and settle in Canada generate severe trauma and pain. Receiving an HIV positive diagnosis during the process of migration may aggravate the trauma, and cause profound feelings of depression. Interestingly, the intersection of living with HIV and other stigmatized dimensions of identity, such as being homosexual and a refugee applicant from stereotyped nations, not always brings negative consequences for the subjects. This is not surprising if we consider that one of the basic tenets of the intersectional approach suggests that the addition of multiple stigmatized dimensions of identity does not always aggravate stigma, but it can potentially generate contradictory effects (Collins, von

Hunger and Armbrister, 2008).

For applicants who seek obtain a legal status in Canada as permanent residents, an HIV positive status may mean not being allowed to settle in the country on the grounds of potentially generating “excessive demand” health and social services funded publicly. This consideration does not apply to refugee applicants; furthermore, being an individual living with HIV may even be the reason for being permanently accepted in the country. In this way, when an HIV positive status, which has been socially constructed as a condition that requires strict medical care and supervision, intersects with the identity “refugee claimant,” the outcome might be favorable for the individual located at that intersection. In fact, for some individuals, this is the last option to obtain status in the country after a refuge claim has been denied.

During the process of settlement in Canada, Latinos and Latinas living with HIV, as many other newcomers, have to deal with a series of structural factors, such as barriers in access to social services, which make the process of adjustment to the new society more difficult and sometimes even painful. In the next chapter, health care services and the main barriers that Latinos and Latinas living with HIV/AIDS encounter in access to such services are analyzed.

CHAPTER 6: Access to health care

In this chapter, the barriers in access to health care services for Latinos and Latinas living with HIV are analyzed. Such barriers are not exclusive to the Latino community, but they affect other immigrant communities as well. For individuals living with HIV, structural difficulties accessing health related services may be more severe and damaging. The chapter starts with a brief description of the characteristics of the universal health care system in Canada and how it works for new immigrants and refugees.

Health care services in Canada

The health care system in Canada is publicly funded with the purpose that all eligible residents can access services such as hospital and physician without having to pay directly at the point of use. Federal and provincial/territorial administrations share the responsibilities for the proper functioning of the health care system in the country (Health Canada, 2007).

The Canada Health Act is the legislation at the federal level that set the basic goals of the public health care system in the country: “to protect and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers” (Health Canada, 2007: 3). The Canada Health Act points out that immigrants' health status should be similar to average levels within the whole population.

After immigrants are accepted in the country, responsibility for assuring their good health, as the general population's health, devolves to the provinces (Beiser, 2005). The health care related needs of individuals going through the refugee process (refugee

claimants) until the point that they have been formally accepted as refugees in Canada, are covered with the Interim Federal Health Program (IFHP), which guarantees refugee claimants' access to basic medical treatment and drugs, including HIV medications⁹. Once the claimant obtains refugee status, he or she will be covered with the public health insurance of the province of residence (Canadian HIV/AIDS Legal Network, 2012).

Participants in this study, who are already permanent residents or citizens, as any other resident of Ontario, have access to health care services through provincially funded health coverage (OHIP). OHIP covers a broad variety of health services, even though the program does not fund services not deemed as medically required, as in the case of surgeries of a cosmetic nature (Ontario Ministry of Health and Long-term Care, 2012).

In the case of HIV related health care services, OHIP covers appointments with specialists and hospitals, blood tests and other specialized laboratory tests. At the time of the interview, most of the participants had access to OHIP coverage. Only three individuals out of 30 did not have access to OHIP, two being refugee claimants whose cases still are not resolved, and another participant who was recently granted refugee

⁹ Effective since June 30, 2012, the government implemented significant changes to the IFHP: Accordingly with refugee claimant's country of origin, two categories of coverage have been produced. Refugee claimants still waiting for their hearing or decision will have full coverage, except if they come from a "designated country of origin." Claimants who have been granted refugee status will have also IFHP full coverage while they wait to obtain provincial coverage. A second category entails a reduced coverage for those claimants with refused cases who still cannot be deported. IFHP reduced coverage is also granted to claimants who come from "designated countries of origin" waiting for a hearing or decision. The list of nations consider as designated still has not been released, but it is likely it will include European nations, the USA, Australia and New Zealand, among other nations. The basic difference between both coverage categories is that while under full coverage urgent and essential services are still covered. Under the reduced category, services are covered only if they are deemed as necessary to prevent or treat a condition that may generate a risk to public health or public safety, such as HIV. Services that have been utterly cut from IFHP, regardless of the category of coverage are vision care, dental care, occupational therapy and physiotherapy, among others. Prescription drugs will not be covered for any recipient either. The exception will be medication that is part of the treatment of illnesses that imply a risk to public health – included in the Public Health Agency of Canada list of diseases that are a risk to public health – or a condition of public safety concern (HIV and AIDS Legal Clinic Ontario, 2012).

status but has not yet received a health card. They have access to medical services through the IFHP.

In this study, most of the participants recognize the importance and good quality of the health care services they receive in Canada. They are thankful for the significant difference that having access to these services makes in their lives:

Well, since I arrived I had access to health. Since I arrived I had a family doctor since I took tests and everything, they decided which medication I would get, antiretrovirals. Honestly in that regard I have always felt very comfortable because the support that this country gives, what this government gives, because, conversely to [country of origin] where they absolutely do not care whether you live or die, you get medication when it is available, any kind of it. Doctors do not know where they are standing, nor do they have the sensitivity to treat patients, people. Comparing one thing with the other, here Canada is a paradise for persons who need help (40-49, gay male).

In spite of being thankful for having access to health care services, and recognizing the high quality of them, several barriers and difficulties in the access and use are still acknowledged by the respondents.

Barriers in access to health care

One of the first barriers accessing health care services that many newcomers to Canada confront is a lack of regular status (Magalhaes, Carrasco and Gastaldo, 2010); for HIV positive newcomers this is no exception. Studies with immigrants and refugees living with HIV have described the lack of legal status as a significant barrier (CAAT, 2001; Shedlin and Shulman, 2004; Dang, Giordano and Kim, 2012). In this study, respondents who entered the country with a tourist visa and overstayed, did not have access to health care services at all. One participant speaks of getting access to the service thanks to the good will of service providers:

At some point, I did not have access to the [health care] service, but that was due to my status. But even at that time the hospital helped me to have access to medical appointments and *blood work* and those things... At that time, I did not take medication,

but there was a time that the stress was too much... Fortunately I did not reach the point where I needed drugs and had to obtain them. By the time I had to take them, I already had health coverage (40-49, gay male).

Another of the most salient barriers in access to health care services for newcomers already identified in the research literature (Elliot and Gillie, 1998; Newbold and Danforth, 2003; Beiser, 2005) is the language difference. Upon arrival to Canada, this is the first barrier that many of them have to face, and even after many years living in the country, language can represent a source of misunderstanding and miscommunication among patients and health care practitioners. One of the participants commented on the difficulties he found with his physician due to language differences until finally he decided to change doctors:

When I was diagnosed at Sherbourne, the doctor, it was a female doctor, and I had diarrhea and with the diarrhea, herpes also came up. Then every time that I had to go to the toilet with the diarrhea the pain was terrible, and I did not know what was happening and the doctor did not understand me. Then with that lack of good communication, even though I speak English fairly well and I had friends who went with me, the fact of her not understanding where I was coming from, I decided to see another doctor (40-49, gay male).

Language differences can also create gaps, not experienced by the broader English speaking population, in access to information and understanding of available opportunities and services.

Many times it is the language that we do not know what it means, but it is there, right? We read it one hundred times and “oops I never knew what it was” and the service is right there... There is promotion but many times the language is a barrier; the language issue, that we do not know much English and we do not know what is offered... (40-49, gay male).

Overall, language difficulties are a significant barrier in the access not only to health care related services, but in access to jobs, training opportunities, service organizations, and information:

For me, English is a very very big barrier. Sometimes one does not imagine how big the barrier is because you cannot talk or communicate. You have to depend on everyone and

sometimes without more communication; one feels frustrated as happened to me at PWA, when two years ago I wanted to have access to an air conditioner, because in the apartment where I was living there was no AC. Then I brought all the documents that my physician gave me to ODSP, one person takes you in; you are told that they will pass your request. When you call or go they tell you that the [social] worker is not there, that other person passed on your documents. I struggled and in the end, after two years, I just received the AC (30-39, heterosexual female).

Closely related to language differences, cultural misunderstandings also represent a challenge for good access to health care services. Hyman (2001) points out that, in situations where users and service providers belong to different cultural groups, it is more likely the presence of values and norms that inhibit communication. Thus, the recognition and interpretation of health related conditions will be influenced by cultural beliefs. One participant offers a sophisticated explanation of how cultural differences, based on long lasting political and historical differences between Latin America and North America, play a decisive role in how Latinos relate to institutions and access services in the Canadian context:

We were not invaded from Europe by the same people who invaded the North. When you come to an institution, you are Anglo-Saxon and come to an institution in Canada; you already know the structure, and how things are. From Mexico, the relationship between people and institutions is more negative than positive; it is one of fear and stigma and... (I: You have to be careful with the institutions...) Well, one does not go, I do not go, I rather pay. When I got sick, I preferred to pay a doctor than go into an institution (40-49, two spirit¹⁰ male).

This way, important differences between the Latin and the North American culture and history create occasionally different idiosyncrasies which might represent a significant barrier in access to services for Latinos and Latinas living in Canada due to trust issues at

¹⁰ Two Spirited People of the 1st Nations, organization formed by Aboriginal 2-Spirit in Toronto, defines the meaning of “2-Spirit,” “In our culture, before the Europeans came to North America, '2-Spirit' referred to an ancient teaching. Our Elders tell us of people who were gifted among all beings because they carried two spirits: that of male and female. These individuals were looked upon as a third gender in many cases and in almost all cultures they were honored and revered.” (Two Spirited People of the 1st Nations, unpublished: 7). One participant in this study self-identify as 2 Spirit because, even though originally from Latin America, once arriving in Canada, he felt more welcomed by the Aboriginal community. In addition, his identification with two spirited Aboriginal people is a way of acknowledging his own Latin American indigenous roots.

the moment of accessing institutions and services. On top of this, when cultural mismatches intersect with a lack of regular immigration status the resulting problem may be more severe. Individuals in the process of obtaining legal status have even greater trouble trusting institutions and services in the new Canadian context, independently of ethnic or national background (CAAT, 2001).

Therefore, language and cultural differences make the health care system in Canada difficult to understand. Li (2007) found that gaps in understanding how to negotiate service access can be a significant barrier. One of our participants comments about the importance of knowing how to negotiate with service providers. Interestingly, the respondent is a Canadian citizen, and after being in the country for more than 20 years, he is acutely familiar with how the system works:

To empower yourself, one has to learn to negotiate with the service providers. I see that there are people who work from nine to five, and they can see their doctor any time. Then I say it is a negotiation the physician knows that person has a limited time. They make time for the person, but if I call and they do not know me, then they give me an appointment for the date they want. They do not *squeeze in*; you know? But if one knows the idiosyncrasies of the society one has to negotiate. At the moment, I was very ill. I did not have any options but to wait there until they gave me service, something that not all people do, especially when you are very sick (40-49, two spirit male).

Participants mention as a strategy to counterbalance language and cultural differences a process of self-education in regards to how the health care system, organizations and services provided work in Canada.

Beyond language and cultural barriers, participants' narratives show the existence of power imbalances in the relationship among services providers, more specifically physicians, and patients. This shows the social hierarchy in the health care system and differences of power and privilege granted to subjects in the various hierarchical levels. In this scale, patients occupy the lowest level, and physicians and hospital administrators

the highest (Jiwani, 2001). Some of the participants speak of those power imbalances which sometimes make the relationship doctor-patient difficult:

I was with this doctor in Sherbourne, and with that doctor I stayed for some time, but all the cocktails that I started to take did not work for me. My virus created resistance... That was in 2006. I was working full time, and I started the medication, but the medicine he gave me was driving me crazy. It did not work. It was making me sick. I had side effects, and he did not understand me... I wanted to change the medication, wanted to change the drug and see what could be done, and he used to say, no that it was good, and he said to me, "No, it is something good. If you don't want to take it, do not take it" I told him, "I am getting sick, the pills are making me sick" you understand? I was stressed by my job, and you say that the medication is all right and you don't want to change it? ... then I decided to change the doctor. From that point, I did not have any other problem because I found another HIV specialist (40-49, gay male).

Since last year, it was in March, April, I do not know why I lost some Tylenol. He [the physician] gave me a lecture that that must be like my money, but the money gets lost as well, and because I lost the Tylenol 3 he did not treat me very well, was a bit rude with me, and at that moment I said, "If you talk to me about medication, you are telling me for a long time that I am going to receive my medication, why haven't you prescribed me the cocktail yet?" Then he made the prescription and said to me, "Here is your cocktail," did not tell me what would happen to me, nothing, "Here is your cocktail and bye"... that was the way he treated me, and I did not take the cocktail until I changed doctor (40-49, gay male).

The existence of power imbalances also creates a lack of accountability from physicians to patients. This may produce stressful situations for the latter due to the fact that it is their health and well-being that are at stake. For instance, one of the participants explained that he was sick with pneumonia for around a year. Even though he visited his family doctor on several occasions, he was not formally informed, nor received an explanation about the treatment. Finally, he found out the reason for his prolonged poor health by coincidence:

I had pneumonia around one year because I did not receive treatment on time. They thought that it was regular flu and let it pass. I almost died, and they did not treat me. That forced me to change doctor. [The family doctor] said the first time that it was a virus that goes away by itself. It was viral. Then that was around October, around December, a temperature and cold and the phlegm even with blood. Then he referred me for a lung X-ray, and he said to me that I had an infection but did not prescribe anything. Then in January I went and I was with one foot in the grave, and I told him that I was very ill, and he referred me for another X-ray and then prescribed medication for the infection I had. He gave me medication for five days. I finished it and waited one week, but I continued

to be sick. I went again, and another physician attended me because I could not make an appointment with him, and the other physician told me that the drug worked in one week or 15 days after one finishes it, that I had to wait for the effects and I showed him the phlegm and all. I had pictures that I took of what I expelled. Then after the 15 days passed, I was still sick, and he referred me to his student for an interview and the student said, "You are still sick. It is due to the pneumonia" "Pneumonia? I did not know I had pneumonia" ... And the whole year I was sick with a cold. Imagine since October until last December when I changed doctor, and he gave me pills for the pneumonia... (40-49, bisexual male).

Many of the interviewees lost confidence in their physicians due to difficult patient-doctor relationship, lack of easy communication, lack of accountability from physicians to patients, and other power imbalances. However, in addition to power imbalances, the narratives show the existence of individuals' agency. Some participants, in the end, decided to change their doctors as a result of the lack of a trusting relationship with them.

Another aspect of the power imbalances that characterize the health care system is the presence of discrimination based on class, gender and racial intersecting dimensions. Research on immigrant women of color, domestic violence and health care demonstrates that the relationship among physicians and other service providers with female victims of abuse will be determined by class, gender and racial/ethnic traits. In accordance with her class, the female victim will be treated better or worse, and she might even suffer further mistreatment depending on her racial characteristics. In addition, the abuse and violence that she suffers may be attributed to inherent cultural traits. In this way, health care professionals and the health care system overall are not exempt from racial, class and gender discrimination (Jiwani, 2001). As an example, a female participant in this study affirms that she has felt insidious discrimination due to the intersection of her gender and racial/ethnic identity:

Maybe because you are Latina, right? Because if they do not talk to you, you do not know, they do not listen to you; they do not talk to you, or they do not reply back. Maybe the language or it can be that you are not accepted because of skin color or what you are

(I: Do you feel it is a question of the language?) The language and also, at least there is a lot of racism from whites. Some of them pretend that they did not listen to you. Yes, I have felt that, at the hospitals or at any place where you go (30-39, heterosexual female).

Another form of discrimination in the health care system is the presence of transphobia, which can be defined as the fear of transgender and transsexual individuals. One transwoman in this study commented on the difficulty in accessing health care services. For service providers, there is a mismatch between the person's physicality and her health card, which still shows a masculine name. This way, there is a permanent confrontation among the participant and service providers:

In regards to gender, it always comes up masculine, then when they see me and then my OHIP with the gender everybody changes. It is like, how can it be explained? It is like *aliens* are here, the extraterrestrial, and they start to talk because I feel it. "Man, she is not woman but is a man" and things like that. That is the only problem that I have, but that is fixed so to speak. I do not pay attention to what they say, what they do. I am here to get the assistance, and they have to attend to me like anyone else (40-49, heterosexual transwoman).

Unfortunately, the small number of female participants in our sample (four out of 30) does not permit a deeper analysis of the particular and problematic relationship among cultural minority women and the health care system in Canada.

Another difficulty is the lengthy wait times to access specialized services, and tests that require advanced medical instruments. Some individuals have even waited for a year to access such services:

To take the MRI¹¹ they transferred me and the appointment lasted one year, one year in having a MRI result. I know they have a lot of work but one year I think it is too much... Well they say that there is a lot of work, and there are very few of those machines because are very expensive... One year is too much. Imagine if one had cancer, you die, and the result does not come... (40-49, bisexual male).

¹¹ The technical procedure known as magnetic resonance imaging or MRI is "a noninvasive medical test. MRI uses a magnetic field, radio frequency pulses and a computer to produce detailed pictures of organs, soft tissues, bone and virtually all other internal body structures." The detailed images produced with this method permit to detect body conditions that might not been perceived with the use of other techniques, including X-ray, ultrasound or computed tomography (Radiologyinfo.org, 2012).

The barriers accessing health care services described so far apply to some extent to a broad range of migrants and newcomers in Canada, regardless of their HIV status. In addition to these barriers, migrants living with HIV encounter difficulties that are particularly related to an HIV positive status.

The HIV related stigma that still exists in the Latino community and the broader Canadian society is the most significant barrier in access to health care services for HIV positive individuals. Similarly, in Ontario, Collins et al (2007) found that stigma still is a significant barrier in the involvement in AIDS Service Organizations (ASOs) for people living with HIV. Although stigma and discrimination have changed, they are alive, becoming more subtle and difficult to detect, making aboriginal people, women, and people of ethno-racial groups feel excluded from these organizations. One female participant commented on the feeling of exclusion when she tested positive and turned towards the Latino community seeking support:

The only barrier that I encountered to accessing services was when I went to the Latino community, at that time 17 years ago, so things have changed very drastically, but when I went ... I didn't get what I needed from there, so that's what I found difficult, but all the English, Western, all the health that I can get in the social services, or the social service organizations were fine... I wanted to meet other women, Latinas specifically, to make a connection, didn't have to be women, anyone in the Latino community... I felt so alone, specially 17 years ago, it was even more in the closet than it is now, people in the community testing HIV positive, so I wanted to make that connection because I felt very alone, primarily because, you know? It had shocked my family so much that I also wanted to get some support for my mother. Unfortunately, those things didn't go through... I didn't feel welcome there, I felt judged... judged... I just felt judged by my community... and that kind of helped me going more in the closet in the Latino community, because I felt that, if that was my experience maybe the Latino community was not ready to accept me and so I didn't do anything I just stuck with PWA, and the AIDS Committee of Toronto (40-49, heterosexual female).

The situation inside the Latino community is changing gradually, and now it is possible to find more support, and other HIV/AIDS related services for Spanish speaking individuals. The situation in the broader society has also changed and now it is possible

to find more support and service organizations for people living with HIV. Some of the participants consider that nowadays in Toronto, internalized stigma, the stigma that HIV positive individuals feel and the fear of it, are more damaging than the stigma that still permeates the health care system. Internalized stigma translates into a barrier in access to already available services:

I think it becomes difficult [access to services organizations] not because there is no way of getting the information because they do not speak English; everything is in Spanish, almost everything. The problem that exists is the terror that the Latin person has when is diagnosed with HIV, and the terror, the stigma. Look, over here [Latinos Positivos' office] many people do not come because they think that people are going to say, "Ah! This one is positive," then, it is not the lack of access to information or that there is no information, the problem is each one of us because of fear of *labelling*, of stigma, of what people will say, "They are going to know," that is the real problem... that can cause a person who has been diagnosed recently not coming to obtain the services or even to access medication and... HIV gradually advances and becomes AIDS in many people because of stigma, from the hospital bed, when there are dying already, and that I tell you even makes me feel a bit bad because it should not happen, but from the same bed when they are dying is when they say that they had HIV, *too late*... (50-59, gay male).

As a result of the stigma and discrimination that are still strongly attached to the experience of living with HIV/AIDS, even in a relatively open and more accepting environment as Toronto, participants speak of a concern for confidentiality in access to health care services. Some of the participants share their anecdotes when they feel that their right to confidentiality while accessing a service was being breached:

I do not like Saint Michael's [Hospital] because I had to go with a physician, and one has to explain everything and they speak very loudly and honestly I feel bad, there are people in line, to ask for an appointment. Then they say, "You have HIV? You have AIDS?" They say it loudly. That for me has been bothersome. And the other day also I went to the same hospital because I must ask for medication in the drug store at that place, last Saturday and also I do not know this place, and as I tell you, twice, the first time the lady yelled, "You have AIDS" and I was very ashamed, and the other day I said to the lady that I was going to the drug store because I needed medication, [she said] "Which medication?" was the medication for, I mean very loud, you understand? Then I said that I just need the way to go to the drug store and the lady told me that it was closed, but it was a lie, it was not closed. Then, that is the only part that where I did not like it so much... and what I say, they speak very loud. Imagine, "Why do you want to see the doctor?" "Because I need to get a prescription," something that I had written "What for?"

“Because I have HIV” “You have HIV, have AIDS?” And on top of that she sent me to another place, and the other lady the same, “Ma'am I need to ask you some questions, are you a lady with AIDS?” And I was like, “oops what a shame really!”... (20-29, heterosexual female).

Confidentiality issues occur not only in health care settings, but there are instances in other service organizations where the person's right to confidentiality has not been respected, even to communicate the diagnosis:

At that time, I was doing volunteering work as well... and everybody appreciated me very much because I got along well with people. Then one of the women over there told me, “You have to go to see your counsellor because they called you and had news for you.” But she looked at me, and her face changed, like if she wanted to cry. I said, “What is it? Is it anything bad?” Then I went to jail, and she [the counsellor] told me that she received a phone call from the clinic to say that my blood tests showed that I was HIV positive. That bothered me a bit because I thought that those people had to be more discrete and consulting with me, instead of calling the places where I was going to volunteer because at that moment more people got involved, and they knew, and many years passed, and I did not want to talk about that topic (40-49, gay male).

One participant comments that, as a strategy to deal with stigma in access to health care services, it is necessary to understand that one's own health is more relevant than stigma. Therefore, the HIV positive person has to consider that his/ her access to services does no harm to anybody else while not using the services in place fearing stigma and discrimination results in damage for the person him/herself.

Research has proven that people living with HIV/AIDS have unique mental health related needs (CAAT, 2008). Therefore, mental health services are critical to providing treatment and care to people living with HIV/AIDS. In Ontario, the Committee for Accessible AIDS Treatment (CAAT) found long wait lists and limited service availability as crucial barriers, among other numerous ones, in access to such services for immigrants and refugees living with HIV/AIDS. One of the participants clearly identifies the deficiencies in mental health services for Spanish speaking people living with HIV:

The issue of mental health always has played a bit with me... I have always needed somebody, a *counselor*, a psychiatrist. I had long periods of depression, but obviously the psychiatrists always give antidepressants, but *counseling*, I never could get the *counseling* part... and sincerely I have never liked the psychiatric perspective because I do not know if it is a problem of the practice in itself, or I do not know if that is just here, what I see is that the psychiatrist tends to diagnose, prescribe, but there is no additional psychological evolution, in handling it and saying “Well let's find a solution” or assign certain tasks for you to be able to perform, which *counseling* has, *counseling* works very much with that ... but not psychiatry. For me, going to a psychiatrist it is not good. I do not want to fill myself up with pills. They give you anxiolytics and antidepressants, but that is not all, a psychological piece is needed in mental health practice, and it does not exist. There is no one who works in the area and speaks Spanish and who can provide service to Latinos living with HIV... I believe that there are very confused people because they are not getting the appropriate therapy in counseling as it should be, then many of them have to keep to themselves because they do not speak... One notice what people are lacking and there is not a good access to psychiatry or mental health in your language, there is not... (40-49, gay male).

Access to medication

Access to medication is an acute concern for people living with HIV. Medication grants HIV positive individuals the possibility of maintaining a functional immune system and, therefore, good health. In Ontario, OHIP does not cover the costs of medicine; working individuals can have health benefits; medicine included, as part of a series of work benefits. Employment related health benefits can be variable depending on the employer. Some plans may be the responsibility of the employer while employer and workers can share the responsibility of others. (HIV and AIDS Legal Clinic Ontario, 2012).

The Ontario Drug Benefit program (ODB) provides prescription drug coverage for Ontarians with a valid Ontario Health Insurance Plan (OHIP) card and who are 65 years or older, live in a Long-Term Care Home or Home for Special Care or receive the services of the latter; or live on social assistance (Ontario Works or Ontario Disability Support Program assistance); or are registered for the Trillium Drug Program (HIV and AIDS Legal Clinic Ontario, 2012).

As part of ODB, the Trillium drug program is for Ontarians who do not count

with drug coverage from any other source. Clients of Trillium must cover a fee every year based on the income of their household, equivalent to about 4% of net family income (University Health Network, 2012). Some participants speak about the use of this program at some point in their lives before they were entitled to the ODSP. Usually this was when they were working or in a period of unemployment insurance but without employment related health benefits. They have the perception that even though the Trillium program is useful because there is no need of paying the full cost of medication, the expense still may be significant, principally for a person living with the limited resources of unemployment insurance.

Most of the participants obtain their medication through the Ontario Disability Support Program. However, they commented that various medications, either HIV related or not, health related products and services are not covered with ODSP. In those cases, they have to pay for them, or obtain substitute medicine recommended by their physicians:

ODSP has a list of medicines that are covered. If the medicine is not in those *guidelines*, there is a process that you have to follow. The doctor has to make a special application; otherwise they can say no, not because you have HIV you will be granted everything, there are certain medicines which do not, and you have to take alternative medicine if necessary, but there are things that you do not get (50-59, gay male).

Health related products such as vitamins, proteins, products against nausea and diarrhea, among others, are not covered and can mean a frequent expense for some of the participants, having to expend up to 100 dollars every month. Other health related services, which can be beneficial for people living with HIV, such as massages, acupuncture, some dental and optical services, and minor surgeries which are considered more as a cosmetic rather than a health related procedure, are not covered neither by ODSP or OHIP. Fortunately, some of these uncovered products and services are provided

by AIDS Service Organizations (ASOs) such as People with AIDS Foundation (PWA).

Final comments

In their comparison on access to health care coverage for people living with HIV in Canada and the United States, Adam and Sears (1996) found that Canadians have better access to universal, relatively comprehensive health care services than their US counterparts. Overall, Latinos and Latinas living with HIV participating in this study have good access to health care services as well, and they highly appreciate that fact. However, participants comment on the existence of barriers and difficulties related to their intersecting statuses as immigrants and members of a minority cultural/ethnic group in Canada: lack of legal status, language differences, cultural mismatches and difficulties understanding how to negotiate access to services. Other studies have encountered similar barriers for immigrants in general (Cave et.al., 1995; Kirmayer et.al., 1996; Varcoe, 1997; Elliot and Gillie, 1998; Jiwani, 2001; Hyman, 2001; Newbold and Danforth, 2003; Beiser, 2005), and for immigrants and refugees living with HIV/AIDS (CAAT, 2001, 2008; Tharao, Massaquoi and Teclom, 2004).

Power imbalances among health care practitioners and patients are a barrier that may affect not only immigrants, but also native-born individuals in their encounters with health care professionals. However, it is clear that the intersection of racial, gender and immigration statuses leaves certain individuals more vulnerable to such power imbalances. For instance, accessing health care services, intersecting racial/ethnic and gender identities of women of color will make them vulnerable to racism and sexism; while trans individuals conflicting gender identification will make them vulnerable to transphobia. In this way, the intersecting identities of participants in this study determine

and shape the relationship that they establish with health care professionals and the health system in general.

How does the condition of living with HIV intersect with the barriers in access to health services? The barriers that newcomers in general encounter in their access to health care services, language difficulties, cultural differences and power imbalances may be even more damaging for HIV positive individuals.

In addition to general barriers, HIV positive individuals deal with HIV related stigma that still permeates the health care system and internalized stigma. HIV related stigma, internalized stigma and confidentiality concerns often stop some Latino and Latina PHAs from approaching needed services, which can be damaging not only for individuals' health, but a real concern from a public health perspective.

Some of the strategies participants in this research have developed to counteract barriers in access to health care are, seeking information and self-education about HIV/AIDS after arriving in Canada, or after diagnosis, accessing uncovered products and services through AIDS service organizations, or changing physicians when there are gaps in the communication or power imbalances.

In the next chapter, I will discuss in detail the barriers that our participants face to find and maintain employment in Toronto.

CHAPTER 7: Access to employment

In this chapter, I discuss the main barriers that HIV positive Latinos and Latinas encounter in Toronto to find and maintain a job. I argue that due to their intersectional identities, being immigrant and individuals living with HIV, they have to cope with significant compounding barriers to employment in Canada. The Ontario Disability Support Program (ODSP) and the issues around this disability program are also analyzed.

Economic and employment status of Latinos and Latinas living with HIV/AIDS

At the time of the interview, 5 (16.6%) participants were in full time jobs, 6 (20.0%) worked part time; 4 (13.3%) were unemployed, 1 (3.33%) pensioned, and 14 (46.6%) on disability. The employment status of the immigrant and refugee Latino sample from the OHTN Cohort Study (OCS)¹² shows that 37.1% are employed full time, 13.6% part time; 40.1% is on disability, 8.33% unemployed, and there is no information for 0.76% (OHTN Cohort Study, 2012a). It is likely that our sample's higher numbers of unemployment and living on disability are the result of the recruitment strategy conducted among individuals who rely more significantly on community agencies. However, it is necessary to recognize that the OCS's percentages of Latinos and Latinas PHAs on disability and unemployed are still significant. We distinguish among individuals on disability and unemployed, because even though the latter also receive income assistance, the respondents in this situation said during the interview they were actively looking for a job. As already mentioned, most of the participants are recipients of ODSP, but those who

¹² The OHTN Cohort Study (OCS) is a research initiative that collects clinical and socio-behavioral data on a cohort of participants living with HIV over time. The objective of the study is to build a database that allows the conduct of research for the improvement of the general well-being of people living with HIV in Ontario (OHTN Cohort Study, 2012b).

are working, depending on the wages they earn, either receive less income assistance or do not receive it at all, keeping just access to medication. Many of the participants who currently are on disability worked for a long time before quitting. They stopped working immediately after being diagnosed or several years afterwards.

Among the individuals working in either full or part time positions, 4 out of 11 work in community service organizations, some of them directly serving other people living with HIV. One participant has a clerical job while another works as a professional and is also involved in community work. Two individuals work in factory related jobs, and three more in the cleaning industry.

The majority of the sample, even those participants working, lives with a low income¹³. Three individuals (10.0%) make less than \$10,000 per year while most of the participants, 17 out of 30 (56.6%), have an annual income of \$10-19,999; 5 (16.6%) between \$20-29,999; two (6.6%) between 40 and 49,999; and one person (3.3%) earns 60-69,999. The yearly income shows that the sample in this study has a lower economic status compared to the immigrant and refugee Latino sample of the OHTN Cohort Study. In that sample, 7.6% make less than \$10,000; 21.2% between 10,000-20,000; 17.4% between 20,000-30,000; 12.1% between 30,000-40,000; 5.3% between 40,000-50,000; 22.7% between 50,000- 100,000 or more (OHTN Cohort Study, 2012a). As expected, individuals living solely on the income assistance of ODSP have the lowest incomes, and those working in full time positions have the highest. The latter is not necessarily true in all cases because individuals working in low-skilled jobs, such as in the cleaning

¹³ In fact, Poverty Free Ontario considers that recipients of Ontario Works (OW) or ODSP are condemned to poverty with the current rates of these programs. Going further, even with the current minimum wage rates, a person working in a full-time job during the whole year still will be poor (Poverty Free Ontario, 2012).

industry, even though in full time shifts, receive a lower salary than the participants in part time jobs in service organizations or professional activities.

Barriers in access to employment

Like other newcomers in the country, our participants have found numerous barriers to employment that relate with the immigrant condition. Lack of legal status in Canada was the first main barrier that many respondents in this study had to face. Most of the participants now have legal status, but some of them still remember how at some point, their lack of it was a barrier to working legally in the country, and therefore, limiting their access to job related benefits. One of the participants also recalls the time he was not able to accept a good job opportunity because he was still a refugee applicant and could not go outside of the country, which was required for the position: “What was frustrating for me was that I found the opportunity of working, in 1988, working for *Air Canada* as a *flight attendant* and I could not take the job because I could not travel because I did not have documents. That frustrated me because, at that time, I was 21 or 22 years old” (40-49, gay male).

Participants in this research recognize that sometimes they have faced the necessity of working without declaring their work and paying taxes. This form of activity is commonly known as working under the table. Jobs under the table are related to unskilled tasks, such as cleaning jobs, work in factories and construction companies. Individuals obtain jobs under the table through friends or employment agencies, where the applicants do not have to provide a social insurance number, and the payment is in cash.

For one of the participants, working under the table implies a lot of physical

effort, a low salary, being mistreated by managers and supervisors, and overall exploitation:

All those *cash* jobs of the agencies, which are out of the city, those are jobs of exploitation. The payment is the minimum... You cannot take a *break*; yes those are hard jobs... (I: What kind of work have you done?) All kinds of things, construction, factories, terrible! Horrible, the physical effort is great, and they do not consider it, your work is not valued, like they exploit you a bit, and it is low paid. That is why they use the agency to pay less... In some jobs, they treat you badly, not to me, but to a certain group that is working that has been trained, with bad manners, mistreatment, a lot of pressure but with bad treatment. The only thing missing is that they bring out the whip... They humiliate you, yell at you, yes horrible... (40-49, gay male).

As in access to health care and many other services, language is a serious barrier to finding better jobs. For those individuals with experience and high qualifications, low English proficiency forces them to accept unskilled and low paid jobs where there is no necessity of speaking the language:

The problems that I have over here are because I have been slow to learn English and of course it is understandable that I have difficulties getting better jobs that I have been offered those jobs because I do not know English... I am doing cleaning jobs and that's it. In [country of origin] I was not used to that, and over here I am doing it because of the language difficulty. So I must improve my English, and also come back to school, see if I take a course to get a better paid job and with less physical effort because of my condition as HIV positive (40-49, gay male).

For the newly arrived, to learn a new language is frequently problematic, because there is little spare time to take English lessons when the first priority is to get enough means to survive. One participant mentions that, at some point, he suffered discrimination and mistreatment at his workplace because of the lack of language proficiency. “Yes, I was mistreated because I did not speak English properly, because at that moment I did not speak English and yes I was mistreated a lot in many jobs, and I had confrontations with certain persons” (40-49, gay male).

The intersection of low language proficiency and a lack of a fully landed immigrant status created a context of exploitation at the workplace for some participants.

They had to accept mistreatment and humiliation for being a refugee applicant and not speaking the language fluently. In the following account, it is possible to see exploitation caused by a vulnerable migratory status, low English proficiency and race differentiation:

I worked in cleaning because of my limited English. I had a bad experience for two reasons: first the supervisor was very full of herself. She thought that she could do and tell you whatever she wants because you needed the job and because you were in the process of refugee application. She does not have the right of putting pressure on people or made them work over time only because one needs the job. She made me work over time without paying me, and she used to say that I must take care of the job otherwise I could lose it, and there was a lineup of Filipinos who worked even for five dollars... (40-49, bisexual male).

Another serious disadvantage that newly arrived immigrants in general encountered to access good job positions is the lack of Canadian experience in the job market. Even though newcomers may have high qualifications and a solid experience in a certain field; the lack of Canadian experience is for many employers an impediment to hire immigrants. This is called the immigrant job certification issue: “any employers refusing to recognize the skill sets conferred by foreign countries or institutions, limiting the economic opportunities of immigrants, and perhaps constraining immigrants to low-skilled, service employment.” (Newbold and Danforth, 2003: 1992). New and established highly trained immigrants are more likely to occupy jobs with low educational requirements than are their Canadian-born counterparts. This way, the proportion of underemployed immigrants has increased since 1991 (George, et.al., 2011). Participants in this research recognize the crucial limitation that the lack of Canadian experience entails when they were seeking a job, to achieve a better job position and ultimately to fulfill their life goals:

Here in Canada the professional credentials from many countries are not recognized, only the credentials from North America, Australia, Europe, etcetera, but not even from East Europe. I studied in Bulgaria. That is not recognized at all, you understand? One comes with those careers and years of experience that over here is not recognized. It does not count (50-59, gay male).

The issue of recognizing immigrants' professional qualifications is not exclusive to Ontario, but it seems to be an issue beyond the province. One participant who lived in Montreal for many years before relocating in Toronto speaks of this issue which not only negatively impacts immigrants, but Canadian society as a whole:

[I] had more than two years sending around my C.V. I never got a call for an interview... The problem is that Quebecers, French people have a very strong protectionist law, for example. If you are a doctor, and you come from outside, they do not let you work as a doctor, even if you were the most renowned specialist in your country, they do not let you work. Unfortunately, the system is getting rotten because there are no doctors. To be a doctor you have to be trained in Canada, I mean in Quebec, because not even the French doctors are accepted... French doctors come and enter the same door as the rest. If you want to be a doctor here, you have to have two years of revalidation. You have to pass all the exams, being accepted in the doctors' college, have two years, and so on. Finally, it takes you four years to be able to work as a doctor. The same thing is with the nurses, the same thing with the educators, I mean, the system is getting rotten because they do not have doctors, do not have educators, do not have nurses, do not have this, do not have that and all the immigrants who arrive, who have the skills, who are updated, they do not allow them to work. It is a problem; they are underemployed, working in other things, working as cab drivers, doing this, doing that, in restaurants, in whatever thing because they are not allowed, I noticed. I have a friend who has a PhD and has been seeking a job for ten years and never has got employment (40-49, gay male).

Participants also speak of the existence of overt feelings against immigrants. It is perceived that immigrants come to Canada to compete with the “local” labor force for better job positions:

There exists much discrimination due to the fact of not being Canadian. It is not discrimination for being Latino, even if one is not Latino, but for being from another country, because the fact of being an immigrant we are discriminated against to get work. Canadians prefer Canadians. They discriminate against immigrants, and many hate them, and one hears, “*Fucking immigrants!*” and if I am going to compete in the free market as [participant's profession] with four Canadians, they have the advantage over me, unless one is very skillful in some field... It is not the language, it is discrimination because of skin color, the race. Canadian prefers Canadian... No, it is not the language because as an immigrant one can speak English very well, and one can communicate somehow, but the Canadian has the idea that whites are better and look down on the immigrants... Yes, absolutely yes, wherever one goes there exists racism. At the workplace, there is racism (50-59, heterosexual male).

For other respondents, discrimination is not only against immigrants in general, but it has a racial component directed against Latinos, amounting to unfair treatment and

inequalities in the workplace:

(I: During the time you worked did you ever receive discrimination or mistreatment due to the fact of being Latina or for being gay in regards to sex?) *Oh yes, yeah, yeah*, they want to pay you less because you come from another country. They want to pay you different because they think you come from the trees. I believe all the Anglos think about Latinos that we came from the trees that we do not know anything and things like that (I: So, you really see racism and discrimination as real facts) *Yeah*, but it is not only now, it is everyday, and it is not only with me, with many persons behind me, in front of me, what can be done? (40-49, heterosexual trans-woman).

Teelucksingh (2006) contends that Canada has a long history of racialization that is manifested in the labor market and rooted in the immigration process. Racialized groups take on labor that other segments of the labor force will not do for menial wages. Many jobs in the country, such as domestic labor, the garment industry and contract farm labor, among others, have been racialized¹⁴

Respondents also talk about age as another factor that determines the personal success in the job market. For individuals over 40, it is more challenging to find a suitable job when they have to compete with younger candidates, in addition to other already mentioned “disadvantages.” Age was a factor of unequal treatment for one respondent during the time he was working, leading to longer shifts than for younger coworkers:

When I was working at [clothing store], I suffered discrimination because I was the oldest one. Then when I was working there I was 40, 42, 43 years old, and I was working with young people, in their 20s, 22 who go to school. I found that I was used; I mean they took advantage of me. I worked 14 days in a row, 8 hours, I rested one day and came back to work seven days again, I mean there was a lot of manipulation. If I asked for hours off, I did not get them. There was a lot of manipulation I would say, a lot of manipulation of power... I believe that was because of my age (40-49, gay male).

For many participants, homophobia has been another form of mistreatment and rejection at the workplace. One respondent comments that discrimination based on sexual

¹⁴ Tanya Basok's research (2002) is an excellent example of the employment of Mexican temporary migrant workers in contract farm labor in Ontario. Another compelling example of a process of racialization in the industry of cleaning is the work of Aguiar (2006) and Herod and Aguiar (2006).

orientation was the reason for not being offered a better job position:

Yes, I really was discriminated against in various moments for being gay, even in two hotels where I worked. I was working and I was about to get a better position and one person in management rejected the idea, and I was told by one of the person's friends, "As he says that you are gay, he does not want to give the position to a gay person." But the person who told me this did so risking himself, but I felt rejection myself. I knew; he never talked to me, never said, hi. He said hi to everybody, but not to me... (40-49, gay male).

The comment of another participant shows how ironic is the fact that in Canada discrimination based on sexual orientation locates many of the interviewees in a difficult and disadvantaged position at their workplaces, when many of them fled their countries of origin for the exact same reason, coming to this country expecting to find a place free of discrimination and harassment:

Once I worked in carpentry, and I had problems with the supervisor. They were talking about women and all. It is not comfortable. I do not care; I follow the game, but they were saying that they would go with women, and I always looked for an excuse, I did say even lies, as I was married just to avoid going... I said, "Shit, I left [country of origin] for this!" but well what could I do? That was the job I had, and that was happening over there... There were problems at the end. He [the supervisor] stopped talking to me. Sometimes he just talked to me out of necessity, or sometimes he passed and pushed me, then for me those were problems (30-39, gay male).

The existence of multiple barriers in the labor market leaves many participants with the perception that finding a suitable job, in accordance with their capacities and experience, is close to impossible. One participant comments, "One has to realize that over here one is an immigrant, who does not speak the language perfectly. I am also of an age that there are already many youths in front of me, and perhaps the competition is a lot" (Int 6, gay male). In this way, the intersection of immigrant status, language proficiency and age locates respondents in disadvantages positions in the labor market. Some of them have the feeling of being underemployed and stuck in a job position where their capacities and experience are being wasted:

The job I have is temporary, I do not like it, it does not make me happy either, it is only

for the economic help. I would want to get a job in my field, even if I could come back to study and get a job according to my educational level. I would like to study something... to do something because I am not happy with my current job, nor with the life style that I have now. Yes, something more related with what I used to do [in my country of origin] maybe, or to a higher level, I don't know, a job where I feel more comfortable with myself, not because of the money, that is an important reason too, but more than anything else to feel that you really are in your level... (40-49, Gay male).

On top of all the structural barriers that Latinos and other immigrants encounter in the labor market in Canada, the condition of living with HIV creates additional dilemmas around employment. The workplace presents challenges to be negotiated by HIV positive people, and job loss can lead to a decline in standard of living and quality of life.

Unemployment can also generate a feeling of lack of worth, whether by self or others (Adam and Sears, 1996).

In a series of interviews with 35 persons living with HIV, Maticka-Tyndale, Adam and Cohen (2002) found that finding a job after time off work, the management of drugs and symptoms, disclosure and the threat of discrimination including AIDS-phobia, and homophobia, and the perception of being “trapped” on disability were all barriers that make it difficult for PHAs to come back to work.

There are instances of HIV related stigma and discrimination at the workplace among our respondents when they disclosed openly their HIV positive status. One participant comments that stigma and discrimination at his former workplace presented as a quarantine action:

I could not explain that to my boss because I did not want him to know, but they checked, they noticed that I either did not come or came for short times, and then went. They asked me, and I had to say it ... When I had to leave the job, they prepared a party, and if we are talking about discrimination and *labels*, the party was a breakfast or lunch and my plate was a cardboard plate, and my fork was disposable, and everybody else's no, ah what would you think? What did they want to say? My only, for me, my spot at the table had disposable cutlery, ah! Immediately I said to myself, “You know what? Thank goodness that I am leaving the company,” because I knew what I could expect if I continued working. For me that would have been hell, [co-workers] looking at me like a strange bug, spoiled goods, like a bag of infections, you know what I mean? At that

moment, it had a terrible impact, when you understand the message they are trying to send you, then what I did was to finish the event and never went back to that place, I never went back (50-59, gay male).

Quarantine experiences are common to all kinds of HIV positive people regardless of gender, sexual orientation or race. Quarantine has a very strong negative connotation while actions such as sharing food and dishes can be read as a true sign of loyalty and support (Adam and Sears, 1996).

One of the respondents working in a religious community per a few hours weekly, comments that without even fully disclosing his serostatus, his HIV condition has been a barrier to get a full time job. An HIV test is requested to obtain the position, and because of the conservative nature of the Catholic church, he thinks he would never be admitted to work a full time shift for the religious congregation:

If I haven't gotten a *part time* or *full time* position, as an office assistant at the parish, it is precisely for my health condition... My boss knows about my condition, I mean the pastor knows about my condition... He personally says, "I do not have any problem. What I am interested in it is the job that you do for me at the office. Your private life is your private life, period." You understand? But you know that everything is a hierarchy and the Church never... is going to accept that. That is like a barrier for me, to be accepted by the archdiocese because obviously to be accepted I have to take the tests they request. And I was checking the requirements and yes, they request an HIV test... then, that has been a barrier to obtain a *full time* in that place, yes... (40-49, gay male).

Many participants have managed to keep their HIV positive status unknown at their current workplace, or they did so when they were working. This has helped them to avoid HIV related stigma and discrimination in the work environment. One of the respondents working at an ASO affirms that it is up to the individuals to disclose their serostatus in the workplace, and it requires a process of evaluation of the whole context. For instance, in some notable cases and depending on the nature of the job, an HIV positive serostatus can be seen as an asset. This is particularly the case for some job positions at ASOs

(AIDS service organizations) which explicitly required a lived experience of HIV infection. However, the interviewee also suggests being cautious when disclosing at the workplace, because it can have unexpected consequences:

There are many [persons living with HIV] who say that their bosses are super cool, very fond, and they say: “it is just that I have HIV” and then the next month they are fired for X or Y reason, (I: Which is not legal either) It's not legal, but obviously if they want to fire you, even though you are *unionized* if you are with a boss who does not like the fact that you have HIV, and suddenly you made one or two mistakes in your job that can be an excuse to say, “Well, your performance on this month has been so bad, and you have this fault or this other and so we have to let you go definitely,” obviously there are underlying things. What I say to people is “do not do it.” You have to know very well how to make the *disclosure* of what you need; people do not have to know, principally for the wellbeing, the mental health... (40-49, gay male).

For the person living with HIV, it is beneficial to learn how to negotiate at the workplace certain conditions and accommodations which will allow them to continue performing their work duties while coping with the virus. In the same way, individuals have to learn how to request periods of absence, which sometimes can be relatively frequent, for illness or doctor appointments, without disclosing an HIV positive status. Some of the participants are fully knowledgeable about this topic.

When somebody has a disability or a chronic illness and wants to talk with the boss, what one has to say, “I have a chronic illness, and I need one day every month to take medical tests.” That's it; the law says. The labor law says that what you have to say to your boss are the causes or symptoms you have that do not allow you to perform any specific task, not the nature of your illness, which is HIV, but “around noon I feel exhausted, and I need more time for lunch, I need a nap to recover my energy, I need to go for a walk, or I get very tired seated, then I need times to go out and relax and be able to concentrate again” but one never is talking about HIV. I am simply saying, I am requesting permission to take *breaks* of 20 minutes, two *breaks* one in the morning and one in the afternoon. That is the accommodation that I have because I live with a disability, and that's it (40-49, gay male).

The lived experience of HIV can be deemed an asset for individuals working at ASOs. For a person living with HIV, it would be easier to understand and empathize with HIV positive clients, their issues and lived experiences. However, some of our respondents

speak of certain issues working at ASOs. One participant comments on the misunderstandings about the nature of HIV as a disability among HIV positive and HIV negative employees, which can give rise to feelings of unfair treatment and resentment among coworkers:

When you are in an organization, whether it is an AIDS service organization or not, if you are working as a team and there are some team members that there are not necessarily there because of their illness, you don't necessarily do as much work as you do when you're present because of the illness. Although you know we are told we have to respect disabilities, which HIV is although we are told that we have to accept the fact that if they are going to hire people with HIV they're going to get sick. But unfortunately I think that, within a team primarily, those who are HIV negative are not very understanding about that, and I think is because HIV is a different disability... It's not a physical disability, like people see it, you know what I mean? You can't see if I am completely exhausted. You can't see that; you can't see if I am completely depressed, there are certain things about HIV. There are team members there that are not happy and they feel like either you are using it as an excuse or simply because they are working so hard they get bitter because others are not working, or you feel others are not working that hard (40-49, heterosexual female).

Another participant comments about being dismissed from his work duties at an ASO at the moment he became sick. As a result of the experience, he questions the principle of GIPA (Greater Involvement of People Living with HIV/AIDS), coming to the conclusion that, unfortunately, this principle is only for healthy HIV positive individuals:

When I have been sick, it has been difficult to negotiate for employers. Once I got sick for five weeks, and that has been the only time, I had pneumonia... and I was sick, but I continued... quite involved in a good deal of things. Then I got sick for five weeks, then gradually I was left out of each program, a contract that I had with [ASO's name] included. Then the fact that I got sick cost me my job, but it was not my fault, but my employers' who could not commit to the principle of working with seropositive people and not fire them, but accept them at the time they are. If an organization works with sick people and is going to hire sick persons you must know that sometimes they get sick. The problem is that they do not know how to deal with that. I ended up with no money, marginalized, I isolated myself more; I stopped coming to receive services because I felt very bad about how I had been treated... I had to go to therapy. I was nine months in therapy dealing with the fact that I had lived not only with discrimination, but marginalization, and well the stigma that that the GIPA principle is only for people with HIV, people with AIDS who are healthy, right? Because in that sense that I was in a leadership finished at the moment I got sick... (40-49, two spirit male).

In fact, Collins et al., (2007) in a study about the barriers and advantages for a greater

involvement of people living with HIV/AIDS in AIDS Service Organizations, found precisely tensions among HIV positive and HIV negative individuals, and organization staff's concerns when the HIV positive individuals stop or quit the job due to health or personal related circumstances, as obstacles for a greater and more meaningful involvement. Other barriers for the involvement of people living with HIV/AIDS are PHAs' poor health and medication's side effects, confidentiality issues around serostatus disclosure, feelings of stigmatization, agencies' climate being unwelcoming to PHAs, and the consideration that PHAs lack the required skill and background.

The participants living with the condition just for a few years, or those with better health, have managed to keep an active working life while coping with all aspects of living with HIV. These individuals might be on and off work and ODSP income assistance. Individuals working in community service organizations and professional positions – jobs perhaps not as physical demanding as low-skilled jobs – have successfully kept their work for long periods of time, even many years.

However, a significant proportion of participants in this study have had to leave their jobs, or have never worked since the arrival in Canada. The main reason for this is long periods of poor health caused by HIV related illnesses or due to side effects of medications.

I did not have energy; I got *shingles*, that is part of herpes, it is part of the herpes family and we call it chicken pox, but it is not the kid's chicken pox. The adult's just attacks a nerve and it did attack me, which is strange because it always affects this part of the hips; then it attacked my face, this part, the right half of my face. I almost lost this eye. It was really bad; [the illness] was eating this part. They could fix it and all that. I started to feel that my defenses were coming down, coming down, and I did not have HIV, but it was AIDS already. Then it was hard for me even to walk, my knees, my calves hurt, I could not walk, I could not breathe, it was very difficult for me to go to work, but even with all that I got up, went from my workplace straight to home. I sort of ate and then went to sleep, because I could not do anything else (I: due to the health issues, weren't you taking medication?) Yes I was taking medication, but it was not working properly and because

of that I had depression and locked in myself for six months and stopped taking the medicine. I did not do anything, and I felt better, that gave me energy, strength, but after six months, I came down again, sick, I had to go back to the medication again because I could not make it (40-49, gay male).

(I: Have health related issues ever stopped you from work?) A lot, a lot, a lot, a lot. First it was the problem I had with the medication which affected my stomach very much, and a lot of stomach pain, a lot of diarrhea, I used to go from constipation to diarrhea. I mean my stomach was changing all the time, due to the medicines, the *side effects*, then I had stomach problems by nature, in addition the strong medication, plus diarrhea, plus tiredness and working you get more tired. I had quit many jobs... I had to quit because I got sick... (40-49, Gay male).

For HIV positive individuals, another barrier to find a suitable job mentioned in the literature and also encountered for some of our participants is a perceived lack of job skills (Martin, Steckart and Arns, 2006; Brooks et al., 2004), or that previously acquired labor skills are not updated any more. The gaps in job stories (Brooks and Klosinski, 1999) related to periods of poor health are also a barrier to return to work because it becomes difficult to explain periods of unemployment without fully disclosing an HIV positive condition to job interviewers and potential employers.

Participants' narratives show how barriers to employment that immigrants in general face and obstacles for HIV positive individuals have worked their way on the employment lives of the respondents, stopping them from full participation in the labor market, therefore, locating them in marginal social positions. For instance, one participant comments that when he arrived to Canada his lack of migration status and a low English proficiency were significant barriers to employment. Later, soon after he tested HIV positive, poor physical health prevented him from work. Now that he is in better health, his lack of Canadian work experience, the fact that he has been out of work for a considerable time, and his lack of updated work skills, result in significant barriers for him to find a job.

The difficulty of finding or keeping a job position may have a profound impact on people's self-image and self-esteem. This is not difficult to understand if we consider the psychological, emotional, in addition to economic benefits that a paid job may have (Brooks and Klosinski, 1999). One respondent clearly relates the fact of having a job with a life style, and the feeling of being a productive member of society, while he links joblessness with marginality and a stigmatized identity:

Once my personal life gets more stable [I want to] go back to work and have my own apartment and those things, right? My life is going to change, and I am going to socialize more, going to meet other kinds of people whom I am not used to treat much by now, and that I cannot because I cannot meet coworkers because I do not have a job... then all those kinds of things are a motivation for persons like me who are out of the field for a long time, things that help to make you feel more secure and perform better as a citizen, not as a marginalized person or an HIV positive, or as *disability* [sic], but as another member of society, without all those *labels*... (40-49, gay male).

As other studies show (Adam and Sears, 1996; Maticka-Tyndale, Adam and Cohen, 2002) participants in this research considered work as a source of satisfaction, self-worth and connection with the world. For those participants who have been out of work for some time, volunteering is an alternative to gain some of the psychological benefits related with employment.

Ontario Disability Support Program (ODSP)

The Ontario Disability Support Program (ODSP) is one social assistance program which provides income and employment support for individuals with disabilities who are in economic need.

Income support helps people with disabilities to pay for living expenses: food, clothing, necessary personal items, rent or mortgage payments, heat, utilities (electricity, water), property taxes, home insurance, and condominium fees. In addition, income support includes benefits such as drug, dental coverage and vision care, among others. To qualify

for income support the applicant must meet financial criteria and disability criteria as defined under the Ontario Disability Support Program Act¹⁵

The employment support helps those individuals who are capable and willing to go back to employment, or those interested in starting up their own businesses. At the time of the interview, the majority of respondents received income support from ODSP. Some of them did not receive monthly income support because they were working and their salaries, after the calculation of the 50% exemption¹⁶, was higher than the maximum amount given by ODSP. However, these individuals still qualify for drug coverage. One participant, newly arrived to Ontario, was in the process of applying for ODSP, and another one, even though he was not a direct beneficiary due to his immigration status, received income support and drug coverage through his partner who is an ODSP recipient.

In regards to economic support, most of the participants acknowledge the importance of the service and are thankful for having been granted access to it. Few of them consider that the income support provided is enough to cover their basic everyday life expenses. However, the large majority agrees that the support is not enough to meet their basic needs:

¹⁵ The Ontario Disability Support Program Act defines a person with a disability as “someone who has a substantial mental or physical disability that is continuous or recurrent, expected to last for a year or more, and significantly limits their ability to work, look after themselves, or get out in the community, and has been verified by an approved health professional” (Ontario Ministry of Community and Social Services, 2012).

¹⁶ ODSP recipients, who are working or have a spouse working, receive less money as part of income support. ODSP reviews applicants' income per month; such income might be formed by the salary earned from work after deductions like income tax, Canada Pension Plan, Employment Insurance contributions and union fees. Fifty percent of the net earnings per month are calculated (50% exempt rule), and from this amount monthly child care and disability-related work costs are deducted. This final amount is subtracted from the Income Support amount, and the individual receives an extra \$100 work-related benefit. In this calculation is also considered the money earned by the ODSP recipient's partner or children 18 years old and up who are not enrolled in full time secondary school (Ontario Ministry of Community and Social Services, 2012).

I am alone, but it is not enough. Life is expensive in Toronto. I get less than 1000 dollars [of income support] it is very basic, too basic. For instance, you go to the store every two weeks and spend more, between 100 and 200 dollars in *groceries*. You have to buy things for your house, such as toilet paper, deodorant, tooth paste, things to clean the stove, everything, your personal stuff, razors. I do not pay for haircuts I do it by myself, and sometimes you want to eat out, and you think about it because that is ten, 15 dollars and you say, "I do not have money already." The 20th I already do not have money, but I have food at home, "I better go eat at home." I have to pay phone, Internet, pay electricity, my rent, which is low but I have to pay... (40-49, gay male).

(I: Do you think, your current income is enough or not enough to cover your basic needs?) It is not enough because the rent I receive is only 400 dollars and a fraction and my expenses are 850, one bedroom apartment that is what I pay, then you have to seek what you are going to eat with the rest of money, and have the money for the rent. You receive 1200; 800 almost go to the rent, 850, the rest is to buy the metropass and cover your nutrition needs (30-39, heterosexual female).

In a study with disabled women in the province, Chouinard and Crooks (2005) found that the women in the study were facing the same issues in regards to income assistance. As interviewees often commented, the women in their study affirmed that paying for daily necessities has become harder, and there is seldom money available to pay for recreational activities.

Participants speak of a series of strategies to solve economic constraints, such as obtaining food from PWA's food bank or church banks; participating when possible in research projects where they get some small compensation. Other strategies include avoiding expenses that for other people could be unavoidable such as home phone service, TV cable, and public transportation; buying clothes out of season; relying on friends, family members, and partners to obtain food or other goods; participating in projects and events where there is some available food, or help for transportation; preparing food to sell among friends and acquaintances; going to community kitchens to make meals. In general, participants try to adjust their expenses to a tight budget, which implies adjusting their whole life style, avoiding recreational and social activities as much as possible.

Another strategy to deal with economic constraints is working under the table. If they work and declare their salary, income assistance will be cut according to the wage earned. Thus, to keep both incomes, some of them engage in undeclared work, which as already mentioned, is more physically demanding and with lower wages.

To make ends meet and being very honest, and because this is anonymous, working under the table, doing work extra, you understand? That is the only way that one can say; well you understand... I have had to work cash. One feels bad because to work cash, what kind of jobs can you find? Cleaning, work is work, but well, one has to work those jobs which are not degrading but it is not your profession at all (50-59, gay male).

Participants working in permanent and/or full time jobs do not rely economically on ODSP. Among these interviewees, principally those in well paid positions, there exists a negative image of living on social assistance, especially when an individual makes use of the service for a long term. It is considered as a sign of “laziness” and lack of willingness to move forward.

I consider myself different from the rest of the people who have HIV in Toronto. I work, because the majority lives on welfare, very comfortable with the money from *ODSP*, and the government gives them an apartment, “Hey, hey I receive *housing*.” *Housing* plus 1200. Well I do not know if it is 1200, but with the money from *ODSP* and *housing*, they live very comfortably. The majority do not worry anymore. There are people that yes go to study and work, but I work regularly (50-59, heterosexual male).

Individuals living on ODSP confront a series of stereotypes and discrimination while dealing with physical and mental issues (ODSP Action Coalition, 2012). Stereotyping is also related to the existence of negative perceptions in the society in general that ODSP recipients are scamming the social assistance system (Edmunds, 2004). In his work with welfare recipients, Bratton (2010) found that the negative perceptions of welfare recipients is so pervasive that individuals on welfare hold stereotyped ideas about others on welfare, preventing this way the expression of collective agency and mutual support. This discourse is encountered among PHAs concerning other PHAs living on welfare. Some of our participants consider that the majority of Latinos/as living with HIV in

Toronto prefers to live on social assistance and lack the willingness to find a job and stand up by their own means. This “laziness” is associated with the complex stories of Latin people, coming to Canada as a refugee with traumatizing experiences in their countries of origin, the stress of the immigration process, the cultural shock that a new life in an Anglo-Saxon culture represents, and sometimes the shock of finding out an HIV positive status during the process of immigration:

Most of the people I met... come as refugees and live on *ODSP*, yes (I: What do you think is that? What happens?) Well I think there are various factors, but one of the factors I believe is the culture shock of immigration ... Some find out about their HIV status here, that adds another pressure, like a surplus *shock*. It is as we arrived so beaten, and then the mix of coming beaten and finding some crumbs here, thinking about *ODSP* as crumbs because it is enough, but we are in a country where that is a crumb. We come with a perspective, and of course here we receive the minimum which is way more than we receive over there and that for a person who does not receive anything seems wonderful and between the migratory impact and to receive that... then I came with my story from Latin America, and I got this monthly check, “That's it; I do not want to know anything else, I got where I had to get,” that is the simplest version of what I think happens... In all cases of conformism to give it a name, well I am talking of two particular cases where I notice the emotional issues, the shock of coming, how hard it is to connect because of the language; it is constant depression. Those two persons that I am thinking of; for me they are depressed, they only have the minimum speed to do the minimum and get their check, and that's it (30-39, gay male).

For others, in addition to previous traumatizing experiences, it is the intersection of different aspects of people's lives, such as socioeconomic background and educational level, that plays a decisive role in how they adapt to their new conditions in Canada and the level of success attained to leave social assistance:

Many Latinos that I see came from very harsh conditions, a lot of poverty in their countries of origin, with a very low educational level. Many did not finish secondary school or just made the second grade of elementary school. Then they come here and find a country that offers them many things. People sometimes stay there, standing there, stuck, because I did not have anything in my country, I arrive here and receive money, 1200 dollars, which is not much, but people adjust themselves to that and then once in a while work for cash, work under the table, do cleaning here and there. They do not have to report it to *ODSP*; many people stay in the phase... I do not want to call it an easy phase because everyone lives his/her life as he/she pleases. I do not want to judge either, but many people stay here in that because there is no vision. People need a vision of life, and if I want to do, if I want to be this, but the system offers them that, if you want to stay living on social assistance okay stay because nobody is going to force you to leave [social

assistance]... and we are human beings and do not come with just one face, with one phase. We have a bit of baggage behind, all that baggage is where all things come from, depending on whom the person is and on what she/he brings, where she/he wants to change, and if here if you are on *ODSP*, the system is not bugging you, like, “Well, when are you going to stop living off the system? When are you going to stop living from us?”... (40-49, gay male).

In this study, we find among the participants who were not working at the time of the interview, more than a lack of willingness to improve their conditions of live, a critical perception on the ODSP as a double edged sword: on one side, all of them recognize and appreciate very much the support provided by ODSP, which is a valuable help to survive during harsh times. On the other side, some of them consider it a hindrance that prevents the ODSP recipient from moving forward with his/her life and fully belonging to the society, rather than being a marginalized member of the social group:

Living on *ODSP* or someone else is suppression for me... suppression because I am limited, limited and limited and I cannot get out of there. I need to feel I am productive, but also is very *comfort* [sic]. It is a great area of *comfort* being there without doing anything, and well, you say “I do not have to do it really because nothing is pushing me to do it” but my mental *comfort* says to me that I am not comfortable with this, then I want more... (40-49, gay male).

Even for some of them, it is the system of social assistance, in addition to numerous structural barriers, which generates the state of “stagnation” among the ODSP clients, or the feeling of being “trapped on disability” (Maticka-Tyndale, Adam and Cohen, 2002). As mentioned before, when the ODSP recipient is working, he/she must report his/her salary, and then half of that salary will be discounted from the economic support granted. Even though the individual could make more money when holding a job position than just staying on the support of ODSP, the situation reverses itself for people living in assisted housing because once working, rent fees will go up, depending on the person's wages. In the end, with the discount of the income support and paying higher rent, the money available is the same or even less when the person is working than just living with

ODSP income and paying a subsidized, significantly lower rent. Following this rationale, one participant came to the conclusion that he is better off just living with the help of ODSP, and once in a while working under the table, without reporting this income to ODSP:

I am going to tell you something, the financial help is very comfortable for me, because I am also in *housing* that is paid by *ODSP*, but ,on the other hand, that is something that keeps me paralyzed from the professional viewpoint because I tell you, due to the system they have, you have to report... In the end, if I had a job, at the end they take all the help away. I mean, maybe that is fair, but I say, “Well, what am I going to work for? If without working I am going to receive the same?”... Of course if I found a professional job with a good salary, it would be worth it, but a job where, really, a job of 12 or 13, 14 dollars per hour it is not worth it because practically with the monthly deduction for taxes, in the end it is the same amount that *ODSP* gives me, then I better stay at home... In my case, I live in a building that belongs to the government, to *Toronto Community Housing*, then, on the other hand, you pay according to your salary, then I would have to pay more, the *ODSP* is taken away, and on top of that I have to pay more because I receive a bit more money, the salary, but I would have to pay more rent, then I say I better stay paying 130 dollars or whatever it is and it is covered anyway by the ODSP... Sometimes I feel that they paralyze you, and you do not do anything because of that (50-59, gay male).

This way, structural barriers that immigrants confront accessing a well-paid job and being on disability due to living with HIV, which for many individuals is not a significant barrier to work anymore, intersect to locate many PHAs, a good proportion of participants in this study included, in a marginalized position in Canadian society. It is also necessary to highlight that, in spite of the circulating discourses that place Latinos and Latinas living with HIV as lacking interest in moving their own lives forward, we found that the majority of participants have strong desires to improve their lives in many aspects: trying to go back to school to improve their English skills or seeking to start a new career; looking for jobs, and even those working want to get more fulfilling, and rewarding positions. In addition, a vast majority do volunteer work at community organizations, especially at HIV and AIDS related organizations, contributing in this way to the Latino and other communities of people living with HIV and trying to give

meaning to their own existence. Therefore, it is fair to say that stagnation and a lack of willingness to improve their lives and succeed is hard to find among the Latinos and Latinas living with HIV in Toronto.

Volunteer work

Many of the participants in this study, even though not holding paid positions, still are involved in activities that allow them to have the feeling of being helpful and productive members of society. Some are part of research committees; participate in forums, workshops and trainings for people living with HIV/AIDS. A good proportion of our sample performs volunteer work at community organizations and ASOs. Volunteer work is an excellent opportunity to gain new abilities, improve skills, obtain information about available services and valuable resources, even extra money, make social networks and connections with other peers and community members, and in general strengthen the self-esteem and a feeling of belonging. In some cases, participants currently working in paid positions started as volunteers in different service organizations:

Although I've been involved in the AIDS movement for 16 years, that does not mean that I've been receiving a salary through all those 16 years. I've done a lot of volunteering to get where I am today, so the various reasons for that is that I didn't have time for education... and what I ended up doing was volunteering for organizations and slowly and surely understanding the community... so it took me about six or seven years to move into the work force... (40-49, female heterosexual).

Some others are involved in volunteer work with the idea of starting a new career in the area of community work and HIV/AIDS services.

The volunteer work that people in our sample do is highly diverse. As already mentioned, a good part of the participants volunteer for ASOs, such as PWA and ACT; others at community or church managed kitchens; while other individuals are involved in community organizations working with people with addictions, and some do, or did at

some point in their lives, volunteer academic work directly with city based universities.

The work that volunteers do is not only valuable for the individuals themselves, but it is a vital resource for many service and community organizations which commonly recognize the significant contribution of volunteering for the performance of the organization. For instance, Collins et. al., (2007) found that when HIV positive individuals engage in the work of the ASOs, they set positive examples for other PHAs, and help in the struggle against HIV related stigma. Their participation also allows ASOs to be grounded on the real experiences of individuals with HIV, resulting in healthier communities, reduction of fears and misconceptions about HIV, and the increasing of the organization's credibility among community members, among many other benefits.

Final comments

In this chapter, I discuss the main difficulties that Latinos and Latinas living with HIV face accessing employment at the same time that dealing with HIV and the difficulties they have encountered at their workplaces. Many of these barriers are the same that other immigrants and newcomers might encounter in Canada: lack of legal status, low language proficiency, feelings against immigrants, racism, ageism, homophobia, lack of accreditation of international education and lack of Canadian work experience. These barriers are not exclusive to Latinos and Latinas living with HIV, but are the same issues that either other immigrants and refugees face in Canada, beyond health status and ethno-racial, cultural group, or HIV positive individuals encounter as well. Most of them are structural barriers that exert a powerful effect on the lives of immigrants, refugees and people living with HIV, beyond culture and race.

Other barriers are directly attached to the experience of living with HIV; concerns

related with disclosure at the workplace, HIV related stigma and discrimination, poor health status and side effects of medications, tensions among HIV positive and negative co-workers, the stress of employers when HIV positive employees have to take time off of work due to illness, perceptions of lack of job skills and difficulties explaining gaps in personal job trajectories.

Unfortunately, participants in this study have to overcome too many structural barriers in their access to employment due to intersecting dimensions of being an immigrant/refugee and living with HIV. This way, they have to cope with barriers to employment that in general immigrants and refugees encounter, in addition to the barriers that people living with HIV/AIDS face. These barriers do not present separately, but act together, compounding each other, to complicate the access to work opportunities.

Unemployment and structural barriers in the labor market that immigrants in general confront are further reinforced by employment difficulties caused by HIV infection. As a result, participants in this study have a limited access to job opportunities, and therefore, many of them occupy a marginal position in the Canadian society.

Due to their limited access to well paid employment, social assistance is a vital support for most of the participants. However, there still exists stigma and discrimination, even among employed PHAs, towards PHAs living on social assistance. The stigmatized views of social assistance among employed PHAs mirrors the conceptions of the larger society: Individuals living on ODSP are regarded as unable to stand on their own feet and improve their lives. However the narratives show that Latinos and Latinas living with HIV, contrary to the generalized social perception, actively attempt to improve their live conditions in Canada.

What seems to be true – Goar (2010) found the same dilemma when she talked to other ODSP recipients – is that even though ODSP is a valuable help for the individuals during unemployment and illness, it reinforces the location of recipients in a socially marginalized position. Frequently, the rules of ODSP make it more feasible to live on social assistance than going back to work, and therefore, generate among their clients the perception of being trapped on disability (Maticka-Tyndale, Adam and Cohen, 2002). In addition, the economical help of ODSP does not allow recipients to escape from poverty. A single individual receiving ODSP support is 30% below the low-income cut-off calculated by Statistics Canada while a couple still is 10% below such line.

Unemployment, underemployment and living on social assistance have significant impact on individuals' self-esteem and overall well-being, leading to feelings of depression, isolation and worthlessness. One of the most beneficial strategies to counterbalance the negative effects and feelings of lack of employment is the involvement in community and volunteer work. Volunteering will allow individuals to nurture a feeling of self-esteem, reinforce personal networks and a greater involvement with diverse communities, learn new abilities and improve work related and personal skills, opening the possibility of a future incorporation to the work force. Participants' narratives also show that Latinos and Latinas living with HIV/AIDS, either working or living on income assistance, engage actively in multiple activities to improve their life conditions in Canada. Doing volunteer work, seeking actively to go back to paid employment, learning new skills through training and trying to go back to school to initiate new careers, even for some of them working under the table in particularly harsh conditions, are all attempts to obtain needed resources.

In the next chapter participants' experiences regarding family, friendship, couples and sexuality are presented and analyzed, making special emphasis in aspects of stigma and discrimination in individuals' relationships, and the importance of these relations in their lives.

CHAPTER 8: The experiences of living with HIV/AIDS. Family, friends, couples and sexuality

Relationships with relatives, friends and partners can be deemed as a valuable source of comfort, support and help for all individuals. Unfortunately for people living with HIV/AIDS this support cannot be taken for granted. Often, the precise same relations that for others are a source of joy and strength, for PHAs are a source of rejection, stigma and discrimination. In this chapter, the experiences of Latinos and Latinas living with HIV in family, friend and couple relationships are described and analyzed, emphasizing the positive aspects of those bonds and how HIV related stigma may affect them. The effects of HIV infection on the sexual lives of the participants are also analyzed.

Family

Adam and Sears (1996) comment that disclosing an HIV positive status may take longer with family and friends than with lovers and spouses, who are usually told right away. Less intimate relationships raise the question of appropriate timing to disclosure; similar results have been reported in other studies as well (Pivnick, Jacobson, Blank and Villegas, 2010; Martinez, Lemos and Hosek, 2012).

Many respondents in this research have not disclosed their serostatus to their families, even after many years. Keeping an HIV positive status unknown to relatives obviously is easier when the family is far away in the country of origin. On the other hand, most of the participants with family members in Canada have already disclosed, and fortunately the general reaction from their relatives has been supportive and caring.

In our sample, there are two significant reasons for not disclosing an HIV positive

status to the family. First, there is a serious concern of causing pain and suffering to family members, who in most cases have limited knowledge of HIV and AIDS. Besides, the rationale is that most relatives are not with the individual. Participants consider that disclosing would bring negative results rather than positive outcomes, principally for family members who have to bear health related conditions themselves:

No, nobody knows... They do not know because... in one case my sister is going to apply [to reside in Canada] in December. When she comes it will time to let her know, but my family in [country of origin] no. My mom is sick. She has a heart disease; she worries a lot because I am alone in this country. My grandmothers are old. What is the reason to worry them if they are away from me? I do not want them to know (40-49, gay male).

Secondly, individuals who have tense family relations argue that disclosure would bring further rejection and stigma. This is the case for participants who, having coming out as gay to their families, received mistreatment, abuse and contempt. In those cases, the interviewees consider that it does not make any sense to disclose:

No, nobody knows, nobody... and I thought about telling them, but finally I came to realize that I will not say anything (I: Why?) No really, the stigmatization. Imagine, they stigmatize me already because I am gay. Imagine because I am HIV [positive] (40-49, gay male).

It is worth noting that discrimination against HIV positive individuals by other family members may be due to the intersection of a homosexual identity and an HIV positive diagnosis. In this regard, Weitz (1990) considers that the diagnosis emphasizes the participation of the individual in homosexual activity. In this way, an HIV positive diagnosis reinforces the belief that homosexuality must not be tolerated and that the infection is a divine punishment.

There are instances where, even though participants had decided not to inform their families about their serostatus, one family member found out due to the indiscretion of service providers, and often that family member communicated the news to the rest of

the family. Fortunately in most of those cases, the individuals encountered support and compassion rather than stigma and discrimination. However, as a result of such situations, rejection might be highly likely as well.

The narratives show that in those examples where participants decided to disclose their status to their families, they first undertake a process of evaluation to decide which members of the family will be informed and which members will not. The decision depends on factors such as closeness and trusting relations with particular family members and considerations of the personality and characters of individuals in the family. In addition, participants tend to rely more on members of the nuclear family: parents and siblings, keeping their HIV status secret from other relatives. Frequently, instances of discrimination by family members occur with relatives who are not part of the nuclear family:

With my father's side of my family, my relationship has not been the same since I told them that I was HIV positive... I think that it's more of a problem that it is embarrassing for them when people know that someone in their family is HIV positive, and you know; there is still that stigma, and I know that they still genuinely love me, but at the same time it's difficult for me to accept that because if you love someone you should accept them fully you know? We don't see each other very often; you know? (40-49, Heterosexual female).

However, some of our participants also mention examples of rejection from the nuclear family members after the disclosure:

(I: With your brother here what was his reaction?) I think it was hard for them, for him and his family, because everything changes; one feels the big change, you understand? And that is the other thing that I see, he is a person who likes to study. He is also aware of many things, about the news. He is a boy who likes to know stuff and sometimes I see that he does not shake my hand and things like that. Then I feel very bad, you understand? Because I feel he is rejecting me and then I say this is a bit serious, what is happening because I feel that he is a person who knows, who has gone with me to the centers where they say, "Well, this is not transmitted this way, that is not like this or that." He has also received information that I received, and I feel that he has taken it to the other side (30-39, Heterosexual male).

One respondent speaks overtly of the AIDS related stigma inside the family group as a

result of the generalized association that exists between HIV infection and specific stigmatized social groups and behaviors considered being immoral:

My family knows it, yes. They do not take it well. I had to tell them once years ago over the phone, yes. Then they did not like it at all (I: What was their reaction?) Rejection I imagine. I mean, when you test positive that is something. I tell you in life there are stigmas, then they think that if you got that, it is because you are garbage because you were a slut, because you were, because of the promiscuity, for many reasons (50-59, gay male).

Even though the existence of stigma and discrimination in the family group is still real and hurtful, there are also many instances among our participants that show how family, and in particular some family members, give support, comfort and care during the hardest times. For many respondents, their families are a valuable source of strength which protects them against the stigma and discrimination encountered many times in the outside world:

My mother fortunately still is alive, and I talk to her very often. She is my major link with my city, with my family, with my roots, with everything. Yes, in fact, she is the one who helps me to bear it here. If I were not able to talk to her, I do not know; maybe I would have gone back, or something different would have happened with my life. I think that communication with her is always a psychological and emotional support that gives me strength to continue far away from where I am, and try to overcome depression and a thousand things... (40-49, gay male).

The first that I told was my brother. He passed away two years ago. I told him, "Look I tested positive." "What are we going to do? Who knows?" he told me. I remember that my brother told me that perhaps he would die before me, and look he died two years ago. My brother told my cousin and afterwards all my family knew, and I have not received a rejection at all from my family. Well one brother I do not know, but my family who are in [country of origin], my nephews, my brother who lives in [country of origin] told me, "Are you sick, do you feel bad? Come over here if you want to stay here." I felt that support from my family. That is the reason why I don't feel affected what other people say. If my family and my best friends are who support me, who are with me if I am good then, I do not care what other people say (40-49, gay male).

Support and care or overt rejection and stigma are not the only possible reactions from the family to an HIV positive diagnosis of one of their members. The analysis of the narratives also shows instances of silence and secrecy around issues of sexuality, sexual orientation and HIV status, even among the most supportive families. For gay men, the

silence around their serostatus is added to the frequently existing secrecy around their sexual orientation. Secrecy may be a new phase in the lives of heterosexual respondents. At the interior of the family group, HIV, sexual orientation and sexuality in general are still unspoken themes. Some of the participants have a clear perception of the sense of isolation that silence and secrecy in regards to HIV status and sexual orientation may create around their lives:

None of my siblings ask me if I am going out with somebody if I like someone, hardly, "How is your health?" When I spoke with the doctor, "What did the doctor say? How are you?" But none of them ask me if I am dating anyone if I have a boyfriend, or if I am with someone. We do not talk about that topic, however, with my sister in [country of origin] yes, she does not ask me, but yes when I call her over the phone, I tell her if I met someone, how I feel, with her I have that contact (I: Do you get together with your sister?) Yes, with the one living here, yes. She for instance, in spite of living here, deep inside does not accept my condition as a gay person. I remember she lived before, now she lives alone before she lived with a *roommate* and sometimes I used to go to visit her, and the *roommate* was not home, well and I commented and said to her, "You know? I met a boy, and we are going out," and she said, "Be quiet, do not speak so loud. Someone can hear." "But if your *roommate* is not home." I told her, "and well, how were you doing with this?" She tried changing the subject; then I noticed that she did not want to know ... Sometimes I want to talk with somebody, especially with someone close to me, right? Talk a little bit, I mean I don't know, "I met someone. I feel this," maybe to receive advice, like having someone who listens to you, someone to share these experiences. Then I opted for not talking any more about this. When I talk to her or when I visit her, we talk of other things and do not talk about that... (30-39, gay male).

Often there is a tacit understanding of an individual's homosexuality, and HIV positive status as well, without an open discussion of the matter with family members, avoiding the possibility of breaching esteemed family bonds. This way, in the family, there is a tacit agreement not to talk about questions of sexuality in general and homosexuality in particular (Decena, 2011). However, this secrecy might take a toll on individuals' wellbeing. For instance, Díaz (1998) believes that, among Latino gay men, sexual self-regulation is jeopardized by complex sociocultural factors, sexual silence and family loyalty being among them. For people living with HIV/AIDS, secrecy in the family around seropositivity may generate in the HIV positive person a sense of isolation and

being 'incomplete' (Martinez, Lemos and Hosek, 2012).

Friends

Adam and Sears (1996) found that friendships carried an emotional depth related to support, trust and intimacy. Similarly, participants in this study comment that friends form part of valuable social networks. For many respondents, even having relatives in Canada, friends become a second family.

We say that she [my best friend] is our big sister, now with my ex we are like brothers. We are always together, giving support to each other, also with her. The three of us are always together if something happens to me. We are always together. I have never missed support [from] the friends that I love that I am fond (40-49, gay male).

Participants who have been in Canada for longer periods of time have a group of friends that extends beyond language and culture. Many of them comment that racial or cultural background is not determining their friendships any more. Those with less time since arrival, and perhaps less fluent in English, tend to befriend other individuals from the Latino community, especially people from the same country of origin.

For some of the participants, it has been easier to open up their serostatus to friends than to family members. However, the opposite is also true; many individuals decide never to disclose to friends or to very few, but did so to close family members.

Participants share examples of support and understanding when disclosing serostatus to friends.

The first time that I disclosed to my best female friend, I told her before my ex-partner, and she came running to my apartment because, we lived in Montreal then, she came and said, "But are you okay?" and started to cry a bit. Afterwards, she started to study more, to know what HIV is, she and her partner, because she is lesbian. She and her partner have studied a lot about what it is, have studied contemporary medicine. I have explained more to her. They are well educated about HIV. At this moment she says to me, "Buy this, look there is a new medicine" (40-49, gay male).

Even though stigma and discrimination seem to be less frequent among friends, still some

of the participants have experienced rejection in these relationships, “My friend... he knows it [serostatus], and I feel that he needs more education about this... I feel, like rejection from him. He has two daughters, and it is as if he were afraid.” (20-29, heterosexual female).

Some of the respondents point out that it is not exactly stigma and discrimination what they found after disclosing their serostatus but they find feelings of pity permeate their relationships with friends and family:

Regarding my friends and the people that I know, it is a feeling of pity, as a result of the lack of information that they can have, thinking that [HIV] is like cancer, that it is the end of your life and that you can die. Then they always see you as a sick person. (I: Why do you say a feeling of pity? Do you feel they treat you in that way?) Yes, of course you pick it up in the treatment they give you, in the attention they give you, in the “you must take care of yourself,” in the... well one must take care, but you feel it (40-49, gay male).

Examples of stigma and discrimination among family and friends may be just a reflection of the stigma and discrimination that exist in the Latino community and the society as a whole. The Latino community in Toronto is a space where aspects of stigma and discrimination are reinforced and challenged. Participants in this study say the Latino community as highly stigmatizing of HIV positive individuals. Some feel that, in the community, HIV related stigma and discrimination are still extremely damaging:

[Stigma] exists, of course it does exist, but interestingly I as Latino, I run away from the same Latin people, from those people I run away. Look I do not feel hurt being told, “He has this or that.” What is hurtful is why don't they say it to me face to face? The same way that they say about me that I am out. But in the case of a Mexican, a Peruvian or any other nationality who is newly arrived and is diagnosed over here, *okay?* or is living here already and is diagnosed with HIV, if you do not have security in your life and your own HIV situation, it is traumatizing, because people are going to point out, going to speak badly about you. They can do it, not everybody, but that is real. That happens. That is real. I have seen it; I have heard it. Everything is registered on *profile*. There is proof that that happens in our communities. I am not saying that just in the Latino community, but there is discrimination, there is *labelling*, in the community in general, still, and the work that has to be done is immense (50-59, gay male).

Participants explain stigma in the Latino community as a result of the lack of information

and education in regards to HIV/AIDS, which is closely related to silence and secrecy that still exist around the discussion of sexuality in general. Some of the respondents made a direct link between the lack of information and education in sexuality and HIV/AIDS in the Latino community and the existence of myths and fear around HIV/AIDS, which consequently lead to stigma and discrimination against Latino PHAs.

I never feel discrimination. I mean; I have felt it more with Latinos so far, with Hispanics really because you go and take a glass and they say, "Hey he is going to pass AIDS onto me," and that bothers me... with people that sometimes are not even friends, people that you just met and they express it that way. Maybe it is the lack of communication or education that Hispanics have about what HIV and AIDS are (40-49, gay male).

For others, stigma and discrimination are direct consequences of silence and secrecy that result, among other reasons, from the profoundly religious character of the community, which impedes discussion and education in regards to sexuality and HIV/AIDS, putting individuals at risk. One of the participants comments:

We were also Christian. We were, you know, very religious. I was in denial about the fact that I was at risk, and the reality was since I grew up in a Catholic school, I did not have much education in regards to how HIV actually is transmitted. There was a lot of homophobia in my church. My church is my Catholic upbringing, in regards to, you know, that HIV and AIDS only happen to gay men (40-49, heterosexual female).

Aiming to counterbalance feelings of stigma, discrimination, rejection and pity, participants speak of having the chance, and to some extent feeling responsible for educating family, friends, and other persons around them, about what it is like to live with HIV:

You feel that they do not have the necessary information that you yourself have to inform them that it is not the end of the world, that you can live many years with HIV if you take your antiretrovirals; you can be healthy eating properly... If you know you are the one who has to break that barrier and let them know that if you are a person living with HIV, you are a person who can socialize, with some limitations (40-49, gay male).

Compartmentalization of social networks is another strategy that some of the participants comment on to avoid stigma and rejection from friends and family. In those cases,

individuals have various circles of friends and acquaintances, heterosexual, gay, and people living with HIV, and they socialize with these different groups according to the circumstances of their lives, not bringing together friends from different social circles. In the same way, the sharing of personal information and disclosure of the HIV status will be discretionary among the various networks.

Other individuals adopt a relatively opposite strategy to the latter; they incorporate HIV positive status as one more aspect of their lives, and without being fully public about it, they consider HIV infection as something normal, that can happen to anybody and they are willing to disclose if the occasion comes up.

Other coping strategies can also alleviate HIV/AIDS related stigma and discrimination in individuals' personal relationships, but they will have a more direct effect on individuals' own perception of the experience of living with HIV/AIDS, and their mental health, such as considering that living with HIV is less damaging than other chronic diseases, forgetting their serostatus during everyday life, religiosity and nurturing a spiritual life. One coping strategy that is especially intriguing is when individuals consider the experience of living with HIV as positive. One participant comments that he is a better human being thanks to HIV.

I want to say that HIV changed my life for the better because if I had not been diagnosed as HIV [positive] I would not be who I am today. I would not have the necessity of living and doing a lot. I would have stayed with the same life style, and well sometimes it hurts that HIV changed my life positively. I do not know, sometimes I think it is something bad for something good, but for me HIV was an energy that has impelled me ... (40-49, gay male).

As strange as this may seem, other studies with people living with HIV/AIDS have found that HIV is a catalyst for personal growth (Schwartzberg, 1993) or that HIV infection plays a redemptive role (Adam and Sears, 1996). This form of thinking shows a

significant attempt to come to terms with an HIV diagnosis and give meaning to the personal biography.

Couples

Adam and Sears (1996) state that a serious disease such as HIV can stress the strongest of existing personal relationships and cast doubt on the possibility of new ones. In addition, the nature of HIV imposes new difficulties on intimate relationships, striking directly at sexual expression as the seropositive person may be deemed a potential threat to his or her partner.

In our sample, half of the participants were in a couple relationship when they were diagnosed. As found in other studies (Adam and Sears, 1996; Wolcott et. al., 1986) participants speak of a high level of support from their partners at the time of being diagnosed.

My partner came with me when I went to pick up the results... We kind of knew already, due to how I was feeling. I felt very weak; I did not eat... The first that he said was, "No worries, I'll be with you, by your side. This is nothing." He never changed about that never, not even in sex. We have protection not because he wants it, but I want it. He is not HIV; he is not. I do not want to pass it to him even though he says that he does not care: if we have to die together, we die together... He is the one who reminds me about pills... You will not believe it, but after we knew everything changed, was different. We were closer, more intimate (40-49, heterosexual transwoman).

However among some couples, more in straight than in gay couples, the diagnosis made infidelity issues evident and difficult to overcome, especially in those cases where one individual's infidelity resulted in the HIV infection of the other partner in the relationship. In the case of women in heterosexual relationships, their diagnosis was especially unexpected and shocking because HIV was not part of their lives at all, being wives in "monogamous" relationships. "One never thinks that it is going to happen to you, and let alone if you are a housewife, have your husband and children. It is like an illusion. It may

be said, what is that?" (30-39, heterosexual female).

At the time of the interview, slightly more than half of the participants were not in a couple relationship, six of them were, three had multiple relationships or a sexual partner not considered as a formal couple, and three maintained long distance relationships with their partners living outside of Canada.

Some of the participants speak of their experiences being in serodiscordant couples with either primary partners or casual/open relationships. In all cases, they have encountered support in these relationships. Most of the respondents comment that the real issue is in starting new relations they have to disclose their serostatus. It is in this situation that most of the participants have been rejected by potential sexual and romantic partners. Respondents' narratives show that there still exists fear of being in a relationship with HIV positive individuals due to the risk of infection. Instances of violent and open rejection are uncommon, but more polite forms of rejection prevail. However, as polite as it may be, the respondents still perceive that potential relationships do not go further after disclosing. In the context of establishing new sexual and romantic relations, rejection is similar for straight and gay individuals:

That [the disclosure] brings problems because I want to live a life in partnership. When I comment to the person whom I want to live with, that I am HIV positive, unfortunately for me, maybe other persons do not have the same experience, but my very personal experience is that people get scared. If the person is not positive, he tells me, no, that they can get infected that the condom can break and show panic. They can get scared, and we end the relationship... *so* yes it has affected me, several times has affected me and affects, the fact of telling a person affects me (40-49, gay male).

I went to a dance party for singles and there I met a Canadian. She was short. The next day, she came to my apartment to have sex and we had it with a condom two or three weeks, and afterwards she did not want a condom anymore and then it was then I had to tell her that I had HIV, and everything screwed up. We had sex two or three more times, and it stopped because of that. (I: You think it was for that?) Oh, of course! Yes, absolutely yes! (50-59, heterosexual male).

Adam and Sears (1996) found that the quandaries related to HIV infection and sexual life

seems to cancel out the chances for intimacy in the future. Many individuals recently diagnosed might even consider that their sexual life has finished. In fact, it is not an uncommon experience that after diagnosis, participants no longer had a formal couple relationship. Some of them, after testing positive ten or more years ago, never established a formal couple relationship again. For many, rejection and fear of stigma and discrimination are key barriers to forming new relationships. Some of them confess to having never disclosed their status precisely for fear of rejection.

Being HIV positive has affected me when, for instance, I want to have a relation with someone, and it turns out that the person is negative. I am afraid of rejection. That is one of the things that scares me the most. Then, I prefer to break up with that person, before a relationship starts, instead of being rejected. That is the reason that I haven't had a partner here because the persons who have been interested in me have been negative and I have not had the courage to tell them that I am positive... I prefer to say goodbye, before being told because it would hit me hard to be let down (40-49, gay male).

Other participants also express a real concern for confidentiality, having to disclose to individuals they hardly know. There is a concern that if the relationship does not work out, in the future the other person could disclose the HIV positive person's status to someone else.

While some participants have decided never to disclose their HIV status as a strategy to deal with rejection and stigma, others opt for openly disclosing when the relationship is just starting. This is a strategy to avoid future misunderstandings, deception and rejection with new partners in the case of the relationship progressing without disclosing:

I do not want to fall down from the second floor; it is better bringing it up from the beginning. I do not want to have false illusions about something that maybe never is going to happen (I: From the beginning you disclose your status) Yes if there is mutual interest, yes. What would be the reason to waste time in a relation with someone who is not going to accept me? I am not 20 years old to be wasting a year dating or anything like that, not at all, or wearing out my feelings and getting sick for nothing. There is no point (40-49, gay male).

Adam and Sears (1996) found among their respondents that those starting new relationships and willing to disclose, follow the same strategy of disclosing as soon as they can; many even disclose during the first date. It is also worth noting that they found that every person who has ever disclosed his/her serostatus to individuals recently met has stories of acceptance to tell. This is in accordance with the idea that disclosure might increase support at the practical and emotional level, create the idea of shared responsibility during the sexual encounter, and boost a feeling of self-acceptance (Vedhara et al., 1998).

Other participants consider as a possible option dating another individual living with HIV. This strategy apparently overcomes two principal difficulties during the establishment of a new relationship: one is the potential risk of HIV transmission to someone else, and the second is the issue of disclosing the serostatus and having to deal with stigma and discrimination (Adam and Sears, 1996). In our sample, only three participants are currently in a relationship with other individuals living with HIV, although other participants had been in seroconcordant relationships before or have considered it as an option. Among the participants in seroconcordant couples, serostatus was a determining factor to consider in entering into the relationship:

It was very strange because it all started the same night we met. We were sitting, talking, he told me that he did... volunteer work at an organization for people living with HIV. Then I asked him what he thought about people living with HIV. Then I saw that he was tense. He did not know what to say, and to ease the moment, because I saw that he was nervous, I saw that something was going on, I told him, "because I am!" (I: You said it?) Yeah, and when he heard that, he started to cry, and told me, "Me too", uif jay no! From there on I knew I wanted to be with him. That was like one more point, in that moment I knew that I wanted to be with him. [We had] something else in common (40-49, gay male).

Some of the interviewees, even though not in a formal relationship with another individual living with HIV, maintain sexual relations, often without using condoms, with

other HIV positive individuals. Commonly in those cases there is a previous discussion of the reasons for the use or not of condoms and the establishment of certain rules to decrease risks, such as not ejaculating inside of each other. There is a perception that being both HIV positive individuals, it is possible to have sex with no condoms, but also there is awareness that this implies a certain risk of contracting other STIs and even re-infection¹⁷.

Casual and unprotected sex

Many participants comment that casual or anonymous sex is another option to satisfy sexual needs when there is no stable partner or partners. One of the aspects that first draws attention in regards to casual sex is that there is a generalized perception that in spaces where this kind of sexual activity occurs, such as bathhouses and adult cinemas, there is little chance to establish any other kind of interaction among the individuals other than sexual. Many participants comment that in these spaces there is no real possibility to discuss sexual matters and even less chance to disclose an HIV positive status.

The perception of venues where casual sex occurs as places where there is no verbal communication, and therefore, no need of disclosing serostatus has also been reported in other studies (Ontario Advisory Committee on HIV/AIDS, 2003; Adam, Husbands, Murray and Maxwell, 2008). For many, this is a solution to obtaining sex without the stress of having to communicate their serostatus. However, for others the

¹⁷ Re-infection refers to the likelihood of being infected with a virus that the individual has contracted before. In the majority of viral infections, this does not happen because the immune system generates immunity against a virus, once the former has been in contact with the latter. HIV re-infection is an issue frequently debated. One position in the debate, which includes some physicians, sustains that HIV re-infection does not occur frequently. Based on such a position, some HIV positive individuals consider that unprotected sex or sharing needles with other HIV positive person do not imply risks. However, virologists think that re-infection is not as uncommon as believed. What they do not have clear are the clinical consequences for an individual of being re-infected with HIV. In fact, the results of a re-infection with HIV may be variable among individuals (Project Inform, 2004).

lack of opportunity to make a connection with another person beyond the sexual interaction is frustrating, leaving them with feelings of emptiness.

I think it is funny because I say that when one goes to those *bathhouses* or when you find someone, that person many times is under the influence of drugs. Well no reason to talk, but if you open your mouth and say that your name is X, the moment is spoiled. It is like, do not even open your mouth, it is just sex, nobody even asks your name, nor where you live, nor what you are doing. Let's have sex, and that's it. Then it is a bit frustrating, when one finishes that physiological need, one is empty from a spiritual point of view. It did not satisfy you at all; there was nothing. One gets used to it. I am used to it, but when you see it, I mean, one analyzes and says, it is sad, it is sad because people are cold, very cold (50-59, gay male).

This way, the casual sex experience produces contradictory emotions: for some of the participants, it offers the possibility of having sex without the stress of disclosing the HIV status, but on the other hand, it may leave the person with deeper feelings of isolation and loneliness.

Many of the participants in casual sex, even though not disclosing their serostatus, maintain protected sex feeling responsible for not transmitting HIV infection to others, in addition to having concerns of catching other sexual transmitted infections. This is consistent with findings from other studies (Myers and Allman, 2004; Adam et al., 2008):

If it is casual [sex] if I am going to have sex, because I am a person who is [sexually] active, I go to clubs. We are human beings; I simply have protected sex, with a condom. I am not used to having unprotected relations because of my health and to not infect anyone. I do not think it is fair, and I do not disclose. I simply protect myself, because it seems, and I do it this way for privacy, intimacy, because not all people in this society... they can react in some way and can comment on it, can tell people or institutions that I do not wish to let know (40-49, gay male).

On the other hand, among the respondents there are some who do not feel responsible for other individuals during sexual interaction in spaces of casual and anonymous sex. If the person does not ask for the use of a condom, they will not bring the topic up, or disclose their status. Feelings of social isolation and rejection make the chance of disclosing unlikely. In addition, non-disclosure is backed up by the idea that, in spaces of casual sex,

individuals must be well informed, and each one is responsible for protecting himself.

One participant comments,

If I like the person, I have [sexual] relations and I do not say anything, and I take for granted that the person is an adult and knows the risks, and I know the risks too, that is the reality. If the person pulls out a condom, perfect. If the person doesn't, it will be for some reason. But I think that the responsibility is shared. I am not forcing him. The person is not asking me and I am not telling either because, in a situation like that, it is a lie that a person is going to say, "Listen, I am [HIV] positive!" because if you are alone in this country, if you are depressed, are sad, you are not going to the street to be rejected, and a confession of that kind, regularly, would make that you feel worse instead of better. So, I take for granted that a person who does it without a condom is a person who is an adult and assumes his risks, and that, I particularly think that can be positive as well. I assume my own risk too, because who can tell me if that person besides being HIV positive, has hepatitis or has any other health problem and can pass it to me? Then, I think it is a mutual responsibility (40-49, gay male).

In a study with HIV positive men who practice barebacking, Adam (2005) encountered strong similarities with this rationality of maintaining unprotected sex with partners of unknown serostatus:

For the subset of men who have left safe sex behind, "raw" or bareback sex is justifiable through rhetoric of individualism, personal responsibility, consenting adults, and contractual interaction. Used to being part of networks of men who are already HIV positive, those who employ the language of barebacking typically presume that prospective partners will be "in the know", that is, they will be fully knowledgeable about HIV risk; they will be adult men capable of making informed choices and consenting after having weighed all relevant risks, and often enough they will be HIV positive themselves. Few, if any, actually insist on unprotected sex; they are nearly always willing to respect partners who prefer to use protection. But if a condom is not produced by a new partner, there is a ready-made explanation applied to the sexual interaction that allows unsafe sex to occur. (Adam, 2005: 339).

This way, there is the assumption, which is along the line of a neoliberal mindset that individuals bear whole responsibility for caring and protecting their own bodies, without obligation for the wellbeing of the collectivity or other individuals (Reback et al., 2004).

As demonstrated in other studies, interviews with HIV positive men who do not follow the practice of safe sex regularly show "how attuned their moral reasoning is with the neoliberal model of human subjectivity that constructs everyone as a self-interested individual who must take responsibility for himself in a market of risks" (Adam, 2006a:

175-176). However, this reasoning does not consider a series of factors that predict lapses in safer sex, such as erectile issues experienced with condoms, momentary lapses and trade-offs, personal turmoil and depression, health of the moment, or unreliable strategies of disclosure and intuiting safety (Adam, Husbands, Murray and Maxwell, 2005).

Most of the participants think that if, during a sexual encounter with a person of unknown HIV status, the person does not ask for the use of condoms and is willing to have unprotected sex, the reason is that the individual must be HIV positive him/herself:

(I: Imagine that you meet someone or as you say you are in a relationship, you meet a guy and have a sexual relation, and that person wants to have sex with no protection, what would you think of that person?) That he has it [HIV infection]... because it is the only answer because he does not care if he gets it, because he has it, you understand? I worked as a prostitute for years, and the client who comes to you and says, "No, I do not want condom, I'll give you more money," for sure that person is infected, for sure, because a person who is not infected, who thinks he is not infected, wants protection, even two, "Put two condoms on me." The person who says to me, "ay no, do not pay attention," the person who says that he does not care, has it for sure, for sure (40-49, heterosexual transwoman).

There is a good deal of research that has found the assumption among HIV positive gay men that if another male is willing to have unprotected sex in anonymous settings is because he is HIV positive as well (Ontario Advisory Committee on HIV/AIDS, 2003; Fontdevila, 2009). The response to a request for unprotected sex varies among the participants. Some comment that they would ask the individual his/her HIV status in response to such request or will disclose themselves. Others affirm that they would not have unprotected sex because of the already mentioned concern of contracting other STIs. Another set of participants would be willing to have unprotected sex in such situations.

The analysis of the narratives also shows that there is a relationship between the use of drugs and alcohol and unprotected sex, even among those respondents who usually

maintain protected sexual relations. Many comment that if drugs and/or alcohol are added to the heat of the moment, the chances of unprotected sex are higher. One participant points out the fact that seroconversion occurs in many cases when individuals are under the influence of drugs or alcohol. He remembers:

In a workshop of Latinos Positivos, I remember that I asked, “How many here dare to tell me, in this circle if you have confidence in answer the question, of having acquired HIV for sexual reasons?” Afterwards, I asked how many were under the influence of alcohol or something when that happened, and there was only one person who did not raise his hand ... (40-49, two spirit male).

In our sample, two individuals had addiction issues at some point in their lives. They used drugs frequently during a considerable time. Both individuals affirm that it is likely that they acquired HIV infection having sex under the influence of drugs. One person comments that for her it is difficult to know exactly what happened when she was under the influence of drugs, but she thinks that it is in one of those moments when she was infected:

Sometimes I used so many drugs that you lose your senses, you understand? Even today I do not remember what I did. People come to me and say, “hey!” my name and all that I did, but, in fact, I do not remember, because it is the effect of the drug. You do stuff when you are not you... If it was in one of those moments, you never know (I: Then, according to what you are saying, maybe you were under the influence of drugs and you had unprotected sex?) I think that was what happened. Who knows, because *crack* puts you very *down*, you understand? Your system, you do not eat well, you use drugs, in the street, living in the street and I imagine that I got someone who had it, who did not say anything. My defenses were so low. The pipe came, the kiss, sex, the saliva, you never know if your mouth is broken as well and you use the same pipe, you understand? One never knows. I will never know... that is the truth. Because what I remember is that I protected myself, but the things I do not remember, I do not know what happened ... (40-49, heterosexual transwoman).

Adam (2006b) states that there is strong research evidence that shows the relationship between substance use and unprotected sex. However, this relationship is not easy to understand. In a significant qualitative study of drug use in Toronto, Myers et al. (2004) conclude that the effects of substances varied not only by the substance used or the

expectations of the person who uses them. Drugs' effects are also linked to the context in which they are used. Risky sexual practices do not result just from exposure to drugs and alcohol before or during sexual encounters. Other factors involved in the context of substance use and unprotected sex are individuals' personal convictions, and decision-making processes that occur during the sexual act.

HIV and Criminal law

In Canada, there is a legal duty to disclose an HIV positive status to another person or persons before engaging in behaviors that pose a “significant risk” of HIV transmission¹⁸. PHAs have been convicted of serious criminal offenses, including aggravated sexual assault, and even have been sent to jail for considerable periods of time for not disclosing their serostatus (HIV and AIDS Legal Clinic Ontario, 2012). The current application of the criminal law in relation to HIV non-disclosure is a pressing issue facing people living with HIV in Canada. In fact, Ontario is the province with the highest number of HIV-related prosecutions in the country. At the worldwide level, Ontario is also one of the leading jurisdictions regarding the prosecution of HIV non-disclosure (HIV and AIDS Legal Clinic Ontario, 2012).

The majority of the participants in this study regardless of gender and sexual orientation are well aware that Canadian law regulates and shapes the sexual lives of people living with HIV/AIDS. Many of them comment that awareness of the legal issue that represents non-disclosure to sexual partners is one more stress in their already

¹⁸ The Canadian HIV/AIDS Legal Network (2011) states that courts in Canada are reluctant to define clearly what a “significant risk” of HIV transmission in the legal context means. In particular cases, legal courts base their definition of “significant risk” on scientific and medical evidence of risk of transmission in relation to the sexual practices of the individuals involved, the PHA's viral load, and the use of condoms during the sexual act, among other factors.

stressful lives. In fact, in the criminalization of HIV study conducted recently in Ontario, it was found that the extensive media attention that court cases receive has influenced the general public, risk populations and people living with HIV, giving place to heightened anxiety and vulnerability, especially among women, immigrants and black men (Adam et al., 2012).

Among respondents there exists the clear perception that if they do not disclose their serostatus to sexual partners previously to participate in sexual activity they are breaching the law, and later they could be involved in legal troubles. On the other hand, they are aware, and many have experienced, that disclosure of an HIV positive status may bring rejection from sexual partners. Therefore, many of the individuals feel caught in a dilemma between disclosing and being rejected, or not disclosing and facing the chances of legal consequences. Frequently, the result of such a quandary is the restriction of sexual relations and thus the limitation of sexual life:

One can be with somebody; one likes another person, and can be with the other gay person, but one has the obligation of disclosing and one cannot tell him, because if you disclose to him you can be rejected and if you do not disclose you can get into legal trouble. Then you better avoid those situations and the possibilities of having relations with another person are less (20-29, gay male).

Definitely if, I am not in a relationship, it is very hard for me to be having sex because I don't really want to have sex with someone if they don't know that I am HIV positive, because it's too much stress, because of the law and because of the fear of being rejected. So unless, I'm in a relationship that's the only time that I actually have sex (40-49, heterosexual female).

In fact, some of the interviewees who lived with HIV in the country of origin consider their sexual life was better there because they did not have the pressure of choosing between disclosing their HIV positive status and being rejected or not disclosing and having the chance of facing legal consequences.

It is necessary to acknowledge that criminalization is not the answer to stop HIV

transmission because the enforcement of criminal law generates a context of mistrust where is unlikely people's engagement in more effective practices. Laws, through the reinforcement of HIV stigma, can produce the alienation of individuals who are key for the success of prevention practices (Galletly and Pinkerton, 2006). Besides, disclosure is not always the solution to HIV transmission, nor it guarantees the enhancement of safer activities. It must be understood that due to the context of stigma and discrimination, disclosing an HIV positive status may generate not only benefits, but also significant risks for PHAs (Adam et al., 2012).

Migration and changes in sexual identities

When participants are asked whether migrating to Canada influenced their sexuality and what the greatest changes are in their sexual lives brought by relocation, some gay and bisexual individuals experienced significant changes in how they identify themselves and think about their sexuality. Research with Mexican immigrant gay and bisexual men has found that, after migration, immigrants' sexual ideas and practices are re-evaluated as they immerse in new social spaces charged with different sexual behaviors and understandings. They come into contact with unknown networks and cultures that generate the 're-territorialization' of their former sexual desires (Parker, 1994; Herdt, 1997; Laumann et al., 2004; Jacquemet, 2005; Fontdevila, 2009).

In the case of individuals coming from countries where a Western gay identity was not well established at the time of migration, coming to Canada meant 'discovering' a new gay identity, with new possibilities of sexual expression and new ways of relating to other men, which were not fully experienced before migration in the country of origin.

The new freedom to experience same sex desire implied for some of the

participants the possibility of identifying themselves as gay men, a possibility that was not available back home due to the strong influence of their family of origin, religion and in general, the repressive social conditions at the time.

For me, the big change was to accept that I could live with another man. I never thought that. For me that did not exist. For me, it was like the ignorance that exists in Latin America that the homosexual is only about sex. Gay people are only sex. I found you today; we did everything, and I do not want to see you anymore. For me, the change was that I can have a relationship with other man, I can live with other man, I can love a person of my same sex, things that I did not think about before... Sometimes I met someone and I was attracted to him very much and I said, "No, this cannot be." That even happened to me during my first year here. After the first year, I really started to go out to dance clubs. I looked at two guys dancing and holding hands, and I was, "No it cannot be!" I felt weird; I needed five beers to be able to talk to somebody... I had never seen that before. For me, it was a total change, was a sexual change really because I started to see a man as a relationship, as a partner, not only as sex. It was not just sex anymore, but share, wake up, talk, a relationship, for me was totally a change... (40-49, gay male).

Even for many of the respondents who had an established gay life in their countries of birth, coming to Canada meant more independence and openness in regards to their sexuality. This freedom and independence also brought more satisfaction and possibilities of control over their own sexual life.

However, for some individuals coming to Canada was paired with a perception of being at odds with sexual practices and identities that were not as generalized in the country of origin as in the Canadian gay scene, such as the idea of open relationships and the practice of group sex.

In the same way, some participants think that finding a stable and formal relationship in Canada is more difficult than in the country of origin. They explain this difficulty as a result of cultural mismatch. Back home it was easier to understand the other because of the common culture, whereas in Canada, with individuals coming from all over the world, it is complicated to make fully sense of someone else's beliefs, values and behaviors. One interviewee believes that as part of the cultural differences, there is a

lack of interest in committed couple relationships among individuals participating in the gay scene in Canada. He perceives that there is a generalized over-interest in sex accompanied with a lack of serious interest in a long term relationship, something paradoxical if we consider the prominence of gay marriage in the country:

I notice that here people do not want to get involved in emotional relationships. I mean, for instance they just want a little friend (I: They do not want commitment?) A committed relationship, but just a little friend and another thing, the guys over here, if they have a partner, they are looking for a third person to get laid, like the relationship does not have much of a formal couple... Here the people are like very open... It might be [that] the culture is very different over here (30-39, gay male).

For other participants, it is not migration to Canada what brought substantial changes to their sexuality, but other crucial factors such as the process of aging and testing HIV positive.

Participants find that the process of aging comes paired with more experience and understanding of their own sexual and emotional needs and their likes and dislikes in regards to sex and relations, so being more experienced is linked to more satisfactory and fulfilling sexual relationships. On the other hand, some said that aging can also bring a decrease in sexual desire and emotional issues which affect sexual appetite and performance. For some individuals aging has also meant a shift in priorities regarding sex and partners: while sex is still a prominent part of the couple's life, trust, sharing and support have taken first place on the list of priorities. "As I told you, sex for me has changed already. For me, sex was primordial before. I was, I cannot say addicted, but sex has already passed to a second stage. The first for me now is comprehension, trust and sharing" (40-49, gay male). The change of priorities is not only due to age, but in many cases, changes are compounded by living with HIV.

Final comments

The social construction of HIV as a condition strongly associated with stigmatized behaviors, such as drug use and homosexuality, affects the personal relationships of Latinos and Latinas living with HIV. The narratives presented in this chapter show the rejection that still exists among family, friends and couples of HIV positive individuals. For homosexual participants, HIV infection has been one more layer of stigma added on to an already stigmatized identity, while for heterosexual interviewees the experience of stigma is something new in their lives.

The circulation of more accepting and redemptive discourses around living with HIV, in addition to the shift that HIV infection has had from deadly disease to chronic condition, have lessened the level of rejection experienced by HIV positive subjects at the beginning of the epidemic. Thus, even though there still exist numerous instances of rejection and stigma among family and friends, it is fair to say that discrimination in these social circles is not as acute as it was in the early years of the AIDS epidemic. For instance, Weitz (1990) describes how in the mid-eighties PHAs were isolated, evicted from their homes, quarantined and ostracized by family and friends, although even at that time, she encountered heartening examples of caring and support.

Stigma and discrimination are a more immediate issue in romantic and sexual relationships than with family and friends. Practically all the participants, regardless of sexual orientation or gender, can recount experiences of rejection when trying to establish sexual and romantic relationships. This speaks of the highly stigmatizing traits of an HIV positive status. It is beneficial to remember that according to intersectionality, strongly stigmatized aspects of one's identity may cancel out the privileges associated with the

person's more valued statuses. Therefore in couple relationships, HIV positive heterosexual individuals are subjected to HIV stigma much alike homosexual people, regardless of heterosexual privilege.

Díaz (2007) reports the impact of stigma on HIV positive men, who feel that HIV had made it more difficult for them to find sex, lover relationships and enjoy sex. Stigma can have a strong negative impact on the mental health and well-being of HIV positive men, leading to social isolation, low self-esteem, and psychological symptoms. For Latino gay men, “HIV functions as another oppressor, adding a fourth layer of negative influence to men already oppressed by poverty, racism, and homophobia” (Díaz, 2007: 64). Similarly, in Toronto, Latino and Latina PHAs, at least a segment of this group are located on a marginal position of the social scale, unemployed, living on disability with a low income and confronting multiple forms of stigma.

Our respondents mention as strategies to counterbalance HIV/AIDS related stigma and discrimination disclosing their serostatus from the beginning of a potential relationship, pursuing sexual and romantic relationships mainly with other HIV positive individuals, or even never disclosing serostatus, principally during casual sex. However, not disclosing an HIV positive status to sexual partners before engaging in sex may have legal consequences and participants in this study are aware of this fact. The awareness of the potential criminalization of engaging in sex without disclosing further isolates HIV positive individuals, generating more anxiety and vulnerability during their daily lives (Adam et al., 2012).

In situations of casual sex, most of the respondents comment on being committed to the maintenance of protected sex, although there are few of them who engage on

unprotected sex without disclosing their serostatus and without knowing the partner's serostatus. A discourse of personal responsibility and consensual sex between rational and fully knowledgeable adults is used as a justification for unprotected sex without discussion of serostatus, evidencing what Adam (2005) calls a neoliberal sexual actor, governed by the ideology that everyone is responsible for him- or herself in a marketplace of risks.

Also, there exists a generalized assumption that individuals who consent to having unprotected sex with another person who is barely known must be HIV positive themselves. This assumption is widespread among our participants, even among those who affirm having only protected sex. Therefore, it is vital to consider the implications of this assumption for HIV prevention and poz prevention programs.

Participants' narratives also show the decisive influence of migration on their sexual lives, principally for interviewees with emotional and same sex interests. Changes have been more significant for those individuals who migrated to Canada at a moment when stigma, discrimination and abuse related to sexual orientation in their countries of origin were even more severe than nowadays. For many of the interviewees, arriving in Canada meant coming into contact with a Western construction of gay identity. Such contact shifted participants' previous conceptualizations of same sex relationships. In many aspects, this has brought new possibilities of expression, freedom and ways of relating to other men. On the other hand, individuals also were often at odds with ideologies and practices related with the westernized gay identity. The intersection of a racialized identity and an immigrant status may locate them in a marginal position at the mainstream gay community. Feelings of being marginal may not be uncommon either,

principally when subtle and overt forms of racism are present in such community (Lee and Brotman, 2011).

CONCLUSIONS

In this study, I document and analyze the migratory stories, the barriers in access to health care and employment, and relationships with family, friends and couples of Latinos and Latinas living with HIV in Toronto, paying attention to the strategies that the group has developed to cope with discrimination and the strengths related to living with HIV/AIDS. The general purpose of the analysis has been to visualize and understand processes of discrimination and marginalization that this group of immigrants and refugees encounter in Canadian society. Similarly, with the analysis of participants' experiences, I have tried to understand better the relationship among the condition of living with HIV/AIDS, migration and sexuality, their multiple connections and the mutual influence that they exert on each other.

The use of intersectionality as a conceptual framework has allowed a better understanding of how multiple dimensions of identity – gender, sexual orientation, immigration status and nationality, among others – intersect with an HIV positive status in multiple ways, significantly shaping the migratory experiences, the access to social services and the personal relationships of Latinos and Latinas living with HIV. Intersecting dimensions of race, gender, immigrant status and sexual orientation locate our participants in marginalized social positions in Canada.

The study also shows that in spite of greater acceptance of HIV positive individuals in Toronto, HIV infection still is a highly stigmatized condition. The social discourse that considers HIV as a disease associated with immoral groups and behaviors, such as homosexuality, drug use and prostitution is quite present, making HIV related stigma insidious and pervasive. HIV/AIDS related stigma and discrimination as

encountered in numerous studies (CAAT, (2001, 2008; Zuñiga, Brennan, Scolari and Strathdee, 2008; Pivnick, Jacobson, Blank and Villegas, 2010) are still significant barriers in access to health care, employment and other services. PHAs' relationships with relatives, friends and partners may be marked by the presence of stigma as well, exerting a negative impact on their mental health and overall well-being.

Stigma reinforces existing class, racial, gender and sexuality based inequalities. It creates and reinforces the exclusion of individuals and groups through the marking of significant differences among individuals. In this way, stigma plays a crucial role in the production and reproduction of relations of power and control in society (Parker and Aggleton, 2003). Therefore, for participants in this study, HIV related stigma reinforces their already marginalized position in the Canadian context, and further separates them from a socially constructed image of the healthy citizen.

Participants' migratory stories show that often the intersection of economic position and sexual orientation strongly influences the decision to migrate. Even though economic reasons are a strong motivation to leave the country of origin, relocation is more likely when economic hardship intersects with other aspects of people's lives, such as a stigmatized sexual orientation.

Often sexual orientation is per se a strong motivation to migrate. For some of the participants, fleeing homophobia and violent repression has meant risking financial stability and social position back home and starting again in an unknown society. This way, migration must be understood as a complex phenomenon, with multiple and intersecting motivations, with structural forces in sending and receiving nations and personal aspirations influencing and shaping the process.

During settlement in Canada, Latinos and Latinas living with HIV, as many other immigrant and refugee communities, deal with a series of barriers in access to social services that make the process of adjustment to the new society more difficult and sometimes even painful. Many participants reflect on the irony that after fleeing their countries of origin due to economic hardship, stigma, discrimination, violence and abuse, they also encounter in Canada HIV/AIDS related stigma, discrimination and homophobia, intersecting with anti-immigrant feelings, racism, loneliness and lack of social networks and emotional support.

Regarding to access to health care, participants in this study have good access to service overall; however, instances of racism, sexism, homophobia and transphobia still are present in the health care system. Intersecting dimensions of race, gender and immigration status may hinder access for some individuals, such as women of color and trans individuals. For people living with HIV, difficulties in access to health related services may be more damaging than for HIV negative individuals.

As found here and in other studies (CAAT, 2001; Shedlin and Shulman, 2004; Körner, 2007; Pivnick, Jacobson, Blank and Villegas, 2010; Dang, Giordano and Kim, 2012), migration status is a first and critical determinant in access to health care. Most of the participants in this research have legal status in the country, and their access to health care is not compromised by this factor. However, it has been reported that there are a half million undocumented individuals working in Canada without access to basic social protection (Papademetriou, 2005).

Many of our participants still remember when, before obtaining a legal status, their situation was highly unstable and their access to health care services was not

secured. Therefore, it is during the early stages of arrival and settlement when newcomers become more vulnerable, and exceptional efforts must be implemented to guarantee access to health care and other social services for newcomers in general, and especially for HIV positive individuals. To provide effective care and support for individuals going through the difficulties of migration processes – sometimes compounded for traumatic situations such as testing HIV positive during the process – economic, cultural and language barriers accessing health care related and other social services should be mitigated. In addition, ethnic communities in receiving countries must re-evaluate their beliefs and conducts towards HIV infection and PHAs, with the goal of minimize HIV related stigma and discrimination, enabling people living with HIV/AIDS to rebuild much needed social relationships. Unfortunately, current changes in the norms regulating the availability of health care services for newcomers are going in the opposite direction. For instance, with the recent reform in the Interim Federal Health Program (IFHP), which regulates the availability of health care services for refuge applicants, access to health services for some of them will be compromised, significantly affecting their health and wellbeing.

In the area of employment, due to their intersecting positions as immigrants/refugees, and individuals living with HIV, participants in this study have to overcome numerous barriers to incorporate successfully in the labor force in Canada. Barriers in the labor market that immigrants in general confront are further reinforced by the difficulties caused by HIV infection. In this way, the available job opportunities for many of the participants in this study are quite limited.

Many Latino PHAs rely on social assistance to subsist, due to limited

opportunities to work. There exists a generalized perception, even among employed PHAs that individuals living on social assistance are unable to stand up on their own feet and improve their lives by themselves. This is a discourse that mirrors the perception of the general society in regards to people living on disability.

HIV/AIDS related stigma and discrimination, racism, homophobia, transphobia, anti-immigrant sentiments, and other numerous barriers locate Latinos and Latinas living with HIV in marginalized positions in the Canadian social mosaic. Latinos and Latinas living with HIV, in addition to other immigrant/refugee, ethno/racial groups, other people living with HIV/AIDS, and individuals living on social assistance, form a significant part of the population living in poverty in Canada.

The conditions that Latinos and Latinas living with HIV face in their everyday lives strongly resonate with what Galabuzi (2006: 173) characterizes as social exclusion in the Canadian context.

[Social exclusion] refers to the inability of certain groups or individuals to participate fully in Canadian life due to structural inequalities in access to social, economic, political, and cultural resources arising out of the often intersecting experiences of oppression relating to race, class, gender, disability, sexual orientation, and immigrant status. Social exclusion is a form of alienation and denial of full citizenship experienced by particular groups of individuals and communities. Among its characteristics are high levels of poverty, uneven access to employment and employment income, segregated neighborhood selection leading to racialized enclaves, disproportionate contact with the criminal justice system, and low health status.

In addition, emergent measures of neoliberal global restructuring – including the retreat of national governments from the regulation of the economy and society, and the accelerated migration from South to North– combined with a historical process of racialization in Canadian labor markets, are aggravating the conditions of poverty for the most vulnerable social groups, leading to declining social economic status and further

social exclusion (Galabuzi, 2006).

In spite of this dark picture and the heavy burden that marginalization based on their intersecting stigmatized statuses represents in the lives of the participants, their narratives also show that Latinos and Latinas living with HIV actively attempt to improve their condition in Canada. Among our interviewees, it is possible to find stories of success as well, proving that individuals in general, including persons living with HIV/AIDS, can counteract the effects of stigma and other adverse life circumstances on their well-being (Ramirez-Valles, Fergus, Reisen, Poppen, and Zea, 2005). Some of the individuals interviewed in this study have been able to locate themselves in stable and well paid job positions, thereby accessing a higher socio-economic status. But even among those participants living under economic constraint, there are valuable strategies to cope with hardship and strengths related to living with HIV/AIDS and dealing with stigma and discrimination.

Family and friends are an essential resource for Latinos and Latinas living with HIV. Since the time of arrival and settlement, they provide emotional support and care, and are a valuable source to obtain information, jobs, shelter and material resources during difficult times. In addition, a handful of AIDS Service Organizations (ASOs) is a valuable source of support. Among this organizations PWA, ACT, Latinos Positivos and the Centre for Spanish Speaking Peoples stand out as providers of essential resources for Latinos/as and other groups living with HIV/AIDS.

Regarding personal and psychological resources related to the experience of living with HIV/AIDS, participants' narratives show the existence of two general ways of coping. Avoidance coping strategies (Moos and Schaefer, 1993) or passive coping style

imply a fatalistic and submissive way of addressing problems and stressors. Reactions related to avoidance of an HIV positive status are maladaptive. Thus, denying HIV infection, keeping distance from or refusing to think about the HIV diagnosis and isolation may be considered as indicators of a poor adjustment to living with HIV (Namir, Wolcott, Fawzy, and Alumbaugh, 1987). This form of coping is in association with depression, anxiety, greater difficulties managing physical symptoms, and low ability to rely on personal relationships as a source of emotional support (Nicassio, Radojevic, Schoenfeld-Smith, and Dwyer, 1995; Snow-Turek, Norris and Tan, 1996; Eurelings-Bontekoe, van del Slikke and Verschuur, 1997). According to the stories presented here, avoidance coping strategies also imply a greater risk of transmission of HIV infection.

Conversely, approach coping (Moos and Schaefer, 1993) or active coping style is characterized by a determination to make use of strategies and resources at hand to deal with problematic conditions. Problem-focused, or confrontation coping strategies, such as looking for emotional and other types of support, being assertive, and dealing face to face with the reality of the trauma, are deemed as adaptive strategies. This type of strategies might be more frequently related with a better management of depression and distress, and, greater perceived social support (Snow-Turek, Norris and Tan, 1996; Hampson, Glasgow and Zeiss, 1996; Wolf et al., 1991), decrease in advance of the illness among gay men (Mulder, Antoni, Duivenvoorden and Kauffman, 1995), and less subjective physical symptoms among HIV positive men and women (Vassend, Eskild and Halvorsen, 1997). Other possible active coping strategies found among HIV positive people are a feeling of being on control of the situation and a reinforced self-esteem, religion and spirituality, and positive thinking and reappraisal (Anderson, Elam, Solarin,

Gerver, Fenton and Easterbrook, 2009). All of these different forms of active coping were encountered in this study as well. Understanding forms of coping with HIV/AIDS is crucial because they can have a direct effect on the health status and general wellbeing of people living with HIV/AIDS, and on the other hand, they may be related with risk of HIV transmission, therefore, having direct relevance for public health.

In regards to migration, sexuality and the experience of living with HIV/AIDS, there exists a complex and multi-directional relationship among these different aspects of human experience. The migration stories of Latinos and Latinas living with HIV show that, for those individuals who were HIV positive back in their countries of origin, the experience of living with HIV/AIDS was a factor that strongly motivated relocation. The lack of appropriate HIV related services, in addition to HIV related stigma and discrimination, were structural barriers that to a considerable extent impelled the migration of some participants. As found here and another study (Doyal, Anderson and Papparini, 2009) the significance of HIV related factors as strong motives to migrate is demonstrated by the fact that some individuals would even return to their countries of origin if they considered that antiretrovirals and HIV related health services were appropriate. This way, the experience of living with HIV/AIDS must be added to economic factors and discrimination and violence related with sexual orientation as direct determinants of migration.

On the other hand, the effect of migration on risk of HIV infection and transmission has been studied in more detail (Nunn et al., 1995; Bronfman and Minello, 1999; Crush, Williams, Gouws and Lurie, 2005), showing that migration increases vulnerability to HIV due to changes in sexual habits, loss of social networks, and overall

social disruption. However, there is an unresolved controversy about the relationship between migration and HIV vulnerability: research in the United States has also found that recent immigrants are at less risk of HIV infection than local populations (Flaskerud, Uman, Lara, Romero, and Taka, 1996; Ford and Norris, 1993; Newcomb et al., 1998; Peragallo, 1996). The results found here are not conclusive in this regard. Even though some of the participants came into contact with HIV shortly after arrival in Canada, some of them even during their migration travel, others seroconverted many years after settlement in the country. Thus, research that considers in more depth immigrants' way of life back in their nations of origin, the dominant cultural beliefs back home and their previous exposure to Western practices and ideas is needed to understand better how migration and health relates, particularly to understand the relationship between migration and HIV vulnerability.

It is just recently that academic work has started to illuminate the relationship among migration and sexuality (Carrillo, 2004; González-López, 2005, Cantú, 2009), showing that migration affects and shapes sexuality and that sexuality might be a powerful reason to migrate. Principally for gay and bisexual participants, discrimination, violence and abuse based on sexual orientation were reasons to leave family and country of birth behind. Some of them decided to flee soon after an episode of repression, or after they could not bear chronic abuse from family members any more. Currently, laws that protect the expression of sexual diversity all over Latin America have been implemented. Unfortunately, the implementation of those regulations has been accompanied with increasing violence against LGBT individuals in the region, perhaps as a direct response to such laws, in addition to other social factors.

Participants in this study spoke of changes in sexual practices and their ideas about sexuality after being exposed to new ways of thinking, practices and sexual cultures in Canada, showing the powerful influence of migration on the sexual lives principally of interviewees with emotional and sexual same sex interests. Changes were more significant for those individuals who migrated to Canada at a time when stigma, discrimination and abuse related to sexual orientation in their countries of origin were even more severe than today.

For some of the participants coming to Canada meant entering in contact with a Western construction of gay identity that was not available at the time of migration in the country of birth, shifting participant's previous conceptualizations of same sex relationships. In many aspects, this brought new possibilities of expression, freedom and ways of relating to other men. However, individuals also expressed often feeling at odds with ideologies and practices related with this westernized gay identity, even after many years living in Canada. Feelings of being marginal to the gay community may be not uncommon either, principally when subtle and overt forms of racism permeate the Canadian gay community (Lee and Brotman, 2011).

In addition to migration, the condition of living with HIV also powerfully shapes the sexual life of the participants. The establishment of new sexual and romantic relationships is especially problematic for the vast majority of the respondents. Practically all of them can recount experiences of rejection when trying to establish this kind of relationships. Most of them feel caught up in the dilemma of disclosing their HIV positive status to potential sexual and romantic partners and being rejected, or not disclosing and face the risk of legal consequences. The condition of living with HIV still

is so highly stigmatized that the privileges attached to other dimensions of identity, such as being heterosexual or racial and class privilege, are cancelled out by HIV related stigma. In this way, gay, straight and bisexual individuals talk about similar experiences and dilemmas in regards to sexual life and the establishment of couples, regardless of race, class, or sexual orientation (Adam and Sears, 1996).

A potential strategy to deal with stigma in regards to sexuality is the search for casual and anonymous sex. Participants believe that in spaces where casual and anonymous sex occurs there is no need to disclose HIV serostatus, but there is also scarce opportunity to discuss and negotiate practices of safer sex, which added to the assumptions that exist in regards to behavior and HIV status, might imply a greater risk of transmission/infection of HIV and other STIs.

Contributions to the literature

This study is a contribution to the literature on the experiences of people living with HIV/AIDS, which is relatively scarce in comparison with works on prevention and HIV related risk behaviors. Research on the experiences of HIV positive immigrants is even more limited, with no studies so far that analyze the barriers and difficulties in access to health care and other social services for the immigrant and refugee Latino community living with HIV in Canada. Therefore, this is the first research that, considering intersecting dimensions of participants' identities, specifically focuses on this community in the Canadian context, making a direct contribution to the study of the barriers that Latino and Latina HIV positive immigrants encounter accessing health and other social services. There are few instances of research on access to health care for Latino immigrants living with HIV conducted in the United States. This research agrees with

those studies in that structural barriers are the principal obstacles in access to health care services for immigrants and refugees living with HIV/AIDS, beyond ethnicity, race, or cultural background.

The few studies conducted so far on HIV positive immigrants have a strong focus on participants' experiences in access to health care, but little attention has been paid to other crucial aspects of their lives, such as access to employment and their stories about migration. Therefore, this is a contribution to the study of employment and barriers to employment for immigrants and refugees living with HIV in the Canadian context. This is one of the very few works in North America that particularly studies barriers in access to employment for Latinos and Latinas living with HIV. So far, research conducted in employment explores the barriers that newcomers encounter to incorporate fully to the labor force; and in the other side, the obstacles that seropositive individuals encounter. But to the best of my knowledge, this is the first study that documents the compounded effects of being an immigrant/refugee living with HIV in access to employment. The study uncovers the exclusion from the labor market that Latino and Latina PHAs encounter in Canada due to the intersection of these two dimensions of their identities. Finally, the present research is one of remarkably few examples of studies on immigration that have incorporated sexuality as a key aspect of analysis (Cantú, 2009), contributing in this way to the literature that explores the intersectional experiences of queer immigrants and refugees in Canada. The study documents the changes in sexual identities that some of the self-identified gay participants undergone as a result of relocation in Canada and after entering into contact with a Westernized gay identity; identity that was not available back home at the time of migration. In addition, here we

document the existence of violence and abuse back home due to a non-heterosexual orientation as a strong motivation to migrate, showing in this manner the complex relationship among sexuality and migration.

Study limitations and recommendations for future research

The recruitment strategy in the present study had certain limitations. Participant recruitment was carried out principally through Latinos Positivos and the Centre for Spanish Speaking People, community organizations that work with HIV positive Spanish speaking individuals, and other members of the Latino community. The recruitment through these organizations might have limited the study sample to those Latinos and Latinas who frequently use the services of these agencies, and thus are relatively more 'out of the closet' in regards to their HIV serostatus. Individuals doing well may also be less likely to approach these organizations. The geographical location of the organizations in the downtown core may also limit access to those individuals living in more distant neighborhoods, making them a hard to reach, almost invisible population.

It might be possible that the experiences of those Latinos and Latinas living with HIV who are more fearful of and even more severely constrained by, different forms of stigma and discrimination were not heard in this study. For instance, the voices of undocumented Latinos and Latinas living with HIV in Canada, unfortunately, are not present on these pages. It is likely that fear of deportation restrains undocumented immigrants from accessing much needed services on a regular basis and from speaking about their life situation.

Likewise, the present study would have benefited from having more women and heterosexual men, whose experiences are underrepresented here. Latinas' scarce

participation in this research makes it difficult to conduct a deeper analysis in terms of gender. In regards to heterosexual men, as commented by one heterosexual male participant, their discomfort in approaching ASOs, which they consider gay oriented, and fear of stigma render them a hard to reach group as well.

Future research must develop more extensive recruitment strategies, considering contact with community organizations serving the Latino population located outside of the downtown area and striving to include more undocumented immigrants, women and heterosexual men as part of the study. Analysis of these individuals' experiences might illuminate issues that particularly affect members of these groups, and give voice to individuals that are placed at especially vulnerable social locations.

Research on the Latino community in general and on Latinos and Latinas living with HIV in Canada is almost nonexistent; thus, research implemented on any area pertaining to this community should be encouraged. Areas of research that deserve unique attention in relation to the experience of living with HIV/AIDS are the effects of criminalization on the lives of Latinos and Latinas, particularly of those individuals who have not been granted permanent legal status in Canada. Similarly, further research is needed regarding coping strategies and strengths related to living with HIV/AIDS, such as religion and spirituality, and the role they play as responses to HIV/AIDS related stigma and discrimination and other issues affecting HIV positive individuals.

As mentioned before, the relationship between migration and immigrants' health status in general, and migration and HIV vulnerability in particular is still not well understood. The implementation of research in this area will benefit by paying more attention to immigrants' lives in their countries of birth, the dominant culture and believes

back there, and immigrants' previous exposure to Western practices and ideas (Schneider, Comer, and Hunt, 1982).

In addition, extremely little is known about employment and HIV in general, and particularly research conducted on this area among the Latino community is scarce.

Therefore, it is necessary to explore further the barriers and facilitators to employment in the Latino HIV positive community. The evaluation of intervention programs that seek to facilitate the incorporation to the labor force of HIV positive people would also shed light on the factors that impede a successful return or first incorporation to work for people living with HIV/AIDS.

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APPENDIX 1: Interview Guide

Life in country of origin

- 1.-What is your country of origin?
 - How long did you live there? (country of origin)
 - What was your main activity there? (job, school)
 - Whom did you live with?
- 2.-Did you have an active sexual life?
 - Did you have a stable partner?
- 3.-Why did you leave your country of origin?
 - Would you come back permanently at some point to your country of origin? Why?
- 4.-Do you still maintain communication with anyone in your country of origin? family/friends/partners/others
 - How do you maintain that communication? internet/telephone/mail/travel/other
 - How often?
- 5.-Can you tell me when and where you received your diagnostic as HIV positive?
 - (if in Canada, did you receive professional advice/support post-test?)

Migration

- 6.-How long have you been living in Canada?
Did you come with your family, (partner/friends) or by yourself?
- 7.- Did you come directly from your country or did you live in any other place before migrating to Canada?
- 8.-Why did you decide to establish in Canada?
 - Did you know anybody in Canada when you first arrived?
 - Who did help you to establish in the country? friends/family/partners
 - How did they help you? Information/economical support/ a place where to stay/etc.
 - Have you ever met people through the Internet that have helped you in Canada?
- 9.-What was your migratory status when you arrived in Canada?
 - Has it changed over the time?
 - Which are the main issues that you have had to face to get a regular migratory status? (getting legal information and support and representation, covering the

costs of the immigration process, understanding your status and what services you have the right to access)

- how being a person living with HIV has influenced/affected your migratory status in Canada?
- How have you resolved those issues?
- Have you ever faced troubles (access to services or others) as a consequence of your migratory status?

10.- Do you have access or are you registered on ODSP (Ontario Disability Support Program)? In case of being registered, what kind of support you receive from the ODSP?
Income support
Employment supports

Access to health care services

11.-Tell me about the last time that you went to the doctor, how did it go?
(Difficulties to get access to health care services as a consequence of migratory status, being a person living with HIV)

When you have to go to the doctor where do you go regularly? (family doctor, community health clinics, hospitals, private physician, clinical trials)

- Have you ever been denied the access to health care services? (as a consequence of your migratory status, being a person living with HIV or other reason)

12.-Which health care services you have access currently?

- Do you have health insurance? (OHIP, IFH Interim Federal Health Plan, Private)
- Do you have drug coverage?
- Do you have access to specialists?
- Do you have access to hospital services?
- Do you have access to laboratory tests? (viral load tests, diagnostic tests)
- Have you ever had to pay for medical attention? When? Why?

13.-How did you learn about the health care services available? (Center for Spanish Speaking Peoples, Latinos Positivos, PWA, ACT, through friends, the Internet).

14.-Tell me how you face or have faced the issues to access health care services (physicians, medical treatments, medication, specialists, laboratory test).

Access to employment services

15.-Are you currently working? Or Have you ever worked in Canada?

- what is your job? How long have you worked there? How did you get this job?
- How satisfied are you with this job?
- Have health problems or health related conditions caused you physical or mental impediments to work? How so?
- Have you ever been mistreated at your workplace or fired as a consequence of

- your serostatus?
- Have you ever used employment services?
- Have you ever used employment insurance, workplace safety insurance benefits?

16.- Have you found barriers/difficulties to get this or any other job? Which ones? (as a consequence of your migratory status, for being Latino/a, being a person living with HIV)

- Tell me how you face or have faced the troubles that you have found to get a job or maintain it

17.-Do you consider your current income as enough or not enough to cover your basic needs? Why?

18.-How do you cope or have cope with the problems to cover your expenses (and your dependents' expenses)

- Do you have currently any other source of income? Which one/s?

Access to housing services

19.-Where do you live? (apartment, house, rooming house)

- Do you receive support for housing from ODSP?
- With whom do you live?
- How satisfied are you with the place where you currently live?

20.-Tell me about the difficulties/troubles that you have faced to find a place where to live (as a consequence of your migratory status, being Latino/a, or being a person living with HIV)

- How have you faced those difficulties?

21.-Have you ever applied for public subsidized housing? What is your experience in this matter?

22.-How do you think your experience with migration and the access to health care, employment, and housing services would be different if you were (consider the interviewee's opposite identity categories, i.e. If it is an immigrant woman, if she were a man Canadian citizen, etc.)

The experience of living with HIV

23.-When you received the diagnostic as HIV positive, did you have a partner at that time?

- How did he/she find out?
- What was his/her reaction?

24.-Does your family know?

- How did they find out?

- What was their reaction?
- Do you maintain communication with your family?

25.-Do your friends know?

- How did they find out?
- What was their reaction?
- Do you maintain communication with your friends?

26.-Currently do you have friends here in Canada? Of which cultural group?

27.-Currently do you have a regular partner here in Canada?

- Of which cultural group?
- Is he/she positive or negative?
- In case of your partner being negative, how the difference of serostatus (serodiscordance) has affected your relationship?

28.-Who is the person/s that you trust the most, and that you would ask for help?

29.-What strategies you use or have used to disclose your serostatus to friends, family, potential partners (romantic and casual)?

30.-Have you ever been rejected by disclosing your serostatus? In which situations?

31.-Have you ever felt rejected, mistreated or discriminated as a consequence of being Latino/a, immigrant, or a person living with HIV?

Sexuality

32.-Have your sexual relations been affected by being HIV positive? How have your sexual relations been affected?

33.-Would you consider that if a person is willing to have unprotected sex with you it is because he/she is HIV positive?

34.-Do you have unprotected or protected sexual relations with your current partner/s?

- Did you discuss about it?

35.-Tell me about the most recent occasion you have unprotected sex? Where it was? With whom?

- In which situations have you found yourself having unprotected sex?
- In which situations do you disclose your serostatus? (casual/potential romantic relations)
- Have you ever been rejected by a potential sexual/romantic partner as a consequence of your serostatus? How was that?

36.-If you compare your sexual life in your country of origin with your sexual life here in

Canada, where do you consider it has been more satisfactory? Why?

37.-Do you think your sexuality has changed somehow since you came to Canada? How?

Demographics

38.-What of the following ranges of age are you in?

18-29 30-39 40-49 50-59 60-69 older than 70

39.-Your relationship status is

Single have a male partner have a female partner married with a man
married with a woman Divorced/separated/widowed

40.-Your current educational level is:

Primary school some high school high school graduate 1-2 years of
college/university 3-4 years of college/university post-graduate

41.-Your employment status is:

working full time working part time self-employed unemployed On disability
Retired/pensioned work under the table Attending school Other, please specify

42.-Your annual/mensual income is:

< \$10,000 (< \$850/month) 10-19,999 (850-1,669/month) 20-29,999 (1,670-
2,499 month) 30-39,999 (2,500-3,334/month) 40-49,999 (3,335-4,164/month)
50-59,999 (4,165-4,999/month) 60-69,999(5,000-5,834/month) 70,000-79,999 (5,835-
6,669/month)
80,000-89,999 (6,670-7,500/month) >90,000 (>7,500/month) prefer not to
answer

APPENDIX 2: Consent form to participate in research

Title of Study: **Immigrant, refugee, and non-status Latinos/as living with HIV/AIDS in Canada**

You are asked to participate in a research study conducted by **Angel Serrano-Sanchez (graduate student) and Barry D. Adam (main supervisor)**, from the **Department of Sociology, Anthropology and Criminology** at the University of Windsor. **The results of this research will contribute to the dissertation project of Angel Serrano.**

If you have any questions or concerns about the research, please feel free to contact **Angel Serrano by e-mail: serranoa@uwindsor.ca; or Barry D. Adam at 519 253 3000 ext. 3497; adam@uwindsor.ca.**

PURPOSE OF THE STUDY

This work analyses the everyday experiences of immigrant, refugee and non-status Latinos/as living with HIV/AIDS in Toronto, Ontario as a means to understand processes of discrimination, marginalization and oppression, as well as individuals' access to social services such as health care, housing and employment services. The analysis of the narratives of Latinos/as living with HIV/AIDS also aims to show their strategies to cope with stigma and discrimination, and their attempts to live more satisfactory lives.

PROCEDURES

If you volunteer to participate in this study, you will be asked to:

Participate in a face to face in-depth interview. This interview will last between one hour and one hour and a half, depending of what you have to say.

POTENTIAL RISKS AND DISCOMFORTS

The investigation will raise a potential risk of losing confidentiality as a result of sharing personal information in a research setting. Personal information such as sexual orientation, migratory status, and HIV status will be discussed and shared with the researcher during the interview. The researchers agree about a strict management of all the information produced during the research process and to sign a consent form which assures the maintenance of confidentiality of all the data.

In addition, it is possible that methods of research, such as the interview, could raise issues that may be troublesome to some participants. However, the likelihood of distress is low and The Centre for Spanish Speaking Peoples, and Latinos Positivos, organizations collaborating in this study, offer counselling services where you can be referred if the need arises.

POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

The results of this study will be useful in the construction of a culture of coping strategies and practical knowledge about the experience of living with HIV/AIDS, which can be of direct interest for seropositive people.

At a scientific level, the investigation aims to contribute to the Canadian research on immigrants and refugees living with HIV/AIDS. It will be a contribution to the HIV/AIDS literature and the migration literature as well.

The project also will contribute to the knowledge of the immigrant community of Latin American origin in Canada, where aspects of immigration, as any other aspect pertaining to the Latino population are understudied.

COMPENSATION FOR PARTICIPATION

As a token of appreciation for your time and participation in this study you will receive \$30.00 at the end of the interview.

CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission.

As study participant, you will be invited to select a name of your choosing in signing the consent form. During the interview process your actual name will not be mentioned at all. If you mention names of other individuals, or any other information that permits the identification of you or someone else, that information will not be transcribed.

To maintain the confidentiality of the information during all the research process the next set of safeguards will be follow: (a) interview audio files and transcripts will be identified only by ID number, meaning there will be no method by which tapes or transcripts can be traced back to names or contact information, (b) consent forms and audio files will be kept in a secure location, (c) transcripts of interviews will be inspected to ensure that no identifying information has been retained, and (d) only aggregated and collective overviews of results will be presented. There will be no “key” by which interview transcripts can be traced back to individuals.

It is important to mention that you have the right to review and edit your audio file if you wish to do so. Please be sure that only the principal investigator will have access to audio files, transcripts and any other data derived from the research process; the supervisor of the study will have access to transcripts and summaries of results derived from the research; and a transcriber will have access to audio files.

Audio files and written forms will be destroyed/deleted when the investigation comes to an end. That will be in around a year from now. However, transcripts derived from the interview process can be kept for longer time for research purposes.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and still remain in the study. The

investigator may withdraw you from this research if circumstances arise which warrant doing so.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE SUBJECTS

You will have access to a summary of the results of the investigation. This is important because this information can help you in the construction of coping strategies for the management of HIV/AIDS at a social level, and to improve your access to social services.

Therefore, the post-study information that will be provided is about barriers and difficulties in the access to social services (mainly to health care, employment and housing services), difficulties during the migratory process, and the coping strategies used by the participants themselves to overcome all these issues. This information will be available in participant organizations' websites:

Latinos positivos <http://www.latinospositivos.blogspot.com/>
Centre for Spanish Speaking Peoples <http://www.spanishservices.org>

Date when results are available: June/2012.

SUBSEQUENT USE OF DATA

This data will be used in subsequent studies.

RIGHTS OF RESEARCH SUBJECTS

If you have questions regarding your rights as a research subject, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario, N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: ethics@uwindsor.ca

SIGNATURE OF RESEARCH SUBJECT/LEGAL REPRESENTATIVE

I understand the information provided for the study **Immigrant, refugee, and non-status Latinos/as living with HIV/AIDS in Canada** as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

Name of Subject

Signature of Subject

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Signature of Investigator

APPENDIX 3: Consent form for audio recording

Immigrant, refugee, and non-status Latinos/as living with HIV/AIDS in Canada

I consent to the audio-taping of my interview.

I understand this is a voluntary procedure and that I am free to withdraw at any time by requesting that the taping be stopped. I also understand that my name will not be revealed to anyone and that taping will be kept confidential. Tapes are filed by number only and store in a locked cabinet.

I understand that confidentiality will be respected and that the audio tape will be for professional use only.

Signature of research participant

Date

(Research Subject)

VITAAUCTORIS

Angel Serrano Sánchez was born in Mexico City, Mexico. He obtained a bachelor degree in Biology at Universidad Nacional Autónoma de México and a Masters degree in Rural Development at Colegio de Postgraduados, Mexico. Afterwards, he came to Canada for the Doctoral degree in Sociology at the Department of Sociology, Anthropology and Criminology of the University of Windsor.