



**Contextual Factors Affecting HIV/AIDS
Treatment and Prevention Amongst Recent
Immigrants Living in Rural Centers**

Technical Report

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of Health Research



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CIHR HIV Project Technical Report

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Executive Summary

The HIV/AIDS problem is increasing world wide, and Canada and Alberta are no exception. Over the past few years, Alberta has had an increase in the number of immigrants who came from countries with a high incidence of HIV/AIDS. In 2004, one of the health regions of Alberta experienced an increase in newly-detected HIV positive persons from HIV/AIDS endemic countries. This was followed by a sharp, unexplainable decrease in 2005 and 2006. An emerging health concern is how to assist persons with HIV/AIDS and to prevent further increases in the incidence of this disease among new immigrants. The region's health care and service providers, as well as the Medical Officer of Health recognized that immigrants may experience barriers to HIV/AIDS prevention, early detection, and treatment, posing the risk of HIV/AIDS transmission within the population. We proposed to undertake a multi-phase research study for which the goals were to:

- (1) understand the health care milieu as experienced by recent immigrants;
- (2) identify and implement strategies which would assist recent immigrants to manage HIV/AIDS and its related problems, and limit the spread of this disease; and
- (3) evaluate and facilitate recent immigrants' success in seeking help for and preventing HIV/AIDS.

The project consists of **three phases** of which the first one has been completed:

Phase 1: Acquire information from the perspective of both recent immigrants and their health care providers regarding factors support health care and those that inhibit it.

Phase 2: Based on the information gathered in phase 1, generate and implement strategies that are expected to support recent immigrants' health care.

Phase 3: Evaluate and facilitate the outcomes of the health care strategies implemented.

This technical report addresses Phase 1: Understanding the health care milieu of recent immigrants. Informed by the ecological perspective, the purpose of this exploratory qualitative study was to:

- (a) gather information on how and why recent immigrants living in small rural centers seek help to manage their HIV/AIDS and related problems, practice HIV/AIDS prevention, and deal with social stigma;
- (b) identify intervention strategies that recent immigrants and health care providers perceive to be effective in meeting the needs of recent immigrants living with HIV/AIDS; and
- (c) identify intervention strategies that recent immigrants and health care providers perceive to be effective in promoting the use of HIV prevention activities and early detection.

The following research questions were addressed from the perspectives of both the immigrants who lived with HIV/AIDS and the immigrants who did not have HIV/AIDS:

- 1) How do recent immigrants seek help to manage their HIV/AIDS and related problems?
- 2) How do recent immigrants deal with social stigma and consequences of having HIV/AIDS?

- 3) What factors (barriers and facilitators) influence immigrants' use of HIV prevention activities and services?
- 4) What services and strategies could address HIV care and treatment among recent immigrants?
- 5) What intervention strategies could promote the use of HIV prevention activities and early detection among recent immigrants?

To understand the issues and challenges which health care providers face, we also addressed these research questions from health care providers' perspectives. Because different views of health, illness, and priorities between health care providers and clients can create obstacles to successful treatments and effective health care if a mutual solution cannot be reached, the results from the study were triangulated to identify discrepancies between recent immigrants and health care providers' perceptions of need and solution to health care problems.

The data collection sites were two rural centers in a health region in Alberta. A combination of maximum variation purposive and snowball sampling of approximately 15 immigrants who had HIV/AIDS, 15 immigrants who did not have HIV/AIDS, and 15 health care providers were originally planned. Unfortunately, participants living with HIV were difficult to recruit, possibly because they were unwilling to risk disclosure of their HIV status. In the end, only three participants living with HIV were willing to consent to an interview, and of those only two consented to being audio taped.

Participants included immigrants who (a) lived in a selected health region in a Canadian province within the past 10 years; and (b) were born in Africa or the Caribbean. Recruitment of participants was done via health care providers and HIV/AIDS networks, community individuals and organizations. The method of data collection was in-depth interviews using a semi-structured questionnaire. Demographic data and an Ecomap were collected to assess participants' socio-economic status and social support networks. To ensure the approach was gender appropriate, a male or female interviewer conducted the interview in the language that was preferred by the participant. Each immigrant participant was interviewed for one hour to one-and-a-half hours. Each health care provider participant was interviewed for approximately 30 to 60 minutes. Ten participants were interviewed twice. Informed consent was obtained. The data analysis and data collection occurred concurrently. To ensure the study's rigor and credibility as well as to evaluate the emergent themes, ideas, and concepts, researchers discussed the preliminary results with participants in the second interviews.

The interviews with community members revealed tremendous stigma around HIV/AIDS, with participants commenting that HIV was often a result of promiscuity or homosexual activity, although some mentioned transmission through blood or through shared needles as well. The participants interviewed had a range of understandings of HIV, with many having a minimal level of medical understanding of the disease or its treatment. Not everyone was aware there was treatment available. A number of community members mentioned that they felt HIV positive people deserved compassion and help and that their community would support such people, but for most this belief was hypothetical as they did not personally know anyone in their community who had admitted to having HIV. Most felt that it would be unwise for HIV positive people to tell anyone outside their family about their diagnosis, and indeed the three people with HIV who were interviewed had revealed their HIV status only to their family. Most community members

understood that condoms were one way to reduce sexual transmission, but women in particular pointed out difficulties in getting men to agree to use them.

Everyone interviewed, including community members and health care providers, felt more education on the topic was needed. Sex education in schools, media information about HIV/AIDS testing and general information on HIV (through TV, radio and internet), working with community and church leaders, having public information sessions, using the local large employer of immigrants to deliver health information, and going door to door were all mentioned as possibilities. Promotion of condom use was also recommended. There was some disagreement about how to best go about educating the community, but all agreed that more knowledge about the disease was essential. Community members felt the government should be putting resources into HIV/AIDS education, as well as research.

In addition, practical support for HIV positive people in the form of transportation to the HIV clinic, extended clinic and lab hours, and more culturally competent care and education for newcomers on how to navigate the health system were all mentioned. A local office specializing in HIV/AIDS support was one recommendation from a provider working for an HIV/AIDS service organization. However, cautions were raised against dedicated HIV offices or clinics as people going into these places might be risking their privacy. Recruiting immigrants to work in health care was another suggestion. Recruitment of health care workers in general, and expansion of public health to form a specialized HIV/AIDS unit with trained and informed health care professionals were also noted as strategies to increase accessibility.

Introduction and Background of the Study

The Study

The health region chosen as the site of this study experienced an increase in newly-detected HIV positive diagnosis among persons from HIV/AIDS endemic countries in 2004. This was followed by a sharp, unexplainable decrease in 2005 and 2006. According to the region's health care and service providers, there is likely a significant amount of undetected HIV in this population of newcomers from endemic countries, posing the risk of HIV/AIDS spread within that population. When people are aware of their HIV status, transmission can be reduced between partners through safer sexual practices and mother to foetus transmission can be reduced by half using antiviral drug therapies (Guay, et al., 1999; Shaffer, et al., 1999; Wiktor, et al., 1999). The health care and service providers, and the Medical Officer of Health of the Health Region recognized that immigrants and refugees could be experiencing barriers to HIV/AIDS prevention, early detection, and treatment. Emerging health concerns for this region include preventing further increases in the incidence of HIV/AIDS and finding ways to provide health care to immigrants and refugees who were living with, and vulnerable to, this disease.

Although some research highlighted the problems faced by such immigrants and refugees in large urban centers (Handa & Negash, 2003; Remis, 2003), there was very little understanding of how recent immigrants and refugees coped with HIV/AIDS and its related problems and practiced HIV/AIDS prevention in smaller rural centers. To effectively assist recent immigrants and refugees with HIV/AIDS, investigating factors that influenced these immigrants' decisions to seek HIV/AIDS care and treatment, and identifying factors that limited or increased the spread of HIV infection were urgent research initiatives (Schiltz & Sandfort, 2000). In this study, the term "recent immigrants" referred to people who came to live in Canada within the last 10 years (Citizenship and Immigration Canada, 2000). "Refugees" were people in or outside Canada who feared returning to their country of nationality or habitual residence. These were persons needing protection. Canada, through its refugee protection system, provided safe haven to those with a well-founded fear of persecution, or were at risk of torture or cruel and unusual treatment or punishment (Citizenship and Immigration Canada, 2004). While we fully recognized that the experiences of a refugee and an immigrant might be different, both refugees and immigrants living in Canada faced similar cultural, language, and economic challenges and there were very few differences in the eligibility for services and other institutional supports by both groups. Thus we used the term recent immigrant in this study to cover both refugees and recent immigrants. In addition, we used the term recent immigrants and newcomers interchangeably at times in this report.

Given the need for research and services development for newcomers living in smaller rural centers, we undertook a research project for which the goals were to:

1. understand the health care milieu as experienced by recent immigrants;
2. identify and implement strategies which would assist recent immigrants to manage HIV/AIDS and its related problems, and limit the spread of this disease;

3. evaluate and facilitate recent immigrants' success in seeking help for and preventing HIV/AIDS.

The study consists of three phases, of which the first has been completed:

Phase 1: Understanding the health care milieu of recent immigrants.

In this phase we set out to acquire information from the perspective of both recent immigrants and their health care providers regarding factors that support health care and those that inhibit it.

Phase 2: Generating and implementing supportive strategies for recent immigrants.

Based on the information gained in phase 1, we planned to generate and implement strategies that are expected to support recent immigrants' health care.

Phase 3: Evaluating and facilitating supportive health care strategies for recent immigrants.

In this phase we plan to evaluate the outcomes of the health care strategies implemented, and facilitate the continuation of recent immigrants' success in seeking help and preventing HIV/AIDS.

The Report

This report is a summary of the study's Phase 1 purpose, methods and results, in which the researchers interviewed both community members and health professionals. It addresses each of the five research questions in turn, summarizing the themes from the interviews that answer the questions posed by the research. The interview data often related to more than one question, and as a result there was some repetition and overlap in the sections. The report concludes with a discussion, recommendations, and reflections on the ethical issues and considerations involved in this study.

Literature Review

Changing Demographic Patterns in Canada and Alberta

The number of immigrants and refugees in Canada has increased significantly in the past several decades. In Alberta, the 2001 Census reported that among the almost 3 million Albertans, nearly half a million were immigrants. According to the Alberta's Labour Market Profiles, an average of 13,750 new immigrants arrived in Alberta within the last five years (Enhanced Language Training (ELT) project report, 2004). This number has continued to grow. A significant number of recent immigrants are moving into the health region which is the focus of this study to take advantage of jobs in the oil/gas and meat packing industry. Many recent immigrants from African and Caribbean countries have moved to two cities in this region to work for a business that employs approximately 2700 employees. An increase in the number of immigrants has, to a certain extent, changed the area's social structure and approaches to health service delivery. Ensuring that immigrants have access to health care services is an important issue for them as well as for both the government and the health care providers.

Within the last 10 years, there has been an increase in the number of immigrants and refugees coming to Canada from HIV/AIDS endemic countries. A country is classified as "HIV-endemic" if it has a high prevalence of HIV infection in the general population (generally greater than 1%, but in some countries, the prevalence rate may be 20% or higher), and heterosexual contact is the

most common mode of transmission (more than 50%) (Health Canada, 2003). The available HIV and AIDS surveillance data from Health Canada suggest that there was an increasing proportion of AIDS cases among persons from the endemic countries. Studies from Ontario indicated that people from some endemic countries of the Caribbean and Africa are at greater risk for having HIV/AIDS (Handa & Negash, 2003; Remis, 2003). In 2002, approximately 12% of Ontario's 22,100 HIV/AIDS cases were people from Africa and the Caribbean (Remis, 2003). According to the epidemiological data released by Health Canada in 2003, four Caribbean countries, which include Jamaica, Trinidad, Guyana, and Haiti, and five African countries, which include Ethiopia, Uganda, Somalia, South Africa, and Kenya, accounted for the majority of infections (Health Canada, 2003). Alberta also reports increasing numbers of immigrants from these countries as shown in the table below.

Alberta: 2001 Census

Caribbean Countries	Total Immigrants	Recent Immigrants
Jamaica	3,710	310
Trinidad	2,700	95
Guyana	2,150	135
Haiti	270	147
African Countries	Total Immigrants	Recent Immigrants
South Africa	4,025	1,310
Kenya	2,880	No data
Congo	No data	180
Somalia	No data	415
Sudan	No data	177

While epidemiological data indicated the growing development of an HIV/AIDS crisis among Black Canadians, less than 50% of key informants from Caribbean and African communities thought that it was having a large impact on the community (Health Canada, 2000). According to key informants (Health Canada, 2000), community members felt a great deal of fear about being abandoned by their community and sought HIV as a taboo subject in the community. In their countries of origin, HIV positive individuals may be at risk for many negative consequences, including abandonment by family and friends, discrimination at work, loss of land or children, and violence and abuse (UNAIDS, 2001). A study conducted in Toronto examined the sources of HIV denial and stigma and the mechanisms by which these are perpetuated among African newcomer communities (Gray et al., 2006). The research revealed that even though individuals in African newcomer communities are accessing HIV testing there are still issues surrounding confidentiality and anonymity that call for education and advocacy around HIV testing practices (Gray et al., 2006).

It has also been suggested that the increasing incidence of AIDS cases among persons from endemic countries was possibly due to late diagnosis of HIV, decreased access to treatment, and increasing infection rates among these groups (Falconer, 2005; Health Canada, 2003; Mill & Anarfi, 2002). There were significant challenges in providing health care to these immigrant populations. The HIV Endemic Task Force (HETF) in Ontario reported that in some cultures, discussion of sexuality and sex is taboo (Handa & Nagash, 2003). Furthermore, the fear of

community censure/backlash and social stigma prevented these individuals from accessing the professional support and assistance which might be available to them (ACCHO, 2001, 2002, 2006; deBruyn, 1998; Falconer, 2005; Handa & Negash, 2003; Mill & Anarfi, 2002).

Given that half of the HIV/AIDS diagnosed cases among persons from endemic countries were infected after arrival in Canada (Remis, 2003), it was important to stress prevention and treatment of HIV/AIDS amongst recent immigrants. However, the Health Region's Medical Officer of Health and several key community stakeholders reported meeting significant challenges with providing care/support for immigrants with HIV/AIDS, and preventing the spread of this disease. They acknowledged that these challenges resulted from a limited understanding of (a) how immigrants with HIV/AIDS coped with HIV-related problems; (b) what immigrants did to prevent the spread of HIV/AIDS; and (c) what kinds of support they needed.

The Health Region's health care and service providers were of the opinion that to provide timely and effective health care services, and to provide culturally appropriate outreach to immigrants living with HIV/AIDS, we needed to investigate factors that influence HIV/AIDS health care seeking, prevention practices, and barriers to care among immigrants living in rural centers.

Ecological Conceptual Model

This exploratory qualitative research was based on the theoretical foundation of an ecological conceptual framework. The ecological conceptual framework, which refers to the interaction between individuals and their physical and sociocultural environment (Sallis & Owen, 2002), has its roots within the ecological perspective. This perspective has been used as a theoretical foundation that informed the Canadian health promotion framework as stated in the Ottawa Charter for Health Promotion (Epp, 1986) and several other documents such as Lalonde's (1974) and Epp's Framework (1986). Based on the ecological model, individuals' health care behaviour is seen as influenced by their physical environmental variables, intrapersonal, and other social determinants of health (Green & Kreuter, 1991; Green, Richard, & Potvin, 1996; Hamilton & Bhatti, 1996; Vollman, Anderson, & McFarlane, 2008).

Thus, to facilitate the most healthful outcomes and individuals' behavioural changes, efforts should be directed at changing unfavourable environmental conditions in which one lives. Not only should health promotion interventions address what was identified as the population's needs, but also interventions should happen at multiple social, cultural, and environmental levels (Hamilton & Bhatti, 1996; Poland, Green, & Rootman, 2000). Furthermore, to promote and maintain population health, we must (a) provide health information and life skills necessary for the individuals to make health care decisions, (b) offer economic and social conditions conducive to health and healthy lifestyles, and (c) increase individuals' accessibility to social goods and services (Green, Richard, & Potvin, 1996). Thus, in order to address the problems associated with HIV/AIDS and promote HIV/AIDS prevention, we investigated how environmental factors and other social determinants of health influenced individuals' health care practices and the choices they made.

Immigrants' Health Care Practice

Individuals' cultural backgrounds have shaped their explanatory models of illness and disease, and their expectations toward treatments, which in turn, determined how they made decisions regarding coping with illness and health care practices (Good, 1994; Kleinman, 1978; 1980). Kleinman (1980) suggested that “[people’s] beliefs about sickness...including their treatment expectations ...affect the way individuals think about and react to sickness and choose among and evaluate the effectiveness of the health care practices available to them” (p. 38). Individuals’ explanatory models, derived from their knowledge and values that are specific to their different social cultural backgrounds, provided an explanation for sickness aetiology, symptoms, pathology, course of illness, and treatment (Kleinman, 1980). One of the major deterrents of client compliance, satisfaction, and appropriate use of health care services was the difference between explanatory models of recipients and providers of health care (Kleinman, 1980). Providing effective health care requires that providers be able to elicit and recognize recipients’ beliefs and values with respect to their understandings of illnesses and treatments and to negotiate these differing perspectives (Kleinman, 1980).

Immigrants’ conceptualization of health and illness, cultural beliefs, values, and expectations towards treatment have influenced the ways in which they viewed and used Western medicine and shaped the ways in which individuals/families coped with illness (Donnelly, 2004; LaBun, 1988; Maltby, 1998; Stephenson, 1995). The different environments and circumstances from which immigrants came have not only created many health problems, but also created barriers to accessing health care (Stephenson, 1995). Also important to the recognition of HIV as an issue and response to it are cultural attitudes toward gender and sexuality among African newcomer communities. The prevention and treatment of HIV requires some degree of openness about sexuality and sexual behaviour. As previously mentioned, the HIV Endemic Task Force (HETF) in Ontario reported that in some cultures, discussion of sexuality and sex is taboo (Handa & Nagash, 2003). This might help explain why even relatively well-educated populations are not necessarily knowledgeable about HIV/AIDS (Huang, 2008). In predominantly Muslim countries, HIV is considered proof that an HIV positive person is not a good Muslim, since sex outside of marriage is forbidden. (ACCHO, 2006). In strong patriarchal cultures, women are particularly vulnerable to HIV risk as they may not be comfortable raising issues of sexuality, fidelity of partners, or condom use (Keeping, 2004; Tharao et al., 2004). Among some communities, there is acceptance of extra-marital sexual relations for men, but not for women (UNAIDS, 2004). While women may find a diagnosis of HIV/AIDS doubly stigmatizes them as promiscuous, the link between homosexuality and HIV/AIDS creates a double stigma for men (Zuniga, 2008). Homophobia among African and Caribbean immigrant communities may also create risk situations for men who have sex with men (HIV Endemic Task Force, 2005). Spiritual and religious beliefs may be important in cultural attitudes toward HIV and sexuality. For example, within some African communities in Toronto, there are beliefs that HIV is a punishment from God (Baxter et al., 1993). It is important also to keep in mind that in many areas of Africa, untimely death is common and to a certain extent often random. This contributes to a feeling that one should not worry about death, as it comes in many ways or is in the hands of God (ACCHO, 2006). While this fatalism helps Africans cope with the constant presence of death in their home country, it may lead to passive behaviour in their adopted country when it comes to seeking medical help. Indeed, in focus groups Guyanese and Trinidadian participants mentioned a

tendency to avoid medical help until illnesses are very far advanced, particularly among men (ACCHO, 2006).

Furthermore, immigrants' health care behaviour is influenced not only by their cultural knowledge and values, but also by their marginalized social position within a society, which in turn, affects how they access available health care resources (Donnelly, 2004). Studies by Donnelly (2004, 2006) and Stephenson (1995) found that immigrants often experience difficulty accessing existent health care services. This finding, although not specifically related to HIV/AIDS, suggests that immigrants might be less likely to access health care services to deal with their HIV/AIDS and its related problems compared with people in the general Canadian population. There is a tendency within the wider Canadian society to view HIV as a Black or African disease, but even within African or Caribbean immigrant groups, people feel that HIV was brought to their country by other racial, ethnic or national groups (ACCHO, 2006). Worldwide, stigma against people with HIV is known to discourage them from seeking diagnosis and treatment. According to ACCHO, service providers report that people from Africa and the Caribbean often fail to seek out the services that they need because of their fear of stigmatization (ACCHO, 2006). Foley (2005) also found in a study of recent African immigrants in the United States that fear of social rejection was the biggest barrier to testing. In addition to the fear of stigmatization, Fakoya (2008) stated the main barriers to HIV testing included poverty, unemployment, poor housing, lack of child care, and fear of death/disease. Mitra (2006), in a Canadian study looking at women from HIV endemic countries, found that in addition to fear of stigmatization there was also fear of informing their partners and possibly losing them.

Barriers to accessing and providing health care services for immigrants included language difficulty; different cultural health beliefs and practices; a lack of cultural acceptance; appropriate health care services; social resources (Anderson, 1998; Donnelly, 2004, 2006; Hirota, 1999; Stephenson, 1995; Uba, 1992); and low socioeconomic status, low level of education, and poverty (Donnelly, 2004; McPhee et al., 1997). A recent study conducted in Canada suggests that gendered roles and expectations, diminished institutional and social support networks, and low socioeconomic status contributed to immigrants' inability to access the available health care services (Donnelly, 2004). Studies also found that the length of residence in the adopted country might affect immigrants' participation in health promotion and disease prevention activities (Cheek et al., 1999; Lesjak et al., 1999). Bloor, Barnard, Finlay, and McKeganey's (1993) study of HIV-related risk practices found that health care-seeking and/or illness preventing behaviours are largely shaped by individuals' immediate circumstances, and are affected by contextual factors of their situations. Thus, research investigating individual behaviour related to HIV needs to explore the context in which these behaviours occur (Zwi, 1993).

The Study Purpose and Research Questions

The Study Purpose

We proposed a research project for which the goals were to:

1. Understand the health care milieu as experienced by recent immigrants;

2. Identify and implement strategies which will assist recent immigrants to manage HIV/AIDS and its related problems, and limit the spread of this disease;
3. Evaluate and facilitate recent immigrants' success in seeking help for and preventing HIV/AIDS.

Research Questions

To meet the research purposes, this study answered the following research questions from the perspectives of both recent immigrants and their health care providers:

- 1) How do recent immigrants seek help to manage their HIV/AIDS and related problems?
- 2) How do recent immigrants deal with social stigma and consequences of having HIV/AIDS?
- 3) What factors (barriers and facilitators) influence immigrants' use of HIV prevention activities and services?
- 4) What services and strategies could address HIV care and treatment among recent immigrants?
- 5) What intervention strategies could promote the use of HIV prevention activities and early detection among recent immigrants?

The Study Methods

Ethics Approval and Informed Consent

This research was reviewed by the University of Calgary's Conjoint Health Research Ethics Board and the Health Region Ethics Board. Informed consent was obtained from each participant. Prior to conducting an interview, each participant was given an explanation of the study and her/his rights according to the standard interview guideline. Participants were assured that all information would be confidential, and would be kept in a locked cabinet and password protected computers. Code numbers were used, and transcripts and interview questionnaires were stripped of identifying information to preserve confidentiality. At the conclusion of the study, all identifying information and audiotapes will be destroyed. Electronic and paper versions of interview transcripts and field notes, stripped of identifying information will be retained for educational and other research purposes, subject to ethics approval.

It is imperative that we investigate what immigrants are facing in a timely manner in order to help them manage health problems and to prevent the increasing incidence of HIV and AIDS. Recognizing that there is potential public backlash when HIV is linked with immigrants, cultural sensitivity and reflexivity to spoken and written texts have guided the construction and representation of the research participants' lived experiences. We paid close attention to the language of the participant and the analysis, and what it was interpreted to mean in English. To avoid creating any stereotypical assumptions about the AIDS problems in the immigrant population in this small community, we critically and consciously exercised our sensitivity and reflexivity to what kind of information we presented, how we presented our work, and the kind of impact that our research results will produce for the community.

Data Collection Recruitment Process

In-depth interviewing is "a data gathering technique used in qualitative research when the goal is to collect detailed, richly textured, person-centered information from one or more individuals" (Kaufman, 1994, p. 123). In this study, the process involved in-depth ethnographic interviews in which the "watch, ask, listen, record and examine" approach (Schwandt, 1994) could be described as open but focused. The participants were able to describe their experiences as openly as possible while still maintaining a research focus because dialogue between the researcher and participants was interactive, reflective, and open-ended.

It was important for the interview process to be gender appropriate. The Principal Investigator of this study, Dr. Donnelly, a female, conducted the in-depth interviews with the women community member participants. A male nursing student from the University of Calgary, who is of African decent was hired and trained as a research assistant to conduct interviews with the male community member participants. However, there were participants who agreed to be interviewed by either a male or a female interviewer. Because investigation into the HIV/AIDS experience is difficult due to the social stigma and perceived threats associated with its diagnosis, it was essential that the interviewer not only have the interpersonal and interviewing skills, but could also relate to the experience of being an immigrant in a new country. The research assistant is a male immigrant and a person of colour, and Dr. Donnelly is a woman who has gone through the experience of escaping from war torn Vietnam, living in a refugee camp, and being a refugee living in Canada. This helped the research assistant and Dr. Donnelly to establish trusting relationships with the immigrant participants.

Every effort was made to be respectful towards the participants' concerns and ensure that participants could withdraw from the study voluntarily if they so desired. Because many of the immigrants might not be familiar with the research process and may come from a country where the political turmoil created mistrust and a fear of authority, and additionally, many might have a history of traumatic experiences, immigrants might have been hesitant to answer personal questions. Therefore, sensitivity and careful explanation of the research project was exercised by the researchers. Recognizing that social, economic, and political issues exist for participants who came from different environments and contexts, we paid careful attention to the diversity of participants' experiences. We emphasized that as health care professionals, we are concerned with health care issues, and that our purpose is to find ways to help people who live with HIV/AIDS to deal with health problems and to prevent HIV/AIDS from being transmitted to others. If during the interview the participant experienced any level of distress, appropriate measures were taken to support the participant and if at all possible, the interview would be rescheduled at a later date and time convenient for the participant. For example, one participant had experienced emotional distress, and the researcher discontinued the interview and asked the participant if she would like to talk with a counsellor. The interview was not rescheduled due to the participant's high level of emotional distress.

Originally the individual in-depth interviews were to be conducted in the language that was preferred by the participant. If the participant did not speak English, gender appropriate translation services were to be arranged using professionally trained translators from outside the region, to protect the participants from being identified as HIV sero-positive within the local

community. However, the researcher found through consultations with a group of healthcare providers who form a Newcomers Advisory Committee in the region, as well as several community health nurses who work with immigrant and refugees, that this approach was not well supported. The informants said that a face-to-face interpreter would not work for these individuals living with HIV/AIDS. They felt the participants would be much more comfortable with having a Language Line interpreter, a service provided through a company in California. This service would be much more anonymous, since confidentiality was a huge issue and concern for these individuals. In the end, the language line was used for some of the interviews and when this was not working well, the interviews were conducted in English, with careful attention to clarifying and double checking the meaning of what was said.

At the beginning of each interview, the researcher again explained the study to the participants, answered their question(s), and asked each of the participants if she/he would be willing to participate in the study. Each immigrant participant was individually interviewed twice for one hour to one-and-a-half hours. Each health care provider participant was individually interviewed twice for 30 to 60 minutes. All the interviews were audio taped with consent from all of the participants. An interview guide with open-ended questions was designed specifically for the study. In addition, we also assessed socio-demographic information about the immigrants which provided additional information about their socioeconomic status and social support networks. When the data reached saturation, a point at which no new information was reported by the participants (Morse, 1994), no further interviews were conducted.

Individual in-depth interviews were also conducted with the health care providers to gain their perspectives about the challenges they faced in providing health care to recent immigrants living in small rural centers, and what they perceived as the needs, concerns, and strengths of the immigrants with whom they interacted. The main reason for this avenue of inquiry was that high quality and efficient health care services could only be achieved if there was a mutual understanding between the health care providers and the immigrants. To investigate whether or not discrepancies exist between the immigrants' perspectives and the health care provider's perspectives, health care professionals were asked similar questions. We also inquired what these professionals believed motivated or prevented immigrant men and women to seek help and engage in HIV/AIDS testing and prevention; what they perceived as barriers for the immigrants to access health care services; what information, health care program and services would best benefit immigrants; and what they perceived as the best possible strategies for caring for these patients and promoting prevention among immigrants.

Interviews with Health Care and Service Providers

In total, 34 health care and service providers were interviewed (Please see health care and service providers' profiles – Appendix A). Selection criteria for health care providers included that (a) they are residents within the health care region in the study; (b) participants provided direct services to immigrants who live in the two rural centers in the study; and (c) there be a health care policy maker, a social worker, a family physician, pharmacist or a nurse. We sent an information letter about the study to health care organizations to inform them of the study. These organizations, in turn, passed on the information or informed the appropriate health care providers about the study and criteria for participation. Health care providers who identified

having immigrants living with HIV/AIDS as patients, and who worked with HIV/AIDS programs/services were invited to be participants in the study. Individuals interested in being participants were asked to contact the co- investigator, Dr. Schnee or Dr. Donnelly, via email or telephone. They were also asked for permission for Dr. Donnelly to contact them via email or telephone.

Interviews with Community Members

In total, 39 community members who met the study's inclusion criteria were interviewed (Please see community member participants' profiles – Appendix B). Selection criteria for immigrant participants included immigrants who (a) have lived in the region within the past 10 years; (b) were born in Africa, and Caribbean countries; (c) immigrants who had been diagnosed with HIV/AIDS and immigrants who had not been diagnosed with HIV/AIDS. We anticipated that recruitment of immigrant participants living with HIV/AIDS would be a challenging process due to social stigma and discrimination. Therefore, every effort was made to connect with the community through our co-investigators and collaborators who worked with immigrants living with HIV/AIDS in the region. The Health Region's Medical Officer of Health was successful in convincing the Regional Board and Management to hire a Newcomer Health Services Liaison Worker (fully dedicated to the needs of newcomers), and a Community Development Worker who was familiar with the issues relating to immigrants. These workers proved to be very important collaborators who assisted us in establishing contacts and trust amongst recent immigrants. Even though we made every effort to recruit participants who lived with HIV, it was very difficult due to the stigma and discrimination associated with the disease. In the end we were only able to interview three individuals who had HIV positive status.

Data Analysis

Data obtained from interviews with the three groups of participants (immigrants with HIV/AIDS, those without, and health service providers) were transcribed as soon as possible. All of the interview data were coded for referencing key words and accessing examples or experiences to be quoted. The data coding and analysis followed the methods used in qualitative research approaches in which data are gathered, transcribed, reviewed for coding and analysis by several research team members (the principal investigator and two graduate research assistants), and then used to clarify and expand emergent ideas, concepts, and themes. The process of data collection and data analysis occurred concurrently. Data from the first interview was transcribed and preliminary data analysis was done prior to the second interview. This approach helped to identify themes, emergent ideas and concepts that needed to be clarified and/or expanded with the participant in the second interview. The approach in working with the transcribed data included profile construction, continuous data analysis, and interpretation. The data analysis became an ongoing process that involved thorough reading, markings or comments in the transcript margins, identifying, refining, adding codes, and categorizing themes. An audit trail was established and monitored by the principal investigator of this project to ensure rigor of data analysis process.

The process of data analysis included specific steps. **Step 1:** As data were obtained, they were transcribed as soon as possible. To ensure accuracy, the transcripts were rechecked against audio

tapes, corrected, and the final hard copy was printed for preliminary data analysis. The principal investigator of this project, Dr. Donnelly, and two research assistants were each given a copy for data analysis. **Step 2:** In the early stages of analysis, transcripts were coded to identify preliminary themes and to formulate a list of code categories to organize subsequent data. These code categories were refined as subsequent data were gathered. **Step 3:** Data coded in one category was examined for its relevance to other categories. The final outcome of this analysis was a statement about a set of complicated interrelated concepts and themes. This process of data analysis, which was flexible and evolving, consisted of systematic and rigorous development of code categories and subcategories. During this step, research team members met to review the preliminary results, and the process of conducting the interview, personal feelings, and analytic descriptions. **Step 4:** Emerging or identified themes and concepts were used to compare within and across data set transcripts and across research subjects. This generated a higher level of data conceptualization and broader theoretical formulations. This step also included a second interview in which we returned preliminary results to 10 participants who the principal investigator of this project believed could give insightful and reflective responses, as a form of “member checking.” This process enabled the researchers to clarify, expand, and discuss with the participants the emergent themes, ideas, and concepts. It also helped the research team develop deeper understanding of the data and gain more insight into immigrants’ HIV/AIDS health care experiences, and the social processes and structures that organize these experiences.

Because data categories were developed partially on the meanings that participants attributed to their experiences (Carspecken, 1996), we paid particular attention to the ways in which meaning was reconstructed. Meaning reconstruction involved the way in which researchers mentally noted the possible underlying meanings and/or messages that the data conveyed. In this study, meaning was understood and contextualized by reflection into the everyday life of the participants. As pointed out by Carspecken (1996), the articulation of possible meaning involves the researchers' inference of meanings, often implied, either overtly or implicitly. Because there is always an element of uncertainty and ambiguity in what researchers’ interpret, validation with participants of reconstruction of meanings is necessary.

Carspecken (1996) recommended several ways that researchers could support articulation of meanings. First, the more familiar researchers were with the culture of their participants, the closer their articulated meanings would be to that of the participants. Having gone through a refugee experience, Dr. Donnelly was able to understand some of the issues immigrants faced and continue to face. Furthermore, Dr. Donnelly was supported by members of this research team who had extensive experience in doing research with immigrants and HIV/AIDS. Peer-debriefing with members of the research team during meetings gave additional insight into the social, cultural, and economical processes with which the immigrants were coping. Second, the use of member checks helped refine our articulated meanings (Carspecken, 1996). In this study, member checks were conducted by sharing the results of our preliminary data analysis with 10 participants in the second interview. Member checking was also conducted by consultation among the research team members through meetings that included reporting what was conceptualized from the data and research seminars that included formal presentations and consultations with the health care and service providers, and community members.

Another form of member checking involved generating dialogical data, in-depth interview data generated through dialogue between the participants and the interviewers. In this study, an open-ended mode of inquiry guided the interviewers' interaction with participants and interpretation of data. Active interactions between the participants and the interviewer were employed. The participants and the researcher discussed, negotiated, and decided on what the researcher understood as the meaning of the data. Further exploration and clarification with the participants of the researcher's interpretations has led to greater understanding of participants' experiences. These activities provided ways for further "member checking."

Trustworthiness and validity are important issues in research. To ensure rigor and credibility of this study, in addition to "member checks," "critical self-awareness" and "self-decentralizing" (Lather, 1991) were employed through recognizing that the researchers' social position and perspective influence the research process. Validity, to Carspecken (1996), referred to "the soundness of arguments"(p. 55). Validity is, thus, "inherent in the structures of communication...[and] how well it meets validity criteria derived from the communication itself" (Carspecken, 1996, p. 57). In this study, for our analysis to be considered as "valid," our interpretations needed to be agreed upon (or to achieve consensus) with the participants. Besides making sense of the data, paying attention to the politics of creating meaning, exercising self-reflexivity and self critique, and ensuring rigor and credibility of the study, there were ethical issues which needed consideration.

Results

In the following sections, each of the five research questions was addressed in turn. Given the degree of inter-relationship among the themes, there was some repetition of themes across the research questions. All names of participants used in the text are pseudonyms.

Research Question 1: How Do Recent Immigrants Seek Help to Manage Their HIV/AIDS Related Problems?

Coping Styles

Interviews revealed two main coping or management styles or approaches which recent immigrants with HIV/AIDS used to cope with or manage their illness and related problems. These coping styles have an effect on how, and if, an immigrant seeks help for his/her HIV/AIDS diagnosis. The first primary style or approach was identified as strengths in coping with disease, more specifically what health care and service providers describe as personal, family and community supports or strengths which recent immigrants with HIV/AIDS engage to help them cope with their illness, in particular, as well as other related problems. The second approach demonstrated by some of the recent immigrants with HIV/AIDS included alternate ways of coping. These included the less effective, passive, and sometimes self destructive behaviours.

Strengths in Coping with Disease

Family

There were several supports or strengths identified by health care and service providers which they felt gave the recent immigrants with HIV/AIDS the capacity or ability to not only survive but also manage their illness. One area of strength was the individual's family support. Not only was the family support seen as comfort and connection for the individual with HIV/AIDS, but the family provided the health care and service providers with added information. The family member(s) accompanying the individual to appointments often provided key information about the individual and helped translate when language barriers were an issue.

...family wise, they seem very connected, you know. Almost any time there's an older client...there is a younger family member always who comes with them....And they are the ones who helping to look after and who are usually able to tell pretty, you know, a good story about what's really happening at home.

Family members were also seen by health care and service providers as their interpreters for those individuals whose English was very poor. Health care and service providers indicated that they depended on family members or close friends to help them get all the vital information and not miss anything that was critical to the care for the individual.

Community members also mentioned family support as being pivotal when someone received a diagnosis of HIV/AIDS. Two of the community members with HIV said their partners were supportive. For most community members, HIV was a well known disease, and while they may not know everything about it, they indicated they were supportive of family members who had it, or felt that they would be supportive, if they learned a family member had the disease. Community members indicated that there was strength, encouragement and hope through family involvement with family members who have HIV.

Family is part of your flesh and they will be sorry for what has happened to you. Family would suffer more than you. Family would help me very much. Like anyone else they will help with anything. In my family, if I have a brother who has this, I would think of it more seriously.

Ashley, who has HIV, is one example of this strength and support. She said her baby is her inspiration to keep going, and her family provides support by distance via telephone. She indicated her husband who was HIV negative is also supportive in many ways. The community members felt family members could be trusted more than friends or others, both to be supportive and to keep the diagnosis secret. Participants felt that if family members play an active role in the care and treatment of the individual with HIV, they could also be involved in helping financially, or with accommodation, cooking, cleaning or providing transportation to treatment clinics in the city. Without support from family, it was reported that those with HIV were often isolated. One HIV positive community member had no family in Canada and was sending financial support to his family in his country of origin. When he was first diagnosed, he felt very depressed, to the

point of being suicidal. Fortunately a social worker helped him through counselling, and he claimed to no longer feel suicidal, but was still worried about his future. He did not feel he could have a girlfriend or ever have a family. In his interview, his loneliness was obvious. In contrast, the other two HIV positive community members had strong family support both in their home and at a distance, and were much more positive. Lena said, “Obviously they have given me more love, they think that I’m (laughs) depressed somehow, somehow, but, they don’t know that I’m very strong (laughs).”

Family support was not universal amongst all immigrants, however, as one health professional pointed out. As Sarah said, “... one of the big things with our new Canadians is being away from family and the people that you might have ordinarily gone to for questions, my mum’s not here, my grandma’s not here, my aunts aren’t here.” Much of this particular immigrant population is transient, and their family may still be in the country of origin, dispersed around the world, or even largely gone due to war or famine.

Independence

A second strength or support identified in recent immigrants with HIV/AIDS was their desire to be independent. Health care and service providers indicated that there were some individuals who were adamant about taking care of their own needs without assistance from the local health system. Instead, the individuals preferred to travel to a clinic in the city. The health care and service providers did not voice concern about these individuals as they demonstrated that they are coping in a positive manner, are more compliant with their medications, and will seek reading materials, information, and medical or financial help if and when they needed it.

Resiliency

Another strength which health care and service providers observed of recent immigrants with HIV/AIDS was their resiliency. Those interviewed mentioned the courage and adaptability of immigrants in leaving their home countries, and in many cases their families, in coming to a very different country where they most likely knew no one and could not speak the language. As newcomers, they were described as hard working and committed to improving their lives and supporting their families, whether those families were still in the country of origin or living in Canada. These individuals appeared to be quite resourceful and resilient with or without their family supports. Many individuals were described as having to be resilient from a young age back in their home countries where many experienced political turmoil, war and other horrors.

...here they’ve been resilient too and if they are working, I mean that’s remarkable, that they have been able to work with this illness and get to this country. I mean, just in, even if they’re immigrants or newcomers to this country, I can’t imagine the amount of determination that’s taken to get here. So, it’s hard to know what are the strengths, other than they survived, they’ve gotten here, they’re resilient group of people, obviously, or else they wouldn’t have, I can’t imagine the journey to even get here.

While the community members interviewed did not talk about personal resiliency per se, a few mentioned that having HIV would motivate them to seek treatment so they can stay alive. Their view was that becoming educated about HIV, and knowing where to go for good information, helps individuals to be more aware of what they need to do to prevent getting it or to treat it. The theme of taking responsibility for one's own health was recurring in the interviews. One community member said: "I think one of the most important things with HIV/AIDS is to control it, make sure you don't become a victim." Getting tested was also seen as important to ensure community members take action immediately upon getting an HIV diagnosis. Others talked about the need to stay safe and to protect themselves when they have HIV, especially from getting other diseases or opportunistic infections.

Well, the final thing I have to say here is I just, people don't have to neglect things. Because by doing that you causing yourself a problem, by then, by the time you knew it you've already, you're already gone. So advices that I have is to my fellow Africans, um, I think prevention is better than cure. So, if you prevent yourself --- As I was saying, prevention is better than cure so we don't need to take chances on those things. We need to be very, very careful with ourselves.

Community

The health care and service providers pointed out that recent immigrants with HIV/AIDS have a sense of community and the ability or capacity to seek out or develop community supports with others who have the same or similar background cultures and language.

They have much more of that community sense. So if community is their strength, I really think we should build on that to strengthen our own sense of community, because we seem to be lacking in that respect. In comparison to these cultures, we lack greatly in that. I mean, you know everybody raises their children. The whole village raises their children in Africa. Here, you don't know your neighbour. So, there is a strength in that you have to really admire. Their optimism, you know? The sun will come up tomorrow. They'll be okay.

In keeping with the health care provider's observations that the immigrant population seems to have a strong sense of community, community members talked about "koob" which is a type of financial support which family or friends in the community provided to those in need. A group of close friends put money into a box every pay-check which can be given to different people in the community who need financial help. Community support provides additional strength to individuals in the community.

When we recognize that we are one we will able, we will know how to treat those that have AIDS. Even those that are far away from us we will know what to do for them to encourage them. But when we're not together, no. We can't do nothing. We only say it and we only see. As an individual, you go there you say oh, this encouragement, encourage them but beside

that – so now the community not together we can't do anything.

Positive Attitude

Having a positive attitude towards life generally was seen as a strength in many of the recent immigrants with HIV/AIDS. As a result of this attitude, health care providers claimed that some immigrants also appeared much happier and less bothered by their problems, including having HIV/AIDS. Community members mentioned the importance of having a positive attitude towards life if one has HIV and towards coping in a proactive manner with the disease. As one of the community members living with HIV said, "I'm not going to let this thing to hold me down, I'm not going to do that. I still have my dreams." Another community member with HIV also believed that wholesome nourishing food will give strength as well. The community members with HIV also claimed to be compliant with taking their medications and attending their frequent doctor's appointments.

Those interviewed observed that individuals cope in different ways with their HIV/AIDS. There were many factors which could be attributed to influencing attitudes, coping and outcomes related to dealing with an illness like HIV/AIDS. One of the factors identified is that a person's employment or place of work could have a positive impact on individuals with HIV/AIDS which would help them to cope better with their diagnosis and illness management, if that workplace is supportive of the individual's health needs and flexible about medical appointments. In fact, one of the community members living with HIV met a social worker through work, and reports that she has helped him greatly.

Some individuals also take the time to research and understand their illness and medications. This gave them some control over what happened to them and was an added strength in helping with their long term management of HIV/AIDS.

Health Care Professionals' Support

The community members with HIV acknowledged support from health care professionals such as social workers, nurses, and physicians. They described how they valued their relationships with these health professionals, and that the support had been both in terms of physical health and mental health. The social worker provided good advice as did the nurses, but the nurses are often more available to talk. In terms of community supports, some thought the social worker is most accessible and accommodating. However, when it comes to testing, diagnosing and providing direct care and treatment, most community members felt that their doctors were the first point of contact and the ones they would feel most comfortable giving information to as he/she would be making all the decisions about tests and treatment. Community members trust their doctors to be the most knowledgeable about HIV. Even those community members who do not have HIV said that the doctor is their first or primary contact for testing, diagnosing and follow up care. They cited the hospital as the place where some might go first to find a doctor who has the expertise in HIV. One individual claimed that the doctor is also the one who can refer the patient to others needed in his/her care, such as a psychologist who can help with depression or providing some hope.

Counselling support is also important from the perspective of some community members. They felt that it is important to keep reaching out to those with HIV who are down or depressed about their situation, and to show them acceptance. However, the HIV positive community members did not express any interest in group or peer support. One member stated quite firmly that he would not be interested in a peer support group. This is possibly due to the risk of disclosure of HIV status, which will be discussed later. One health care professional commented, “But we haven’t had anybody that had taken them up on peer support and wanted that support.” Jen, another health care provider, pointed out that in a smaller community, running a peer support group and keeping information confidential would be a challenge. Individual counselling from a social worker or a nurse, however, was instrumental in giving individual hope for the future.

Spirituality

The three community members with HIV all mentioned how their belief in God strengthened them. Other community members also mentioned faith as important in their lives. Pam stated:

I believe in prayer. If, if somebody can be prayed for, for every other sickness and get well, so AIDS is not a different thing...I believe in God.... . Some people might be very faithful that prayer can heal them. Some wouldn’t. Some would seek help and at the same time seek prayer. Some would use prayer more than the medications. So it depends on the faith of the person.

Mangahsu also knew people who believed faith could heal them, although he was personally more sceptical of this belief:

Even here in Canada, some of those private churches ... they can pray for you, all your sickness out from you....somebody have HIV, pastor will say we pray for him the sickness will be out....To me, I don’t believe in that.

One community member mentioned that the church minister (or equivalent) would be a good place to go for support.

Some health care providers interviewed also mentioned spirituality as a strength with some of the immigrant population. They have observed these people had a belief or trust that someone was caring for them. As Mary stated, “They have a spiritual faith, most of them that I’ve found y’know, beyond any that I see here, they truly trust that somebody is caring for them, somewhere.” Those interviewed described this belief or faith in God as being their strength to either be healed or to seek medical care to help them get better.

Alternate Ways of Coping

The health care and service providers described individuals who were often the most difficult to treat or talk with about treatment. They either fear finding out that they might have HIV/AIDS, or if they do have HIV/AIDS, are in denial over the seriousness of the disease. Some have limited education which makes it difficult for them to grasp the importance of immediate and consistent treatment, or to learn to manage living with the disease. Some of these individuals

choose denial as a coping mechanism, and are so deeply in denial they refuse treatment and do not wish to be educated about it.

We have patients who are positive who won't listen to health promotion strategies or ways to keep themselves and keep the public safe. But they're very elusive as well, y'know, if you become too forceful and you start throwing around words like public health act, they disappear and you can't find them, but ... their name pops up every so often, so you know they're still around. As far as the myths that go, y'know, they all come here with an idea that well, for starters lots of them won't even go for pre-assessment... because they just think they're gonna die.

Other individuals, particularly the immigrant women with HIV/AIDS, were described as having passive behaviour. One female service provider participant said, "... with the first woman, whose partner left her, she sort of dealt with it as if, oh well, I guess, I don't know if she felt that she deserved it, but she probably wasn't surprised and that was her lot in life to go through this without her partner." Another female, who was HIV positive, allowed her HIV negative husband to have unprotected intercourse with her. She was not happy about it, but she felt it was his choice.

Community members without HIV spoke of some individuals who, either through anger or indifference, spread their disease by neglecting to use condoms. The community members gave examples of persons they know, some of whom are married with children, who have unprotected sex with others in the community. There are issues with using condoms as well. As previously mentioned, a participant reported that her husband did not always use a condom when they had sexual relations.

But all the time I say to him, let's have protected sex. He'll say, it doesn't matter, I don't want to. And then, I'll feel so bad at the end of the day. I'll say, no, we have to use, and then he'll say, y'know what, you are my wife, whatever happens to you, it doesn't matter, whatever happens to me, doesn't matter. That's how he'll say and like, but sometimes, I'll try to say, no, it's not right, you have to protect yourself. Then he'll be like, why? It doesn't matter, we've been together for so long, so...

Some described how difficult it was to accept a diagnosis of HIV. Depression and hopelessness can drive people with HIV to self destructive behaviours, such as drinking and drug use. A participant reported drinking excessively when he was first diagnosed, before he talked to a social worker and found new hope. Tracy described a colleague of her brother's who turned to alcohol for comfort: "... he did everything for that guy and every week they took him to the hospital, for his treatment and my brother made sure he took the drugs because if he don't give it to him, he won't take it. He didn't care." The individual lived with HIV in this manner for 18 years, and had it not been for those around him it appears he would not have coped nearly as well.

...even if they know that they can make a normal life, they are not, they are unhappy with that, because it is like, yeah, I can have a normal life but I still

have to take care of me, I have to take those pill[s] every day, I have to do this, I have to go to the doctor, I have to drive to [large urban centre], you know, and yeah, I think my feelings is like, sometimes some of them, they feel so depressed, like, sometimes, they really want to, to kill themselves you know, and sometimes they just want to cry, and cry...

Summary

This section looked at the first research question, *How do recent immigrants seek help to manage their HIV/AIDS and related problems?* Immigrant's coping styles influenced how and when they sought help to manage the challenges related to an HIV/AIDS diagnosis. Both the health providers and the community members mentioned the resources of family and community. However, while family was seen by both groups as people one could turn to for support, not everyone was convinced that the community would necessarily rally around a member with HIV. Some community members felt the immigrant community would be loving and supportive, but many of these participants were speaking hypothetically and had not necessarily tested this assumption. Others were not so sure the community would understand or would want to risk exposure, and felt a person with such a diagnosis would be wisest not to risk it. The participants with HIV had not told anyone outside their family of their diagnosis. The health professionals remarked on strong community, but not to the extent of saying that an HIV positive community member could self identify with impunity.

Spirituality and faith were mentioned by health care providers as an important strength, and some of the community members also mentioned this. Not all community members shared this strong faith, however.

Health care professionals remarked on the courage and resiliency of immigrants, and two of the community members with HIV spoke of being positive and keeping their dreams alive. The community members with HIV remarked on how much the health professionals they saw had helped them, in terms of both the clinical and the psychological aspects of managing their disease.

Both health care professionals and community members also mentioned that some individuals with an HIV diagnosis resorted to denial, suffered from depression, or turned to destructive behaviours, such as having unprotected sex or excessive drinking. Others may have defeatist or passive attitudes.

Research question 2: How Do Recent Immigrants Deal With Social Stigma and Consequences of Having HIV/AIDS?

For recent immigrants with HIV/AIDS who participated in the study, there are identified stigmas with being an immigrant and also with having HIV/AIDS. The individuals dealt with the different factors related to these stigmas and the resulting consequences. Immigrants living with HIV/AIDS coped by knowing who to trust with the information about their diagnosis, and being assured of confidentiality within the system.

Gaining Trust

One of the biggest challenges for the health care and service providers was gaining the trust of the recent immigrants with HIV/AIDS, so that a conversation could be had about the care they needed, their fears of stigmatization and learning to live with their illness in their community without fear of ostracism. Building a relationship with the immigrant requires time and patience. The discussion needs to be based on trust so that the individual will talk about their health and their fears, including fear of deportation. Health care providers in this study talked about the need to take the time to develop trusting relationships with recent immigrants with HIV. One health care professional commented:

And that's a big factor so to gain that trust from them is a challenge. And when somebody's not opening to you and there's nothing you can do. So that trust is an issue that we have to communicate properly or maybe to express themselves and then feel comfortable with the person they are talking to. So that's the, that's the challenge apart from the cultural communication, the trust and confidence that they lost maybe back home has to be built up again and show the compassion and that they can trust ... other human beings, so that is also a challenge.

Another health professional, Julia, remarked:

My big fear is that if our African population was labelled as the people who were spreading HIV in our community that would be a disaster. There would be so much intolerance... I would be very fearful of how they would be treated and how probably targeted they would be, and victimised, and I think that they would completely retreat. We would have no access to those people in terms of health seeking, and they probably wouldn't practice any of the prevention piece because they wouldn't want to maybe self identify, you know, for fear of even losing that little bit of social acceptance."

It is clear from the interviews that community members living with HIV/AIDS needed to have trust and a relationship with their health care providers in order to get the best care possible. While a good relationship with health professionals is important for everyone needing medical care, in this case the importance cannot be over-emphasized. As Julia mentioned in a quote in the previous section, "if you become too forceful... they disappear and you can't find them." Immigrants with HIV/AIDS cope with the stigma by being very careful who they trust, be it family or health care providers.

Community members indicated that beliefs from the home country played a key role in the newcomer's life in Canada. The newcomer faced stigma from not only the general population in Canada, but equally so within his/her own culture. In many places in HIV/AIDS endemic countries, poverty made it difficult for infected people to acquire medication. Death from HIV/AIDS was therefore much more imminent. Many of the community members interviewed

mentioned that they now know in Canada medications are available to them, but fear of proximity to people with HIV/AIDS remained. One community member said:

I know that if I know my friend has HIV, I know that first of all, I would not bring this person around my baby, just in case, but I will be friends with them. I will comfort with them in any way that I can...

When asked what would happen if she was diagnosed as HIV positive, she said:

(but the community will be) like, hi, from far away and they'll keep a very long distance from me. And like, even now I go to like so many parties with my community, if somebody from my ethnic group has a birthday party for their own kid, I have to go. And I have to go with my daughter. So, I know that I will not be included in those little birthday parties, those little baptism events...

Reduction of Stigma

Interviews with community members and health and social service providers suggest that finding ways to reduce the stigma associated with HIV/AIDS amongst new immigrants within the larger community are part of the challenge faced by health care and service providers in the community. Many factors were reported to contribute to the stigma and community views that exist. Whether it is the bias against the disease or the immigrants, or ignorance about HIV/AIDS and how it is or is not transmitted, the fear associated with getting HIV, the judgements made about the people who have HIV/AIDS, or other factors, participants felt that all these issues must be approached carefully. As Anne said, "there's a certain population base that has been identified as having an increased incidence. So if you target just that population in educating, what it sends is a message that this population has a problem."

Education on HIV transmission and treatment would therefore seem to be one requirement to reduce stigma and increase the receptiveness to seeking diagnosis and treatment, although how that education should be done is not clear. Julia said:

We can't even get sex education really into the Catholic schools for God's sakes, because if you tell them about sex, they might have it... that's where we are at ... there's a very sort of Christian fundamentalist undertone to our community, so if that was introduced and identified as the immigrants who brought that here, any gains we've made in terms of acceptance or tolerance, I think we'd go right back. You know, that wasn't here before the immigrants came, we didn't have HIV, which is ridiculous, of course we did, but it wouldn't be viewed that way.

Pam, a community member, agreed that education is needed:

Everybody wants to live longer. I think awareness that it's not contagious by mere contact should be enforced in the communities so that people will

know especially the people who are not heard of it, they don't know, they don't read, some of them they can't even read. They need to be lectured that AIDS is not contracted by just holding hands or [unclear word] stay in the same house or just hanging out together.

Some health care professionals felt that rather than talking only about HIV, there were various health promotion and wellness education campaigns which could be provided generally within the community to encourage people to come to the community clinic for help with their questions or health issues. Companies or groups could not be specifically targeted for education sessions on HIV as suspicion would rise and people at worksites might quit if they thought individuals with HIV were working beside them. The intention would still be to promote health education and having people openly talking about health, wellness and safety or prevention in the context of HIV and sexually transmitted diseases in general, and other communicable and infectious diseases such as tuberculosis.

Participants indicated that health care providers were not immune to the prejudices and fears of the community, and have also shown discrimination and biases towards individuals with HIV/AIDS. This creates additional concerns not only for people with HIV but also other health care providers who work closely with those individuals with HIV. Some health care providers said they were afraid that if the other patients knew about the patients with HIV in the clinic, they would stop coming to the clinic, and word would get around that the clinic treats HIV positive people. The majority of these clinics take extra precautions to keep the health status of their clients confidential. However, there were also clinics which also demonstrate discriminatory practices such as making an individual with HIV wait for his appointment often until the end of the day. This indicates a lack of knowledge about universal precautions and practices among health care providers.

Confidentiality and Anonymity

The health care professionals interviewed were aware of the pressing need for confidentiality, both to protect those diagnoses and to reassure them that it was safe to come to their health care providers. One physician said:

...in my own community there is a lot of misinformation about HIV. I think that confidentiality needs to be guaranteed, absolutely, on the same lines as what we guarantee confidentiality as far as Chlamydia and the other sexually transmitted diseases is concerned. In other words, it's a disease we need to report, we need to follow up and everything like that, but we need credibility in that we will not involve people from the community unless absolutely necessary.

It was reported that breaches of confidentiality have happened through something as simple as using the employer as a go-between with the insurance company.

... the doctor was writing out not only the medical note that goes to your employer, but also the short term disability form, the client couldn't read it,

but it just so happened to be that I was there, and the doctor puts on the medical note that goes to the employer, reason for being off work was because of HIV. And so I quickly took that, gave it back to the doctor and said, you need to change this so it doesn't have this on here, and yes, I understand that you need to put this down for the life insurance company that would be providing short term disability ... You need to directly fax it to them, and yes, like, they can have that information, but they will not release that to the employer.

As the first doctor quoted in this section indicated, there is no reason for anyone to know about the person's diagnosis of HIV unless indicated by the person him or herself.

Participants felt that both health care providers and interpreters need to understand the importance of confidentiality. Kellie, a health provider, said:

In a small community having an interpreter, face-to-face interpreter might be hard, because if it's a member of your own community then you may not want to talk about it. Whereas in the city, having a face-to-face interpreter you may not know that person it's a little bit, it's a little bit easier to do that.

Participants indicated that the unfortunate reality is that confidentiality can be emphasized and steps taken to protect people's medical information, but occasionally the system does not work. Kate related this story: "There was another incident with an interpreter, and, in which it was actually released that this person under the age of 18 was HIV positive, and it slipped into that community." Participants felt that even one breach of confidentiality will take years to repair in terms of the reputation of the health care system, besides being devastating to the person involved. Such breaches will be a great disincentive for people to seek a diagnosis or treatment.

One way to assure no breaches to the system would be to set up a communication system so that health care providers do not know who they are talking to, as with one internet service where people asked questions by email. Luise explained: "another way they accessed is through the internet ... They would ask questions, they could email me and ask questions, through the internet so then I would never have to know who they are and stuff like that." However, phone and internet contact would not provide a health care professional with all the information a face-to-face encounter would.

Another theme discussed by participants was confidentiality. Confidentiality for individuals with HIV in the community is an important means to reduce individual targeting and stigmatization. It was generally felt that it is difficult for individuals with HIV to be open about their disease and needs. For example, some community members with HIV have to travel to another larger city for their treatment but they fear this may raise questions in the community and lead to stigmatization. As a result, some of these people choose not to travel for their treatment. For some, asking for the time off work (the travel time one way alone can be three hours) could signal a problem to their employer, and a few of the immigrants interviewed felt someone could be fired from their jobs for having HIV, or if not fired at least harassed until they quit. Others, on the other hand,

reported they preferred to travel because they did not trust the local doctors to keep their information confidential.

While travelling two or three hours to the nearest large urban centre for treatment has logistical and financial challenges, one health care provider pointed out that it at least provides some extra measure of anonymity.

I do think it's a good thing that we do have the clinic in [city] ... because (it is) a big city, so when you go there, then you probably don't know anybody else there, so I think that's a good thing, it would be nice to have a clinic here, but again, I don't know, it's a small community, and people wouldn't want anybody else knowing, so yeah, so maybe it's good the way it is.

Clinics such as STD clinics or HIV clinics can be set up to be anonymous as well – as one health care professional said, the health professionals may know that Tuesday afternoon is the HIV clinic, but it does not have to be advertised as such.

... we tell our HIV clients with our STD clients, I mean it was an STD clinic, that's what it was, basically but, nobody sat in that waiting room thinking, oh, he's got HIV or he's got gonorrhoea, you know and on Tuesdays was when we had our HIV clinic, only our HIV patients knew that, we didn't advertise that.

Jane reported that even to have a strange car pulling up outside the immigrant's residence on a regular basis can create suspicions or curiosity with neighbours, and therefore those doing outreach must be sensitive and allow for other strategies. "Lots of times we'll meet in public places just because it's a little easier, a little more anonymous," she said.

Summary

This section looked at interview data to answer the question, *How do recent immigrants deal with social stigma and consequences of having HIV/AIDS?* Having only three participants with HIV who were willing to talk to the researchers gave us only limited data but this is telling in itself: many immigrants cope with having the disease by hiding it from the community. The three participants had told only immediate family, and sometimes only a select few in their family, plus their health care providers. Even other community members for the most part thought that family would be the only ones one could trust with such a secret, even among their own immigrant community.

Immigrants seek help when and where their privacy is most assured. For some, travelling to a larger urban centre, despite the distance, gives them an extra measure of confidentiality. For others, work obligations and financial issues may make this a poor option. HIV/AIDS carries such a stigma that it seems reasonable that someone with this diagnosis will base many of their health care decisions on whether or not they can get the care they need and still be protected from exposure to their community.

The community members with HIV interviewed for this study were all on medications, attended their medical appointments, and received their emotional support from their families and/or health care providers. However, it is possible that they and others like them would have a harder time taking control of their care if they did not trust and have a good relationship with their health providers. Health care professionals can only establish this trust with time, effort, understanding of cultural issues, and assiduous attention to confidentiality.

Research Question 3: What Factors (Barriers and Facilitators) Influence Immigrants' Use of HIV Prevention Activities and Services?

A number of factors were reported by community and health and social service providers to create barriers to HIV prevention activities and accessing of appropriate health care for those living with HIV. In this section, we looked at some of the realities facing immigrants that may be a barrier to immigrants' access to HIV treatment and care services, as well as prevention services, including cultural, economic and social factors; understandings of HIV transmission and risk behaviours; sexuality, gender and HIV; factors that influence prevention practices and services use; and general health care system barriers. In addition, this section addresses facilitators of HIV prevention from health care and community member perspectives.

Cultural, Economic, and Social Factors

Transportation, Clinic Location and Taking Time off Work

Participants living with HIV/AIDS commented on several barriers and facilitators related to access to and use of HIV treatment and care services. A key issue mentioned was the “far away” location of HIV treatment services which are located in another urban city, and the resulting concerns for resources to arrange travel and time off work for blood work and monitoring every three months. For example, one community member living with HIV said, “...every 3 months, so we need many times to go up and down, and time off is difficult – it’s difficult to tell your boss that, I’m going, after every 3 months I’m going to see my doctor.” Another community member detailed the various forms of travel:

Like, the first time I went to [name of the urban city] I took the bus. The second time, [name], the nurse down here, she organized some transport for me to take me down and bring me back. Then the third time, I went by myself, and they gave me money for gas. I’ve gone there for three times. Yea, I’ve gone there like three times.

Arranging transportation was not always an easy process, and participants indicated funds to support travel were limited. One community member said that she received travel funds when she participated in a study, but that funding ended when the study ended, and local community health no longer had funding to support travel. She said, “I talked to her [community health worker] – was it last week, this week? – she said there is no more funding for that.” She felt that that most important support that could be provided to people living with HIV, in the absence of dedicated support services, was funding:

I think the most problem I know people have, is for funding.... Somebody told me, it's another country, in England, they've got people with HIV, they've got houses, and, they just respect them. They give them houses and special care. I know we can't have special care, but, we just need [financial] support from the people.

According to health care and service provider participants, attendance at the HIV clinic in a larger urban centre for treatment was impeded by the location of the clinic as well as access to transportation. Immigrants taking the bus to the HIV clinic needed to take a day off from work for just one appointment. Requesting a day off from work for a medical appointment every three months was seen as difficult for immigrants living with HIV, particularly in cases where they did not want to disclose their HIV status to their employer. The loss of a day's pay was noted as another barrier to seeking treatment. One public health nurse summarized the employment and transportation challenges immigrants must deal with in order to access HIV treatment as follows:

So not only do you have to ask permission from your work to see if you can get the time off, and you're not going to get paid for that day, and then you have to pay for the costs of trying to get there so, let's say worst case scenario we don't have a vehicle, you have to pay for a bus ticket, so a return ticket to [urban centre] is around 70 dollars, and then you have cab fees or, good luck trying to figure out the transit system between the bus and perhaps wherever you may need to go. Sometimes people are sent to diagnostic places...as well. It's hard enough if you are aware of what [urban centre] is or how it's set up, and you can read English, let alone if you don't.

Health care professionals and service providers believed that some immigrants living with HIV, or friends and family wanting to assist them, may be fired from their jobs just for taking a day off to attend a medical appointment. Jessie explained that immigrants may be "working at jobs [where] ...you may not be able to take time off work without getting fired...." If friends or family members are not able to assist with transportation to a nearby large urban centre there are currently no funds available from social service agencies in the city to assist immigrants living with HIV who cannot afford the bus fare. Anne concluded, "Unless you have a private vehicle, and unless you drive, you're very limited in what you're able to physically access."

Some health care and service provider participants stated that immigrants' health, understanding of HIV and their financial situations combined to prevent them from seeking or following through with their HIV treatment. They commented on immigrants' needs to earn income in order to pay rent, food and other necessities, as well as send financial support to relatives in their country of origin. Service provider participants also felt that if the immigrant living with HIV was feeling healthy enough to work, he or she would continue to work and use all of their income for these purposes, which did not leave them time or money to follow through with HIV treatment. As Kate stated,

You have a whole lot of things that you're sort of working on, and maybe, as long as you're not falling down sick...you're going to just keep on working and not go see a doctor or maybe, want to know more English before that sort of thing happens, and the only time that they might sort of appear, is through emergency.

Jane also commented on this theme when she said, “most of them are very strapped in that area financially, they can’t afford to take days off work and go for help”. A staff member from a large employer in the area indicated that employees missing too many days of work were “written up”, and that they could be fired for being absent.

Cultural Factors

Another important set of issues related to HIV treatment and care-seeking reported by many participants were the cultural, economic, and social factors that presented barriers to awareness of, and comfort with, HIV and HIV care among immigrants. There was diversity of opinion about whether acceptance of HIV was more prominent in home countries or in Canada, but many participants raised acceptance, discrimination and stigma as social barriers for those living with HIV. As Peter said,

I think the community might react a little bit different than they would if they were in Africa, but...there is that cultural aspect you know, just the conception of what they thought HIV/AIDS is when they were in Africa. I think the underlying factor here is that they may accept, you know, the information given in the Canadian society but still there is that underlying factor where people will still kind of stigmatize some other way HIV/AIDS, and may not be as open as somebody who is actually educated and knows, you know, the ins and outs of HIV/AIDS. So I think there will still be a little bit of discrimination – I don’t know, discrimination might not be the right word to describe it, but there will still be that underlying indifference, treating the person with a little bit of indifference.

On the other hand, Manjo felt that communities did care for those living with HIV:

Our community, they try to show love to these people [living with AIDS] because there’s nowhere they can run to....They still belong to the community and they are part of the community. And they need love as anyone else.

Katherine felt that with education about HIV transmission, the immigrant community would accept and care for those with HIV:

...We will treat them the same way we would treat other people. It’s because if there no education to say, this sickness you only get it through this. Yes, but if the education is there you will know what to do to the person to take care of them – even to cook for them, even to wash their clothes, to make them to feel that they are part of you.

And Tracy said:

Another thing that I learned in Africa, and I came here and learned a different thing was, in Africa, like when someone has HIV is they told us that shaking hands with the person will give you AIDS. And when I came here, someone who

has HIV you can shake hands with them, interact with them and you can't be, you can't be affected from the sickness.

Several participants noted that they perceived that lifestyles in Canada centred around making money and “paying bills”; this meant there was no time for, or interest in, other issues, and less time to think about community and community issues. Nathan said, “In my country, we have the free time there. But [in] this country [there is] no free time.” Lena noted:

They all went after money, I mean that's what you came here for... to make money, to be somewhere. And I'm seeing that I think everybody is kind of concentrating [on] what is gonna be next, are they gonna buy a house, what kind of car they gonna buy, what kind of house they gonna buy. I haven't seen anyone talking about HIV. I haven't heard anyone talking about HIV. Ever.

Thus, particularly for those living with HIV or with family and friends living with HIV, awareness and counselling were seen as a service need. Vicky discussed her friends living with HIV:

Well, some of them [friends with HIV] care about to, well, “Let's use protection,” but some of them are like, “Oh yeah, let's use protection,” but when they get there, they are not using protection, right? So, it's like, it's tough... So I think that the community needs a lot of help about that.

Immigrants' cultural beliefs and experiences of HIV in their countries of origin were discussed by several health care and service provider participants as reasons some immigrants may not take steps to prevent HIV transmission. Jane described her thoughts on immigrants' cultural beliefs and understandings of HIV:

For most of them they see it as an absolute death sentence, because in their countries, as we all know, there's not much help available. As far as the myths... for starters lots of them won't even go for pre-assessment, for a period of time, because they just think they're gonna die. Because that's what they do in their country. ...lots of them have very heavy spiritual beliefs and they believe that God will cure them if they pray hard enough. They're willing to buy any kind of product over the internet, or that they think will fix them. There's the old myths that came that if you have sex with a virgin, if you're a man, that you're gonna get rid of this disease if you have sex with a child, you'll get rid of this disease, and when you're desperate, people try anything that it takes...

Cultural myths also surround HIV/AIDS. Lindsay, a health care professional, commented on a newspaper article quoting an African government official: “It was in the newspapers that he had sex with somebody that was HIV positive but he said it was okay because he had a shower.” One health care professional also mentioned a pervasive myth that having sex with a virgin can cure HIV/AIDS.

Another participant talked about the additional influence of an ethnic community's cultural beliefs and communication about HIV, which can be based on incomplete information. This influence, he suggested, can also be a barrier as it impacts an individuals' decisions about disclosure and HIV prevention:

It's embarrassing sometime too, in other communities or to other people when they talk of something related to sex. And I think...it's a sexual transmission disease so, and that's why people are afraid of it, talking about it and it seems like when someone have that kind of disease it's seems like get it from many people and it been wrong person that we hang around...or doing kind of sex business...so it's...something that nobody wanna talk about it.... For some other people they think that they don't want to hurt others or they don't want... to say this is what I have and I don't want you to get it.

Cultural Beliefs and Practices Regarding HIV

Cultural beliefs about HIV were discussed by many community participants as an important barrier to HIV prevention practices and use of prevention services among immigrants. There was much variation among interview participants in the way they perceived cultural values and norms, and many were careful to distinguish between beliefs present in their countries of origin and compare those with understandings that were held in Canada. Thus, the effects of time in Canada (acculturation) and diversity among the cultural groups should be taken into account when interpreting descriptions of beliefs about HIV in this section. The main themes and issues raised by participants were beliefs about the cause of HIV, HIV transmission, and high risk behaviours; stigma, fear and social isolation that might result from HIV disclosure; and sexuality and HIV, including gender issues.

Cultural Beliefs and Stigma

Community members discussed the wide range of immigrants' cultural beliefs about the origins of HIV. Most community members were of the opinion that "sleeping around" or "promiscuity" was a means of HIV transmission. In addition, some also expressed the belief that HIV/AIDS was something that God sent to punish humans as a result of their promiscuity. Alternatively some also believed that HIV was "voodoo" or the result of a research mistake, or even a form of biological genocide deliberately used in Africa to reduce the population. Elizabeth explained the views of community members she knew:

They just gonna say, "Oh, these men have [sex with] many women, maybe he go this woman, this woman, this woman." But it's not true...Just maybe God give you that.

Sadikhe also stated that he knew people who believed HIV was a punishment or "curse" from the Creator:

I know some people who are saying that it's a curse illness.... The people...are cursed because they are not following the rules of the Creator....People are saying every 100 year time there is a disease coming in this earth, destroying people.

Community members voiced the opinion that HIV was transmitted through “promiscuous” behaviour. One community participant said, “If you're promiscuous...you feel so bad and you look at yourself and think God has really punished me, because of all what I've done.” She said others also understood HIV was a punishment:

And they know that most people...especially girls who sleep around, guys who sleep around. So it's like a punishment, they look at it [having HIV] and say, “Oh, it's good, it's good you had it, because you used to sleep around.”

In addition to expressing normative views of sexual transmission of HIV, a few participants discussed several other views about HIV risk and transmission, including travel and prostitution in the context of war and beliefs that men and women have different transmission rates through heterosexual sex. A few community participants expressed a fairly detailed set of HIV transmission factors. For example, Eddie stated:

We know that the highest percent is through sexual relationships, although with the homosexual, heterosexual.... We also believe that you can also come in contact with the virus from un-sterilised equipment, they can be knives, they can be needles, or what ever. We also believe that it can be transferred from the mother to the unborn child... blood transfusion which are very, very, very slim factors.

A belief that HIV/AIDS happens only, or mostly, to the promiscuous could be a barrier to seeking testing or even contribute to denial that inhibits pursuing appropriate care. People may feel embarrassed to even ask for the test, feeling the doctor or other health care providers will judge them for it.

Another community member related the beliefs held by some that HIV is, “some kind of voodoo, telling you have AIDS” because “some of them think, it's a mystery disease.... they'll never believe that there is a medication....” However, there was a great diversity of opinion on this issue, and many expressed the view that HIV was a disease, and not inflicted by God. For example, Zena talked about her understanding of the disease as unrelated to religion or spiritual beliefs:

There's no religion [in] sickness. Sickness is sickness.....when you got a sickness you will just go to your family doctor and you should find how you gonna treat yourself. That's it.

Still others stated that people in Africa, as well as Alberta, do not believe HIV/AIDS existed but rather that it was created by white men conducting experiments in Africa. One community member participant explained:

I know a lot of people they do say it, “There is no AIDS.” They said a white man just create this disease....They are just trying to reduce the number of population in Africa so that’s why they created this...AIDS....so because of this people do go without protecting themselves, so that is their own belief, there is no AIDS.... there are people also carry that belief...even in Alberta here.

Jesse spoke about the belief held by people in his country of origin that HIV was the result of an accident in research and that lies have been told to hide the true origin of the disease:

People in my country know that HIV is...a consequence of a mistake in research....people were not very honest and they told people that it’s a disease that came somewhere.... When White people came in my country they had... [the] green light to do whatever they wanted...they were...experimenting [with vaccinations to develop new medications].... That’s why I said, oh, ok, that’s how it is, because they’re doing [experiments]. They come, just to inject people [with] disease....Like years ago, we didn’t have this kind of disease. But a disease fabricated by people...they don’t know to cure it, because it’s not a natural disease.

Desailly admitted that previously he, too, had not believed HIV/AIDS existed:

Before I never believe in HIV/AIDS...I just say, it’s...something that is manufactured by somebody. So I don’t believe in it from the very beginning. So through debate with friends I came to realize that oh, many people in the world...have that disease. And it has cost almost over a million of lives so I’ve come to realize yea, it is a disease....

Ashley, on the other hand, stated that some people do not believe HIV/AIDS exists or hold on to myths about the disease because they are in denial and, “don’t understand because they don’t want to understand... Some people don’t believe HIV exists. They say, “No, it’s a lie...”, or “they believe it’s a white man disease...”. Ashley emphatically shared her own belief, saying, “As a matter of fact, it’s everybody’s disease.”

Many community member participants described the stigma and fear associated with HIV in African immigrant communities, as well as their own experiences with the disease as it had impacted their families that kept HIV from being discussed in the community and acted as a barrier to prevention practices and service use. Shame, disgrace and fear of the disease were common themes and many examples were shared from experiences in Africa, as Duo stated, “In our realm [having HIV] is a disgrace....You don’t want people to know, that will prevent me if I have it, from going to...make myself known, because I’ll be rendered an outcast.” Lina agreed:

“HIV is more shameful, I think...than cancer.... we grow up with it knowing HIV and malaria. Something that’s like seen in Africa and when we talk about HIV we just have stronger feeling right away for it because

we are raised with it... I have seen people getting HIV, like, from home to home, I mean, in Africa. It was this bad.

Pam explained that the fear of stigma and discrimination spread to every area of life for people living with HIV, and resulted in the choice not to disclose HIV positive status:

So that's the worst thing that is happening to people living with AIDS. They are ashamed to say it...they are afraid they might lose a job, they are afraid they might lose their relationship, they are afraid they might lose their friends, they're afraid they might lose their family—so it's like leprosy in some parts of the world.

Discrimination and the resulting social isolation were common themes discussed by many participants, yet there were differences in opinions as to whether or not these practices were transferred from Africa to Canada within various immigrant communities. Many community member participants described discrimination in every aspect of daily life for people living with HIV in their countries of origin. Ashley described her observations of discrimination in Africa, which were echoed by several others, as well as her thoughts about how people living with HIV would be treated by African immigrants in Canada:

Discrimination against people with HIV is very common in Africa. If you have HIV...your family just like leaves you, they don't care about you and that's what kills a lot of people....Because it's just like, "He's gonna die anyway. So why we bothering ourselves taking care of him?" That's what happens. Instead, they could be giving that person support and stuff. But they don't....That's how it is. Even the people who come down here, they still have that mentality of just discrimination....That's what kills a lot of people. Because they just feel left out.

Sylvia had similar experiences, though she was not as certain about how someone living with HIV would be treated in Canada:

I think, my ethnic group...back home...bring them [people with HIV/AIDS] to a village away and that's where we put them. The HIV, lepers, whoever, we just put them away in a village, put them in huts, that's where they live... usually that's it, you just take them there to go die with God. But I mean, in Canada now, I, not really sure.

Most who shared their thoughts on this topic, though, believed that people living with HIV would be rejected and isolated by their immigrant communities in Canada. Sean commented that immigrant communities, "still...have Africa mind... and it never change.... They do same thing and...never have friend with them [people living with HIV], never sat, never eat with them," and Subsahara concurred, stating, "Socially you are neglected by everyone...back home and even here in Canada, if someone is being discovered as a carrier [of HIV], people will avoid him. Avoid...contact with him. Even to shake hands...". In her opinion this was a result of, "ignorance from all the people... they just isolate that person from the community."

Another participant, Vicky, explained why she thought immigrants would be unwilling to disclose their HIV positive status to anyone in the community. Having immigrated to Canada without family members, it would be very difficult to risk losing your only social supports:

Probably some people are scared to lose their friends, they are scared to stay alone. You know, we are immigrants, we come here...alone, mom and dad, they are back home...so...the support we have here, we have our friends. So, if we tell those people, "Oh, I have HIV," maybe they will say, "Don't worry, I'm with you, I got your back," but maybe there are some that they are like, "Uh oh, I'm not talking to you."

In contrast, there were participants who believed immigrants in Canada would accept and support those in their community who were living with HIV, though most said they did not know anyone living with HIV. For example, Josept stated, "In Canada...the community, I think, they have to accept that person [with HIV]...not...isolate him because of HIV. We have to deal how to help him. Deng agreed that those living with HIV "are not rejected by our communities in Canada" because "people are more informed in the Western country than Africa. And the disease is more scary back home than in Canada...there's medicine for it here. Back home there's no medicine for it." Michelle felt that having lived in Canada for many years had a positive influence on immigrants' attitudes and behaviour:

I think there's some cases [where]...he/she would be...pushed out of the family or...disowned[if they had HIV]...and then I'm thinking about my own family. Like...my family, if I were to tell my dad that I have this disease, um, I don't see that my father...would treat me badly....we've been here [in Canada] for a very long time, whereas... if my family was back home, it would be a different story.

Matthew also believed that attitudes had changed with time and life experiences, even in his country of origin:

Where I come [from], there's war...people are in the concentration camp, so life is so hard. People are doing anything to survive. So, they don't look at that [having HIV] now too much, a lot of people have died of it and nobody's ashamed, but before it was a shameful disease.

Eddie also echoed this sentiment about help and tolerance for those suffering from HIV:

...I want to help this guy, you know, but I see a problem, so what is the problem, the problem here is that he is a gay. But you know, and for me, my culture, that is an abomination, so I said but, you know what, I will give him every help once he doesn't come into my own personal space, because, you can do what ever I want to do, and I can do what ever I want to do, but being that you want help, and I think I can help you, you be who you are, let me be who I am, and let us talk how we can better help...

A common theme in many of the interviews with community members was the silence about HIV in the immigrant communities, as well as a closely related fear of death based on experiences with very early deaths of family members and friends infected with HIV in African countries. Several participants mentioned that their family members had died of HIV in Africa. For Sylvia, HIV was clearly linked to a fear of death and a belief that one could not have a full life once diagnosed with the disease:

I mean, as soon as they mention AIDS, that's it.... that word you've attached death to it. So I think that's why it's so scary for me to even talk about it.... Everything else we see that we can take care of it, even TB... But I mean HIV there's nothing. It's not like you can take a pill.... See your life is over. You can't get married, people think... I think...I would probably try to find a way where I can kill myself.

As a result, HIV was not talked about. Sylvia stated, "We don't talk about it ever... the only thing we talk about HIV is, "Oh my gosh, HIV is really killing people back in Africa. What are we gonna do? That's it." Michelle described a very similar experience within her own immigrant community:

It's [HIV] not a subject that's talked about a lot...I never heard anybody speak about it [in Canada], I never saw any clinics or anything like that [here in Canada].... Here the... community that I know, they don't talk about condoms, they don't talk about AIDS, they don't talk about HIV, none of that.

Another theme about openness and learning new information about the disease and its treatment was evident in the comments of several other community members. Sadikhe held a realistic view based on some knowledge of medications available for HIV treatment. In his view:

There is always a part that depend on each person...if you take your drugs. You see some people take drugs for six, eight years. But when they reach eight, nine, ten years....the drugs [are]...inefficacious.

Tracy was more optimistic as a result of new information about treatment she had learned in Canada:

Before I learned from Africa...that if you have AIDS, five years is the longest you live....Five years you die.... since I came here, I heard of people who have AIDS and...I've seen someone [that had] AIDS when they were like a year old and now they're 27, married. They live with HIV.

Colin agreed that education about HIV could have a significant impact on one's understanding of what it could be like to live with HIV when he shared that he had, "read some books since...programs on TV have shown that if you have AIDS [and] if you take medicine, you can live ten, twenty years. So it's not as, it's not as bad as it used to [be]."

Health care providers agreed with the community members that there is extreme stigma surrounding HIV and noted immigrants' fears about disclosing their status to health care professionals. Nurses noted that some immigrants feared they would have to leave Canada if they were found to be HIV positive and had gone to great lengths to make sure they had negative HIV test results before arriving in the country, as Jane explained:

I've had many immigrants come here and tell me that they bought a negative blood test to come to Canada. ...so that they don't show up here as HIV positive. Whether...they're positive or not...they're not gonna take that chance. I've had people tell me that they bought the doctor off, en-route to Canada. Paid him with something in order to write negative down for their blood test, because they think they would not be allowed to come into this country.

This together with the stigma of HIV, were possibly reasons that HIV positive immigrants were reportedly afraid to disclose their status to health care professionals at the hospital, as one nurse stated:

We don't, in the emergency, see a lot of HIV/AIDS, per se, that we know of, I mean they certainly don't come in telling us and I know from Dr. [name of doctor] who works with a lot of them that a lot of them leave (the city) when they find out because of the stigmatism that's attached to them having it.

Understandings of HIV Transmission and Risk Behaviours

Some community members were aware of the variety of ways HIV could be transmitted.

People get HIV/AIDS, one, by sex, two, by blood and then three, using the same things...machines, razors, needles, all those stuff. Like in the hospital, if the doctors are using these needles for this person and then if another patient come again they will use the same needle to, for the next patient and during this kind of changing those things, then definitely you'll get contaminated of the disease...

Another community member participant explained HIV transmission in the midst of the African conflict, as a deliberate act of governments and the military:

And if there's prostitution it's because of...politics...people don't even have money to buy condoms. They do sex without protection...Like military people they came... they know they have the disease, they know the authority of their country knows they have disease, but because they can't get women from their own country, they bring them to another country because there is war.... So many, many diseases came with people traveling.

Lena expressed another conception of HIV transmission differences between men and women and stated that, "Some, they just believe that...it's very easy for a woman to get AIDS from a man" but that "for a man to get AIDS from a women, they think that...it could be there are less chances for that... So they don't use the condoms." Another approach to preventing HIV

transmission was observation of possible partners in the community. Duo explained that some people conclude a woman does not have HIV, “by simply seeing, looking at her, and looking at her background as far as religion is concerned and her behavioural pattern in the community” though he added that, “some also use condom to protect that. Y’know, they believe surely they will not have any problem.”

Injection Drug Use

In interviews with the community members, participants were asked about their views of drug use in the community. There was a wide range of perceptions on drug use and its relationship to HIV and HIV risk. Some did not perceive drug use as an issue in their community, as Jesse explained: “People don’t want, don’t care about the drugs... that’s why I didn’t say drugs, because...we don’t use it.” Many participants had similar responses to Duo’s, who stated he was not interested in drugs:

For drugs? Well I, to be honest I’m not interested in any of those drugs either. So I don’t, I don’t...get closer to those who use it and I have no idea about whatever they feel that forces them to go into such a thing.

Yet a few participants were aware that drug use was an issue, like Mangahsu, who explained:

“Back home they don’t even have the money to sustain themselves, not to get the money to buy drugs. So, but as soon as they get here they start moving backgrounds and they start taking the drugs.... Even at [company] here, drugs is just like, it’s like market. It’s just like selling tomatoes in the market....So most of those guys...they never take it from home before, they learn it from here.

Alcohol and “Partying”

Community participants were also asked their opinions about alcohol use in their communities and its influence on behaviours and possible relationship to HIV risk. Alcohol use was reported to be quite prevalent, and linked to “loss of control” of behaviours. Peter said that, “people actually go...on a rampage to drink and get really booze[d] up...and then it makes them to squander everything that they made within the past 2 weeks....” Colin added, “The bars are full every weekend. People go from one bar to another. Like, they have a plan”. Carmoon commented on the impact drinking had on peoples’ ability to control their actions:

“People drink excessively....They lose their sense of control....They can’t really behave themselves. Some people believe alcohol and drugs is y’know, they’re being bold to talk to women. They lose control of themselves. They get into behaviour they were not supposed to.

Jesse explained the social challenges for single adults newly arrived in Canada:

Different, single, living in a different country where you don’t have friend[s]. And you have to go to the bar to find someone to talk to,

y'know? And that's where... those people who change partner everyday, you find them in the bar, and that's where you contract disease.

Sexuality, Gender and HIV

Some community members explained that sex was not an acceptable topic of conversation within many immigrant communities, which could make it very difficult or impossible for dialogue about HIV to occur. Discussing this issue, Eddie provided an example:

You will not get support in that area. I mean, the wife went to the husband, "Oh, somebody is coming to me tomorrow to talk to me about AIDS." The first thing that clicks through the husband's mind is, "Oh, she is going to discuss our sex life, so no, I'm not in for that," because many people don't want to talk about sex....It's a very, very sensitive topic, and not many people want to talk about it.

Lena explained that silence about sex was part of intergenerational relationships, but that friends of her generation could talk openly about it, stating, "[In] my culture usually, kids and the family don't talk face-to-face [about sexuality].... Friends can talk.... You just gotta hide to family... Yea, friends...can talk."

Many community member participants commented on the different cultural sexual standards for men and women and how HIV positive men and women would be viewed by the community. Some participants stated that the same norms from Africa were continuing among the immigrant communities in Canada, several others felt that Western culture was having a negative impact on the social and sexual behaviour of their communities' young people.

Sexual behaviour and norms for men were distinct from those for women. Participants articulated the ways in which men were able to have multiple wives, and extra-partners without any of the censure placed on women who had multiple partners. For example, Jesse explained that multiple wives and partners were acceptable for men, and that this was not considered promiscuous behaviour:

So then when you get it [HIV]... means you have...many partners.... It doesn't mean that you cannot have two wives or three wives. That's different. And men in my culture can have two wives. But they must be known by other people. That is, this is his wife and he has two wives and people know that. But not change partner every weekend or every month.

Elizabeth also stated that polygamy was common and acceptable for African men who may have "two wife or three wife," and that when they immigrate to Canada they may, "leave the two wife there" only take one wife with them but return to Africa, "to visit the wife there, yea, in Africa....In Africa it's normal." Desailly agreed and described the norms for men from tribes he was familiar with:

Some... tribes they basically believe [more] in culture than in laws, it's

something different. So in culture...you can be eligible to go to three women, two women...it's up to you to get married to two or three. Or either stick on one. That's all your choice....

One service provider participant, however, felt that that polygamy does not pose the risk of spreading HIV, but in fact would help with the prevention of HIV. He felt men who have more than one wife often committed to those permanent relationships and might not seek sexual relationship elsewhere, where as men who do not tend to seek extramarital sexual relationships, which in turn pose more risk of contracting and spreading HIV/AIDS.

Some participants spoke about men's desires as "natural" and sexual behaviour to meet those needs, with or without consideration for HIV prevention, were talked about as a fact of life, while women were said to be labelled as "promiscuous" by the community if they behaved in a similar way. One community member, Deng, explained that it was stressful for men who did not have "sex for a long period of time" and that "this will force this man to go [with] anybody without thinking about it. Without using [a] condom therefore there's a likelihood that this will result in him acquiring...the disease. If the partner has it, yeah." Lena commented that married men were the ones who often had extra-martial relationships:

Yeah most of husband I think do cheat at times, yeah, you can find some kind of women would cheat too but, in our culture... men are those cheat... They go out with another woman.

Lilly elaborated on the very different standards of behaviour and the consequences for women who had multiple sexual partners:

Yeah, being a woman, especially a promiscuous one, you know, they don't care for you, you get insults. But being a man, ... a man is allowed to take more than one woman, a man is allowed to marry more than one woman, but a woman is not allowed to date more than one guy, that's the culture in Africa... that's the way it go, a promiscuous woman is a taboo, but ... there is no promiscuous man, if the man is going out with a lot of women, he has money, that shows that he is a big man. So being a woman, especially if you are a promiscuous one, and then you have AIDS, you have no place, that's the taboo.

Katherine shared her thoughts about the gender roles, and assumptions that could exist in marriages:

Only the men got to tell the women what to do, but not the women telling the men what to do, especially when it comes to those sickness...AIDS and other things. When you in my community, like [if you are a] woman, you just will... go tell your husband that now go to the hospital go do AIDS test. The... statement for the man will say, "That mean you has it [HIV]. Where you get it from? Who give it to you?"

In terms of HIV, many community member participants expressed the view that being infected with the disease results from being “promiscuous.” Most community members indicated that promiscuity was viewed negatively in many immigrant cultures and that becoming HIV positive implied a person had been promiscuous. Michelle clearly stated this view:

I think that they [those with an Ethiopian cultural background] think that it's a bad disease, it's taboo, it's a disease that you get from being promiscuous. Which is also, like it's taboo to be promiscuous so therefore, taboo to have a disease that is correlated to being promiscuous.

Sean agreed that, “people get HIV because of...cheating on a woman. So people they don't stay with one woman and then they sleep with different people...”. Others, in contrast, talked about a more “Canadian” or Western approach. Some were accepting of more liberal, or equal sexual standards for men and women, like Lilly who described the situations of her girlfriends as an example:

I have a lot of girlfriends, who [experience] pressure in a way. Like, you know girls, when at 26, 25, 27, and you're not married, it's like, “Uh oh, you know, your time is running out.” So...you do stuff, you go out with this guy, you sleep with this guy thinking that he's the one, then trust me, he's not the one, he leaves you and then you're forced to date another guy, because you're looking for the one to get married to. So kind of pressure [to have sex].

Others did not approve of what they saw as different Western sexual norms, and immigrant young peoples' changing behaviour. Andrew noted:

“[In] my community... sex outside marriage is not acceptable at all. Here it is just the opposite.... In my community, now it's being influenced by the free country over here...and unfortunately there are young boys and girls who are going in for that you know, which is not very acceptable, but I definitely advise to use condoms if they going to.

Subsahara shared this opinion:

We came from country in Africa to Canada, ok, and we do have our culture....So maybe because Canada is more open...than Africa, especially, yunno, like the youth who tend to be having a girlfriend or a girl tend to have a boyfriend...they sleep together, and whatever they want to do they can do.... they are losing their values or traditions or customs....But here, maybe you have a girlfriend today, after some time, then you break up and then again you go for another one....And she in turn will go for another person, so if there is one of them that is holding that disease [HIV] so easily could be...spread out to all the community.

Josept also felt that the freedom in Canada was not a positive influence for the youth of his community when he said, “In Africa, no....you're not allowed to go out with somebody...you're

not married with her or you don't have a relationship with him.... So in Africa, it's really, really good" but since "they came to Canada they get...freedom...but they get freedom in the wrong way." Another participant shared the experiences of his own youth in Canada:

There is definitely a pressure.....That's my experience especially with school and that type of thing.... You gotta have your relationships in high school, and you gotta have a girlfriend in order to be cool, or you gotta go to the parties and do whatever y'know.

Health professionals and service providers also noted the influence of gender roles and relationships in HIV prevention. Several commented on the roles of men and women, as well as the power dynamics between them. It was felt that many immigrant men held the decision-making power regarding sex and HIV prevention practices within marriages, as well the option to engage in extra-marital relationships, while women were not able to exercise choice in these matters. For example, Jane stated:

We're also dealing with cultures that are extremely male dominant that poses a bit of a problem for really discordant relationships where they [women] feel they have no choice but to obey what their partners tell them to do, because that's what they were taught from the day they were born. So if their partner is positive and he says, no, I'm not gonna wear a condom, they'll often times put up with that cause they just think they don't have a choice. So y'know, there's that whole barrier that we deal with...and I don't know how we come through that....Like how do you change generations of thinking?

Another service provider participant felt that immigrant women experienced shame when their spouse or partner infected them with HIV, which seemed to emphasize the power imbalance in the relationships:

A man is scot-free with almost all these things because he's a man. A man can go and marry as many times as he wants. A man can have an extramarital relationship, it's not a big deal and things like that....but the stigma will go on the women.... that problem's been brought to her by her husband, but the women will assume more of the shame than the man.

Kevin, a health professional, felt that a man was more likely to be stigmatized than a woman:

Well, I guess number one they will thinking, if it is a man, maybe they thinking homosexual... sometimes they think maybe IV drug abusers. And I think maybe probably less detrimental to women, because they usually see women as a victim.

Remarkably, homosexuality was not mentioned often by the community participants. In one interview Eddie, a community member, did say that in Africa AIDS was largely associated with homosexuality: "But we also believe that, people believe that in Africa, the same way that,

people who suffer from AIDS are homosexual, but it's not always so." The relative silence about homosexuality in the interviews with community members likely reflects a lack of acknowledgement of MSM (men who have sex with men) behaviour among immigrant communities.

The stigma attached to HIV/AIDS as a sexually transmitted disease was so great that an argument over which gender was more stigmatized more seemed almost debatable. Community members often commented that women were more heavily stigmatized for being labelled promiscuous, but men may also want to hide their HIV status for fear of being labelled homosexual. Either way, the stigma alone may discourage people from seeking testing, and certainly once they have a diagnosis could create a burden of shame and fear of exposure.

Factors Influencing Prevention Practices and Services Use

Attitudes toward Condom Use

Community participants reported several factors which discouraged the use of condoms. In addition to not being "pleasurable" and "ruining the mood", acceptable sexual and gender norms influenced the use of condoms, including the dominant role of men in sexual relationships. Alice stated, "... all of the men of Africa don't like to use condom[s]." Sylvia noted that some of her friends did not like to use condoms:

A lot of friends that like to party, they like to have sex but they don't like to use condoms because it's just not pleasurable.... These people are having sex with different partners, different nights. Unprotected. So I see them as the ones that are creating this problem...they're not helping.

Some community member participants spoke about their own preferences with regard to condom use. As Andrew said, "I think that me, personally, I'm not very comfortable with a foreign body on me" while Lena commented, "They just believe that it's...Ok, I will use my language, they can't eat a sweet in a paper (laughs)". For some married participants, sex outside of marriage was not seen as acceptable, and therefore, condoms were not used as there was no perceived risk of HIV transmission. Sean stated:

If I'm with my wife...I don't use it [condoms]...because she's my wife. I believe her, she believes me. I trust her, so that's why. We don't use it....In my religion, [you] only have your woman.

Several community members commented on the theme of condom negotiation which involved gender and trust issues between partners. Several women said that men would often make condom use an issue of trust by implying that women who insisted on condom use must not trust that their male partners were HIV negative, or that the women were HIV positive. Elizabeth explained how this interaction could play out, "Sometime the men are gonna get mad they don't like condom....Because you gonna tell him to use condom he gonna say, "Oh you say I have HIV?" Ashley added that condom use could be turned into an issue about whether or not a

woman loved her partner so that the woman felt she must agree with the partner's wishes to not use a condom in order to prove that she loved and trusted him:

He [boyfriend] will just kinda like insist [on not using a condom], and say, "It's ok, just don't whine about it, it's nothing..." sometimes...how they'll do it, they'll say, "Oh you don't love me, that's why you won't have sex with me without a condom" and stuff like that. That's what they'll say, and then you'll feel like, "Oh, why is he saying that I don't love him? It's ok, let me just show it to him, let me just prove it that I do love him." Then you'll just go and have sex without a condom. Like, which is like you weren't thinking about anything else at that time.

Some female participants shared different types of condom negotiation in which they did not let their partners make condom use an issue of trust or they framed the negotiation as an issue of mutual care between partners. Vicky explained:

Boyfriends, sometimes they want you to trust to him you know, so it's like, "Oh, you don't trust me? I'm ok, I'm healthy." But that's not the point right, the point is like, "Yeah, I trust you, but we have to take care of each other," right? So if we want to be healthy and stuff like that, we have to use it, right?

Using a different approach, Sylvia related her ultimatum to one partner:

The guy said, "I don't wanna use a condom." And I walked out on him. I walked out.... I was... "You don't wanna wear a condom?"... I talked to him, "I'm serious, I'm so fricking serious." He's like, "I can't even get hard," I'm like, "Bye." To me, I don't care, but I know a lot of girls they don't even like condoms to begin with.

In contrast, one man believed it was the woman's responsibility to ask a man to use a condom, and at the right point in time, as well:

Women always wait, wait until they're in the moment, and then they say, "Do you have a condom?" Nobody asks for the condom in the beginning. Nobody. They need to be more aware. Women need to be, to be aware that once you're in the mood, it'll be too hard to put a condom. So, ask for the condom from the beginning.

A few participants also expressed the belief that condoms were not sufficient to protect against HIV. Amet explained his view that condoms were not completely safe:

What I know about condom...all of it is plastic, but within plastic there is some hole, it's small one...and through that maybe the liquid of that sex that you're using maybe it's gonna come through your skin and...it gonna

affect you. That why I say sometime condoms is not enough to be saving from HIV.

Deng agreed, based on his own experience, when he said. “Even condom is not safe... It’s not safe because I wear condom many time but it broke.”

HIV Testing

Community participants discussed several factors that could act as a barrier to HIV testing. Fear of HIV testing was common, although not universal, as demonstrated by Colin’s statement that he, “wasn’t scared to go and do an HIV test” and Duo’s statement that “If I believe myself [to be at low risk of HIV], I’m ok, I go in joyfully to know my stand.” Testing was feared for two reasons: it could be the means of finding out one was HIV positive, or it could potentially expose an individual to negative social consequences. Michelle described her fears:

I think, there’s that scare of well, someone will see me, going into that place, um, they’ll, there’s always that fear that someone will think less of them or badly of them because they have, that they’re going to get tested for AIDS.

Several participants talked about the fear they or others had of finding out they were HIV positive because they viewed the diagnosis as a death sentence. Deylis explained:

I have a friend that she never use condom....So I always tell her why don’t you go and make test for HIV, she says, “No, no, no, I can’t go I’m scared, what about if I become positive?” I say, “You don’t have to be scared because Canada help you!”

Another woman described her fear of taking an HIV test: “taking the test and waiting for the results was very scary.... I think it’s because of how serious it is. There is no cure and you will die with this disease.” Lilly felt the same way, as she said, “I was so scared, regardless of the kind of life I’ve lived...because I was just wondering if...maybe I had it...somehow.” In addition, some felt that people in their community were very careful in their sexual relationships, though attraction could cause them to forego the certainty of HIV testing. Duo says:

They want to be sure the woman or the man whom they’re gonna have contact with doesn’t have it. But how to they get, how are they sure? Sometimes they demand a test. But sometimes with the pressure of sexual attraction, they don’t.

Although community member participants had some knowledge about HIV testing and treatment services, they still expressed uncertainty on this topic. For example, Lena had some idea of how to go about getting an HIV test:

I don’t know about any [HIV] services here. I mean...you just go to your doctor and say hey, I wanna get the HIV test. And then they send to...where they take your blood ...the lab... Yea. You go to the lab and yea, and then take your blood.... So, and then you do the test in the lab and they call you back and — you

get the main results, but I don't know about someone that you can just go and talk to.

Michelle was also aware of HIV testing, but only had experience with a testing service in another city of a different province: "They test your blood to see...if you have the HIV virus and I think it takes about 3 to 6 months to actually get your results, I think it is? So, I do know about the testing", though she found it was "frightening, I had gone with a friend to...a place in [a city name] where they test for different diseases...and it's nerve-wracking...testing for something so big. Um, but, it was...worth knowing." Jordan pointed out that many people he knew believed they had to pay for an HIV test:

I think that when people come to understand the concept of it, the principles involved, they say, "Hey, this is my own life, and my family's life, it's good for me to know because it's free." Cause right now everybody thinks, you go for an [HIV] test you have to pay.

Some participants believed that all immigrants had been tested for HIV before being accepted to come to Canada and, therefore, they had a low risk of HIV infection within immigrant communities in Canada. Peter's comment provides a good example of this belief:

Yeah...that is one of the criteria before you move to Canada, like, you have to go for a blood work...they don't actually tell you that you are going for HIV test, but the Canadian High Commission in Ghana will give you a paper, you go to a recognised medical center that is approved by the consulate in that country, for instance. So they do your blood work.... you go for that medical test, if you have AIDS, it means you cannot come.

Another major barrier to HIV prevention practices and use of prevention services among immigrants discussed by community members were the set of factors related to knowledge about HIV prevention and treatment services, and attitudes toward, as well as ability to access general health care services in the region, language barriers, and lack of visibility of HIV programs and services.

Knowledge about HIV Treatment and Services

There was a general lack of awareness of HIV treatment and care services, as most community member participants indicated they had no experience of HIV and did not know anyone living with HIV. For example, Desailly, stated, "Basically I really don't...associate with people that talks of HIV, that are really interested in HIV, so I can't really tell what should...[be] done or what would happen [if I had HIV]." Mangahsu, when asked by the interviewer if he was aware of any place where people with HIV/AIDS could go for help replied:

"No.... I don't know where they have assistance...I only know about...this Canadian Cancer Society, that they have a lot of assistance given to any patient without pre-cancer or post-cancer, whatever, they, I don't know whether HIV organization have their own services.

Sadikhe did not know of any HIV services in the community but had faith in the health care system to assist those who needed treatment or prevention services:

...Here to be frank, I don't know. I know I have my healthcare card, I have the hospital. But I can't name typically a service who's dealing with HIV in [name of the place]. Because...I don't have the illness, I don't know? If you take care, if you go to the hospital I'm sure they will guide you.

Some expressed uncertainty about the availability of treatment for HIV in Canada. For example, when Elizabeth was asked by the interviewer, "Yea, but you know there's a medicine for it, in Canada, I mean for AIDS?" she responded, "They have medicine here [for HIV]?... I don't know."

General Health Care Engagement Issues

Participants were generally appreciative of the Canadian health care system, and Deng called it "perfect". Lena felt that universal health care was very good, especially when compared to the health care system in the United States, stating, "I mean, in America you get sick you pay for it, whereas in Canada you don't. For medical. That is really good. That is the best part." Peter agreed that, "The strengths... you can readily access the health system, you know...and it is not really something that costs a lot."

On the other hand, there was a strong sense that there was a lack of physicians and nurses in Alberta as well as lengthy waiting times to be seen by a doctor. Carmoon explained, "They need more doctors and they need...some services like the maternity where somebody [is] sick...they have to locate the person to [name of another city]....we're lacking here". Others also emphasized the very long waiting times to be seen by a doctor. For example, Lilly stated:

It's, I guess, the system generally is slow...you have to wait and wait and wait, but eventually...they get to you, so my only issue is just like, the weakness of the system is going to be that, it's the wait time is too much.

Mangahsu expressed his frustration with waiting at the doctor's office when he came early for scheduled appointments, as well as at the hospital:

Like my physician, if I have an appointment maybe three o'clock, I'll be there by three sharp or maybe ten to three. Sometimes five o'clock they will not call me. Sometimes I stay four hours to see a physician, so there a queue of people, so there not enough doctors. If I should go to emergency in hospital the same thing. Sometimes you have to go to a mat or some to sleep there. To wait for the attendant. They will write that oh well, if your case is not a mild, so serious, it's not life threatening, you can wait for four hours, but at the end you will still there for six hours. Before you see a doctor.

Tracy expressed the frustration felt by participants who wanted faster access to their family doctors when they had an urgent health concern:

One thing I have problem with is their appointment system. Because sometimes you need emergency and you wanna see your doctor....Because sometimes you don't wanna go like to the hospital, emergency, you don't meet any doctor. And you chose your family doctor and he knows you well and he knows what is wrong with you. That's the problem I had because sometimes even you talk to them and they tell you, you have to wait for your appointment. Y'know, next time go to emergency. And they just look over you, not the way a family doctor will do. So that's what I see.

Some participants did not even seem to think there were legitimate reasons for delays in getting in to see their doctor if they felt their situation was urgent.

General differences in the pace of life, and the influences on interactions with the health care system, were also noted as barriers. Matthew commented on the impact of having to deal with the fast pace of life in Canada, including scheduled appointments:

[There is] no visiting like in Africa. In Africa I don't need to make a phone call to come to your home....I don't need to make an appointment; I just walk into your house. Say, "How are you?" "Good, how are you? Come in." Boom, that's it. You talk, you eat.... [Here] it so difficult because he or she is not free to move out and go visit friend, right?... Because... somebody might say, "Ah, ok, I'm sorry, I'm busy, can't talk to you now," it's very common here. When people have the program and the appointment it's no time to sit with you and talk....So yea, that's the difference.

Others commented on the difference between physician interactions in Africa and Canada, as Colin did:

I believe that honestly, the doctors back home, if they had the same means as the doctors here, medicine would be way better back there than it is here.... Back home when you went to see a doctor you feel like, y'know, there was some kind of, uh, how I can say it, care! Like...they wanted to make sure that this is done, this is done, this is done. But here...you come, I sign this, you go, you come.... Sometimes the way I think about it is, it's like, somebody gotta make the money off somebody.

Emergency service at the hospital and tensions experienced there were a common themes among community member participants. Desailly talked about using the emergency department at the hospital, "If I have a sickness or I got the flu...then I go directly to the emergency... If I can't drive...I call...911. Make sure I get the ambulance, right away." Deylis, on the other hand, had recently been in the hospital and related her very negative experience with emergency services:

And the other things I see, the emergency, emergency is not good. One time when I have the baby I have c-section. I have c-section. So I ... have my blood anaemic....

I feels dizzy, I have headache and I didn't eat for one week. And I call emergency. Because after two weeks at the hospital, they talk about high pressure....And I call 911 because I have the baby it was very small, it was too cold....and they came to my house and the guy treat me very, very bad. He told me, "Who is the one who have high blood pressure?" I say, "Me." He say, "You know in Canada people live with high blood pressure?" ... Well...they call the hospital, "Oh, here we have a patient that is not really patient, blah, blah, blah, blah, blah, blah, blah." So after we get to the hospital, the nurse was waiting there... the nurse was laughing, laughing, laughing...and then I call the other emergency guy and I told him, "Listen, sometime you think that people from another country they don't understand English, even if I don't speak good I can understand what you say." And he say, "Very expensive stuff," and I say, "If the problem is pay for the bill, who's gonna pay for it, me or him? Huh?".... But they treat me very—it's not even only me. Many people they have the same situation.

It is not always easy for people without a health professional background, immigrant or otherwise, to know what was appropriate to ask for in health services. This has resulted in derisive treatment by health care providers, which was neither respectful nor conducive to trust or relationship building.

Racism and Intolerance/Negative Perceptions

Racism, intolerance, historical tensions from countries of origin, and fear of HIV/AIDS all contributed to negative perceptions of immigrants. The health care provider and the community members both mentioned that the attitude of front-line staff in clinics or service areas, as well as other health professionals, can be viewed as rude or impatient. In some cases this was perceived as racial discrimination.

One day I went with a client to visit the doctor. We sat there for two hours, and there was a black couple that were ahead of us, and then it was my client who was also black. We sat and watched there 3 hours of every white person went ahead of us. So, finally that the uh gentleman, one black gentleman said, "Can you explain to me?" he was very polite, very self-spoken said, "Can you explain why everybody is going ahead of me." And she screamed at him, "Don't talk to me like that!" That seems to be a general thing what they do. As they start screaming, and anyone is listening will think that the man screamed. He didn't. I mean a lot of the front-in desk is really bad.

Sometimes the impatient attitude resulted from the fact that health care providers or front-line staff became frustrated with the newcomer's inability to speak English, and the extra time it would take to address the communication issues when time was a luxury staff simply did not have.

I've had them come where they don't speak any English and they look at you like now it's my problem. And there's times where that's just unfortunately, made me very annoyed instantly. Like this sort of, therapeutic relationship has just hit rock

bottom because I'm so frustrated because you and the other 17 people you've got to look after but what am I gonna do with you?

Community members also provided other examples of negative perceptions within the larger community towards immigrants generally and also regarding immigrants with HIV/AIDS. Difficulties at the large employer where most of the immigrants worked were described as multi-dimensional. Participants described that the employer was having difficulty getting workers and therefore went outside Canada to recruit, a policy the community was critical of. The company hired thousands of immigrants who were not fluent in English and were not familiar with the culture. While this boosted the local economy and addressed the labour shortage issue, it also created pressure on services such as health care. A combination of racism, resentment, lack of cultural understanding and lack of ability to communicate has created problems between the general community and the immigrants, and even between the immigrants and the employer.

It was the experience of many community participants who worked at a large company that English speaking supervisors and even supervisors who have been in the country longer and can speak English sometimes discriminated against people who are just arriving from their home country. There was also mistrust within ethnic groups due to civil conflicts in the country of origin. These feuds were long standing and did not necessarily disappear when the immigrants arrive in Canada. This also made it very difficult for these groups to support one another when needed. One community member commented:

The specific circumstances of where they come from, and the political climate can lead sometimes as a barrier for them to give support to each other, or misunderstanding of their actions. Yeah, I came from a country like that as well.

The general community views were also important to consider. There was resentment towards the employer for bringing in immigrants to the country, as this was perceived as taking jobs away from Canadians. When the union at this company went on strike, the blame was focused against the immigrants, and when a food safety problem was discovered in one of the plants, some blamed the immigrants because the perception was they were not clean. Participants described that HIV/AIDS is already a disease that bears a social stigma, due to the fact that it can be transmitted through sexual activity with multiple partners and illegal drug use. It is also a disease that consumes considerable monetary and human resources, creating a perception that not only are immigrants taking jobs but also depleting scarce health resources and spreading HIV. Thus, participants felt that there is a danger that public knowledge about HIV in the immigrant community will create a stereotype that all, or most, immigrants have HIV. This will be a real barrier to integration and acceptance.

The community members with HIV who were interviewed had all been very circumspect with their diagnosis, with two telling only their partners and close family members. The other community member spoke of his diagnosis only with his health care providers, feeling that he would be ostracized by his community. Other community members without HIV felt the same way, saying the diagnosis should not go beyond the family: "[Family] will not desert you. They will give you all the support. But whether the family or community think, ho! He's got that

disease, he's a scary man now, you don't have to get close to him." Another community member felt the community would be quite judgemental: "To tell you the truth, my people, my community they're gonna be like, she's a slut. Or a drug addict." Another said:

You have to tell your wife, because your wife should know that. If you're married you should say your wife that I have HIV. You could tell it to your children, your some kind of people that don't, don't put yourself, I dunno, don't tell it to all your friends and if not, you will get problems for sure.

Racism in the community and discrimination within or amongst ethnic groups are evident in the stories told by the community members and by the health care and service providers. Immigrants sometimes felt that they were unfairly treated and did not have the support they needed. In many health care situations, the problem might be a lack of resources and limited communication and understanding. These problems, if not dealt with appropriately and in a timely manner, might be interpreted as racism among the immigrants. Sometimes, however, the health care providers indicated that certain health professionals were prejudiced towards the black immigrants and their care was inferior to that given to the white community. The three community members with HIV who were interviewed, however, generally found their health care providers to be very supportive.

Language Issues and Barriers

Although a few immigrant community members indicated that most "or almost all of them can understand English" several discussed the lack of health services with communication available in appropriate languages. Sylvia described the vast diversity of communities and languages spoken in her city:

We're using like 75 languages here in (name of the place)...So for sure I would say French, um, Arabic, Amharic, and...now it depends. You probably need Urdu and um, either Cambodian or Chinese. Cause I know now, it's not just like Africans and all, there's like...Asians too.

While one member of the Sudanese community pointed out the barriers to service use experienced by one of the communities among the many listed by Sylvia:

I know that many people they are just...unskilled. And these people you have to explain them in their own language. It's not in English...Like the Sudanese community...Then you have to take someone who speaks Sudanese to them. That the lack I see of the system. The lack of the system is, the Alberta system.

Health care professionals agreed that language is also a significant barrier for immigrants living with HIV when they attempt to access treatment. Rose stated, "Most of the refugees come over here with no, like zero or a little bit of English, so the language barrier will be huge...." To overcome this barrier Kelly has observed that immigrants:

Rely solely on whoever they can find, who could be their interpreter. Occasionally that's a friend, sometimes it's just somebody they know from the plant that speaks better English than they do and speaks their language. It means they have to wait until they can get this interpreter to come with them.

Health care professionals felt language barriers impacted all aspects of immigrants' contact with the health care system and staff. One nurse described how difficult it was for a doctor to overcome a language barrier when trying to communicate with a patient about something as serious as an HIV diagnosis:

I know on one occasion he [doctor] phoned over from his clinic because a lady had just tested positive [for HIV] and she didn't speak English and he didn't have anybody who could act as her interpreter so he wanted... to borrow the Language Phone and what my manager said was he could come over and use it but we're not gonna get in the habit of handing it out because there's a cost involved....

Several health care providers expressed frustration with immigrants that did not speak English, and implied that some doctors avoided taking immigrants as new patients because of this barrier. One health care professional described her experience:

The physician... in their situation... there is a little bit of avoidance, because I can see five people who speak English in less time than it's gonna take me to try to decipher what's going on in this room with this person who doesn't speak English....

Another participant confirmed this problem with the local doctors when she said, "clients who are HIV positive from another country with a language barrier ... require a great deal of time. And lots of docs are not interested in that." A health care professional who worked with many immigrants patients described the challenges caused by the language barrier and the need for accessible, user-friendly interpretation resources:

We do not have any common language, no commonality, communication. So that becomes a problem and then sometimes you leave the encounter feeling you've not done all you could for this person and wondering if there is something you have missed. There is something in place called the language line which is fairly... very time consuming.... For a consultation that I will spend 15 minutes, I probably spend about an hour.

One nurse related an experience she had when serving an immigrant waiting to be seen by a doctor in emergency department:

We don't have a designated emergency doctor. That during the daytime they will come from their clinics to see their patients [at emergency] and they rotate being on-call. And so people who don't have family doctors have to see the doctor who's on-call...he [an immigrant] was saying that people who had come after him were being seen by the doctor much faster than him. And um, he took that as

I was being prejudiced to him. He took that as I chose to have the doctor see them before him. And I, he sat and tears were streaming down his face and I sat and I said, you've got to understand the system. You don't have a family doctor. And that took a whole lot of communicating and I'm still not sure that he understood. But he took it that I was giving other people better treatment than him and that made me very sad.

Literacy was also identified as a barrier for immigrants seeking HIV treatment and this theme was often linked with comments about language barriers. One health care professional commented that even if the health care providers were able to obtain materials printed in the immigrants' languages, some would not be able to read them. She reported her experience: "many of the women have had hardly any formal education...they don't even have literacy in their first language. Never mind in English."

Lack of Visibility of HIV Education and Prevention Programs

Immigrant community members did not think there was adequate visibility of HIV prevention and education services and were very clear in describing the steps they would like to see taken to address this barrier to service use. When asked whether he knew of HIV prevention programs in the community designed to reach immigrants, Peter responded:

Special program in place, no, not that I know of...I believe, [as an immigrant] I did not see any such program, especially geared towards immigrants where you know there will be the teaching about condom distribution, and about prevention of HIV/AIDS, and just all of the issues associated with how refugees handle people with HIV...what is their reaction, and what should be their reaction and stuff like that.

Eddie commented on the low levels of HIV awareness and silence surrounding the disease in immigrant communities. Eddie also provided a detailed list of the services and strategies that would be helpful for increasing HIV awareness and knowledge among immigrants:

I think we need to have brochures, condoms, to every doctor's office, we need to have that, we need to have a poster, or fliers, to all of the doctors offices, like the sitting room. Like you go to [cancer centre in large urban centre], you see papers on the wall, like to go to [hospital in large urban centre]...how can we prevent AIDS...how can you be protected from it, or how can you get it, how you cannot get it, you know, we don't see that, you don't see it...I think people are missing it...because nobody want to talk about it, people are just not much concerned about it, but you know, AIDS is a slow poison... For example, if there is a poster here, you know, and then we just say that, there are like 5 people living with AIDS in [city], you know, please be on the watch, that would change some of their behaviours, because, I don't know who these 5 people are, but I can come in contact with any of them if I just have a loose life, go and drink anywhere...have sex any time I feel like it, you know, I would try to slow down...But the thing is nobody is talking about it....

Lack of Emotional Support

Another challenge that influenced immigrants seeking HIV treatment was their lack of emotional support while coping with this chronic disease. Several health care professionals commented on the emotional and relational impact of the disease. As one nurse noted:

When you're given a diagnosis of a terminal illness like HIV/AIDS, you need some support.... there's a million questions that goes through their heads on the way back home, and...you always wonder about their mental health.

One of the community members with HIV provided compelling evidence of this, saying that he worried a lot about his future and thought there was little possibility he could marry and have a normal life. He reported that he felt sad and hopeless: "most of the time, this is what I feel."

Another nurse described the depression and unhealthy coping skills she observed among some young immigrant men living with HIV:

I had several males...very depressed, and therefore may be using alcohol...and it's because they were so very depressed because, they thought you know, they could never have the life that they meant to have.

She also described the plight of a pregnant woman who was abandoned by her partner when he found out she was HIV positive and required the assistance of the health care professionals:

It wasn't because she was isolated and she didn't have a partner, she in fact did. But when all this diagnosis and stuff came along, the shock and everything else right?that support from the partner wasn't there, so, that's when we had to step in, and yes, it was very expensive, but when you take a look at what the risk would be of having a positive baby, right?

Health care professionals and service providers identified the lack of social support and home care as barriers for some immigrants living with HIV and commented on the need for more social service agencies in smaller centres to address these gaps. Some participants disclosed that they had helped immigrants living with HIV on their personal time because they believed there was no community supports for these very ill individuals. One nurse shared her own experience with an immigrant family:

I know that our HIV issue is so large and so comprehensive...you can't listen to these stories everyday, you can't haul these people to the hospital because they're so acutely sick they can't sit up at home anymore and they've just got two little kids and they can't take care of themselves. So you end up doing this stuff on your days off and you really do become, you cross that nurse-patient border, you absolutely do, because there's nobody else.

Jennifer provided another example about an HIV positive young patient that was not receiving adequate care or access to treatment. She described the barriers to treatment were more complex

than the patient's 'non compliance', as the family members seemed to be neglecting the girl both physically and emotionally:

She was non compliant with the medication, and we knew that with her blood work, because her viral loads were extremely high. And then we found out that it was a battle of wills between the [family member] and our client. So we've had, we've made other provisions for the paramedics actually going in and supervise the [young patient] taking her medications twice a day, and she's good compliancy, she's very responsible, and we know that because her blood work is just amazing.

Delivery of Information

Health care and service providers discussed the challenges in providing the immigrant communities with accurate information about HIV prevention and treatment. They talked about how recent immigrants would want to maintain very close ties to their communities, almost to the point of excluding interactions with those that were not part of their cultural group. This was not viewed as helpful when health care and service providers wanted to educate immigrants about HIV. Joanne thought that ethnic groups only wanted to protect themselves from being judged by outsiders, "because you don't want anybody to come in who... would not understand... your own cultures I think it's just playing it safe". Another service provider observed:

The way we are in the community... is not gonna change for a long time because people tend to work together, come home and associated with the same group. So there's no new information, there's nothing coming out at them from the outside. They're still in their own world, where they came from... there's no integration, there's no interaction outside the group. And to break that, like they have to see something that is happening outside I think that it would be challenging for healthcare provider or whoever wants to come and educate people. This is not an overnight project.

In an earlier section health care professionals and community members mentioned the tight, cohesive community as being a source of strength and support. No doubt it is, but it may also be a detriment in terms of not allowing new information into the network to counteract myths about HIV/AIDS.

Health Care System Barriers

Unfamiliarity with the Canadian Health Care System

Health care providers talked about immigrants' lack of familiarity with the Canadian health care system as a barrier to providing them with adequate care. In their countries of origin, immigrants may have had very different access to, or quality of, health care. Some health care and service provider participants additionally suggested that immigrants may have experienced abuse in health care facilities in their countries of origin as part of ethnic cleansing campaigns. As a result,

professionals felt that learning to trust and use the Canadian health care system was not an easy or quick process for immigrants. One health care professional commented on her experience:

If we're speaking about newcomers to Canada, it takes them years to learn how the health system works here, and it's takes them years to learn health promotion instead of survival. And you know, I had one [person] say to me, "In our country, I'm just worried if I'm alive tomorrow, do you really think I need to have a pap smear?" and I thought...we have to give them time to adjust to our country.

Rose related her views about immigrants' lack of knowledge and possibly mistrust of the health care system:

A lot of the immigrants have experienced persecution, trauma, torture in home country/refugee camps. So if you have an official government working against a certain group of people or certain ethnic group, there is no limit to which methods they're going to use to against them. So yea, as I said, quite often that that's the case, that they fear the institution with being a healthcare institution or educational institution, in their mind it's all the same. So it's very much how to bring that information to them that it's okay, like yes, you have the disease let's see how we can cope with it and make it better for you.

Another example was provided by a physician, who noted:

[Immigrants] may not realize they have to make an appointment, and not just to walk in, or you know, keeping on time with the appointments, so that presents the problem for them [the doctors] because of their busy schedule.

Certainly in other sections of this report there were examples immigrants gave of their difficulty accessing services or inappropriately accessing services due to lack of understanding of the Canadian health care system.

Lack of information Sharing within the Health Care System

The lack of information shared among divisions of government and among local health care providers was a common theme in the interviews. The federal government managed the medical testing and results required of immigrants on their way to Canada, and it seemed that health care and service providers did not receive this information in the towns and cities where the immigrants eventually decided to settle which made it hard to provide the best care possible. Jane described the challenge this way:

Information doesn't necessarily flow from the point of entry to where the person eventually ends up living, so often there...may not be knowledge through the health authorities that someone is actually living here, and living with HIV/AIDS. So that's, I think that's another concern that has been consistently identified as well.

In addition, medical clinics, pharmacies, and the emergency department often did not have records of all patients' diagnoses or currently prescribed medications, which was another barrier for immigrants using the health care system and the professionals who were responsible with their care.

Lack of Institutional Support for Health Care Providers

Health care professionals expressed frustration over the lack of support they received from the health care system in terms of information, training, and outreach for HIV prevention and treatment. In the area of information and training, health care professionals felt they were not provided with adequate information about HIV or training in how to communicate this information to immigrants with little or no English. A nurse working at the sexually transmitted Disease (STD) Clinic explained her frustration with the local, as well as the provincial health care context:

I also don't feel that provincially they recognize it [HIV] enough either. We go, we belong to the STD nurses' partner notification group and it meets quarterly in [name of an urban city], but we seldom have information provided to us on HIV/AIDS.... And I don't really understand the rationale behind all that....they brought some educators up from the States...but still mostly again, designed around the other STDs, not so much about HIV.

She also stated that her knowledge of HIV only "scratched the surface" and that she would definitely attend training to learn how to communicate information about HIV with immigrants:

If there is one I would go and take it, even after these many years, because there's a thousand things I need to know that I don't know.... I mean when we even look at [name of the place]... different people living with this disease coming from different countries. It's very individual and unique.... But, there's not enough information, they need visual information, they need pictures... it's a different kind of education that we need to provide for them.

One of doctors in one city in this study agreed that health care professionals, including doctors, are not well informed about HIV and HIV treatment, when he said, "...also us physicians, we do not have enough information.... So...the education, maybe we don't have enough".

Shortage of Health Care Professionals

In addition, another theme was the shortage of health care professionals locally which made it difficult to provide adequate HIV prevention and treatment services to those who needed it. Health care and service provider participants specifically mentioned a shortage of psychiatrists and other mental health professionals, as many immigrants in the area are suffering from post-traumatic stress disorder and other mental health conditions because of events they experienced in their countries of origin and in refugee camps. Individuals struggling with such serious mental health concerns and not receiving appropriate mental health services may not be able to focus on

HIV prevention, treatment, or information about HIV testing. Alex noted that psychiatrists are “hard to come by here”, with only one coming to the city for a day or two each week.

Another perceived barrier in the health care system that was mentioned repeatedly was access to doctors in the hospital’s emergency department. It was unclear if this was related to the shortage of doctors in the region, but participants felt that the current arrangement was not helpful for patients seeking care at the emergency department. One doctor explained the situation:

We have a funny system here where physicians don’t see other physicians’ patients until 5 pm...and doctor B specialist goes to the emergency room, and so doctor B will have to see that patient accepted after 5 o’clock... I don’t know, they probably have their reasons for it, I still can’t understand why it’s done, but I think it’s very stupid, it makes life a bit more difficult for the patients.

One nurse added that from a “nursing perspective” there should be an “emergency doc [doctor] at the hospital...the person who’s on-call for that day. Not going back and forth to their clinics...” and trying to manage both their clinic and being on on-call at emergency.

Limited Resources

Limited health and social service resources were another theme found throughout the interviews with health care professionals. Health care and service providers identified a lack of funding as the underlying barrier impacting access to interpreters, pamphlets in various languages, cultural sensitivity training, and a lack of public health education for students and adults in the community. A lack of funding for interpretation and translation services was mentioned repeatedly by professionals including nurses, doctors and social service providers. Several health care and service provider participants agreed that the language barriers are the biggest barrier experienced in the health care system by the professionals serving immigrants and the immigrants themselves. One social service provider spoke about the dire lack of interpretation services available and how she had “begged and pleaded” with hospital staff to gain access to the hospital’s Language Line:

If I phoned and begged and pleaded...there is probably a way [to]... cover the cost... but traditionally no, we rely on the volunteer translator base that we have through our immigrant settlement agency, we don’t generally, as a general rule have access to the language line....”

As a result of such limited interpretation resources health professionals had used family members or friends of people being tested for, or living with HIV, as interpreters at clinics and at the hospital, which posed a problem for a number of reasons, not least of which was patient confidentiality.

Another health care professional, Anne, pointed out that resources were limited in smaller rural centres: “...Because they can’t read English, visual education and in their language are required. I haven’t seen anything related to HIV/AIDS and STD in different languages... Public health

resources were limited ... Physicians' time was limited." At the same time, there were some advantages to living in a smaller centre, according to Kevin:

People live in small town tend to be more compassionate... When you want to access help, small towns still easier compared to a big city... Less time waiting at the emergency ... Better accessibility to health care providers... If you want to have an x-ray done, blood work done, you can do everything on the same day, in a reasonable short period of time.

Facilitating Factors for HIV Prevention: Health Care Providers' Perspectives

Health care providers and community members had ideas to promote HIV testing and prevention of HIV/AIDS. This section looks first at the health care providers' suggestions; the following section describes community members' suggestions.

HIV Prevention

Health care and service provider participants identified factors which facilitated HIV prevention and treatment such as trust between nurses and clients, collaboration with other health care and social service providers, the Language Line at the hospital, and increased skills in HIV management/protocols. Health professionals' HIV prevention work with immigrants living with HIV consisted mostly of counselling individuals with HIV on the need to disclose their status to partners or spouses, and the importance of using condoms. They indicated that their HIV positive clients were comfortable asking questions or seeking advice about prevention once they had built up trust with the health professional. Kate related that in her experience, "most of the clientele... that are diagnosed with being HIV positive take that responsibility... they are using the condoms...", and they contact her, "to see if they can... pick up some new condoms, or they talk to me about scenarios, what might be happening with their partner".

Collaboration with Other Health Care & Community Stakeholders

Health care professionals noted positive aspects of the local and regional health care system which served to facilitate HIV prevention and treatment. The most prominent theme was the collaboration among various health services in the community and the HIV clinic in the nearest large urban centre. Wilfred summarized what he saw as strengths in this collaboration:

I'm really impressed with the [urban centre's] HIV clinic, and the services for treatment and for HIV positive individuals. I'm really impressed with the arrangements and the provincial links for AIDS service organizations and I'm really impressed with the support that this particular organization gets from the other organizations.

A doctor in the community was also pleased with his collaboration with the HIV clinic and the care his HIV positive client received there. The client was HIV positive when first seen by the local doctor, and had already been to the HIV clinic for treatment:

Every 3 months he is seen by them, I get a letter back with a copy of all his results, I have very little to do with his HIV care.... if I have any questions about adding on various medications if he's needed, they're very easy to reach, phone them, ask them a question, they'll give you an answer and it's done.

Communication

Open communication and shared follow-up of clients by local health care services was seen as very positive and helpful in serving clients. Heather explained that when an HIV positive client goes home from the hospital, nurses share the client's personal preferences or needs gathered while in the hospital or from other health care providers and pass it along to the community health providers who will provide follow up care to the client, noting that the information might be "cultural...or just their personal belief" so that "...when this person goes home...community health...can follow through to make sure that their beliefs aren't detrimental with their health". A public health nurse stated that the paramedics have agreed to supervise clients' compliance with HIV treatment, in special cases, by delivering medications to clients at their homes.

Emily summarized the positive views about collaboration as a key facilitating factor when she stated:

I think our strengths are that we ...as a healthcare community, have tried our absolute best to provide the best care. To this ever-changing population. I do believe there's been many, many dedicated people who have tried very hard to provide safe, competent, ethical care. I really do. Our weaknesses are that there are some people who do not want the newcomers in our community.

An example of this commitment to providing the best care possible to immigrants receiving HIV treatment was shared by Heather, as she described the extra steps she took to follow up with an HIV positive infant at home:

I was the first public health nurse that actually went out and weighed the baby, rather than having to go into the doctor and the baby was born in February and it was a huge thing to take the baby outside when it was cold...we went and did the home visit and then we phoned the weights in so that the medications could be adjusted. And I think those little things can make a big thing for the family's ability to...cope with all the things that they have to cope with.

Language Line

The acquisition of Language Line interpretation service at the local hospital was seen as another facilitating factor in improving HIV prevention and treatment. Several health care and service provider participants commented on the value of this tool in helping the hospital staff to communicate with immigrants, who speak many different languages and dialects. The community has also found a way to bring in doctors who are fluent in some of the clients' languages. Kate suggested that further improvements would be achieved if, "the physicians at least could figure out a way that they could fund Language Line for use in their clinics...."

Increased Skill Level of Health Care Professionals

Another theme evident in the participant interviews was the improvement in skills and service levels for people living with HIV in a range of areas, including recent training for the delivery of babies to HIV positive mothers, awareness of possible mental health needs of immigrants, pre- and post-HIV testing counselling skills, and improved doctor's attitudes toward HIV positive clients. One doctor explained that he did pre- and post-HIV test counselling with his clients 'most times', assessed the clients' understanding of the disease, provided them with as much information about HIV as he thought they would be able to take in at a given time, saw them frequently to provide more information and monitor their mental and emotional health as well as their physical health after a diagnosis, and made a lot of referrals to mental health workers and therapists because he found it was "quite helpful" for them. One of the nurses at the local health centre has found that, on the whole, "the physicians are more tolerant... compassionate", understanding and knowledgeable about HIV care and treatment, and that they were, "more aware that they might need to be asking certain questions, investigating certain things...rather than being told... they're seeking the answers".

Employer Support

The major local employer was discussed by a number of service provider participants, as it employs many immigrants, though none of the comments directly referred to prevention or treatment of HIV. Although some aspects of the company function was seen as creating barriers to treatment (see section on Economic and Social Factors within Theme 1), aspects of the company's policies and practices intended to assist employees in various ways were mentioned, including assistance with securing initial housing, transportation to and from the plant, pre-employment medical screening, interpretation arrangements, and several health promotion initiatives. The pre-employment medical screening and health promotion initiatives were viewed as the most relevance factors facilitating HIV prevention and treatment. The pre-employment medical was done overseas with potential employees to determine what, if any, disabilities or diseases they had. According to one health care staff, this medical exam was conducted:

Not to decide whether or not they have the job. It's not the medical nurse's... responsibility to decide if they get the work. Her job is to, to make sure that if they are hired that they are hired into a position that will not exacerbate or make...some condition...worse.... there's many different jobs to do and the idea would be to fit you into the position or a job that would best fit...your needs and make sure we didn't...exacerbate the problem you may have.

The safety coordinator at the company stated that the policy was:

Very clear...which is health of the people, of the employees, comes first. But somebody who's suffering from any kind of disease, we always advise that person to look for the right treatment through his or her family doctor.

According to another health care professional, the company's commitment to the health of its employees was evident in its plans to hire doctors, nurse and physiotherapist who could be

available to serve employees of the plant. The company provided mandatory English as a Second Language (ESL) classes which incorporated health education and allowed community agencies to do presentations and display posters about their services at the plant.

Role of Public Health Nurses and Sexual Health

Public health nurses spoke of their commitment to providing support to clients through HIV pre- and post-test counselling, partner notifications, and community development and education activities. One public health nurse summarized her role in this way:

My role consists of not only HIV... I'm responsible for any blood and body fluid exposures in the community, doing follow up for that, and that's where some of my follow up with immigrants or refugees... has been. Some other ones have been with hepatitis B and C, syphilis, and tuberculosis.

It was evident that the public health nurses were aware of, and sensitive to, the shock and hopelessness that patients may experience upon learning of their HIV positive status. The nurses spoke of taking great care in reassuring patients and providing them with information about the disease and its management in a way that patients would be able to understand, including the medical terminology that would be part of their interactions with doctors who would be monitoring them and providing follow-up care and treatment. One public health nurse, Jane, described the difficulty both she and her patients experienced when talking with them about their HIV diagnosis:

It's the biggest challenge I've faced in my career. It's never an easy diagnosis to give anybody and when these people get this diagnosis, it's very, very difficult for them. And for most of them they see it as an absolute death sentence, because in their countries, as we all know, there's not much help available. So it's about us instilling hope and getting them linked up with the [urban city] HIV clinic and making sure that we give them the education about what this disease is and how you can go on to live your life with it, instead of in spite of it.

Another public health nurse explained in detail her comprehensive role in serving people newly diagnosed with HIV, which involves counselling and addressing sensitive topics like partner notification, as required by the Public Health Act. Kate explained how this new full-time public health position was viewed as a positive development:

Since this position's been full time...I'll have the people, person come by, I can give them more information typically because I have the time to go through things, go through the diagnosis, risk factors of how he might have had it, how it's transmitted, and then partner notification, so why that's really sort of important, right away we will make an appointment with the [urban City] HIV clinic, so it works out best for the client. Usually the issues are concerns about whether it was the family or friends, or confidentiality.

Within this counselling process Kate described the care she took to provide newcomers with information about the disease and its management in a way they would be able to understand, including explanations of the medical terminology they needed to know when interacting with the doctors who would be monitoring and providing follow-up HIV care and treatment:

I try to make it very clear that they understand what it actually means, and what the numbers mean, because that's what they're always going to be quoted right? At the specialist...what is the CD-4 count, what's a viral load...even though they do ok with English, sometimes I'll ask them if they want to do it through the language line interpreter, so it's even that much more clear.

The sexual health nurse was reported to be responsible for coordinating the patients' initial assessment with the HIV clinic in the nearest large urban centre. This involved a pre-assessment with the patient to determine their immigration history, current support systems, access to transportation for the trip to the HIV clinic, and their familiarity with the city. The nurse would travel with patients at times and attend medical appointments at the HIV clinic with a client, with the clients' consent, in order to support them with the medical process and information.

A common theme throughout the discussion of the role of the public health nurse was the importance placed on building or maintaining relationships with clients. The health care providers reported that it is important to build and maintain relationships with newcomers diagnosed with HIV as a critical part of the care and monitoring patients required. Each patient's communication challenges, available relational supports, level of understanding of the disease, and follow through with monitoring and treatment, were seen as unique, and the nurses were sensitive to the individual situations and needs of each patient, as Jennifer explained:

We are still there to maintain that relationship should they require it. I think, they're all really quite different, the people that I deal with...and some are very private...and then others...like us to be involved more with their lives, I think it's a real support for them, and they feel that they're not on their own, because a lot of these people don't have families with them. You know, and I think when you don't have your family with you, then you do need that extra support.

The public health nurses also identified several challenges they face in their work, specifically related to HIV testing and monitoring, and transportation to appointments at the HIV clinic. One challenge with newcomers described by a participant was convincing male spouses or partners of HIV positive newcomers to get tested for HIV:

We have a hard time convincing the men to do the testing if the female partner is positive. Lots of times they just don't wanna know, it's again, ignorance is bliss, if I don't know I don't know.... Lots of time... just going back talking to them.... Trying to get them to come onboard.

Another challenge was figuring out how newcomers would be able to attend the necessary assessment and follow-up appointments at the HIV clinic. As one nurse stated, "how they [HIV positive immigrants] can make it up to the appointment is probably the toughest part."

Facilitators of HIV Prevention: Community Members' Perspectives

Community members discussed a number of approaches to HIV prevention and use of HIV prevention services. Community members suggested that a variety of strategies should be used to promote awareness of HIV and HIV prevention methods.

Condom Usage

Despite difficulties and reluctance to use condoms expressed by some participants discussed in the previous section, most participants felt that condoms protected from HIV. As Mangahsu said, "When you use condom your life is safe." While some participants felt condoms were readily available and easy to use, like Deng, who said, "It's so easy...Condom doesn't cost a million dollars. It doesn't even cost one dollar", several other participants felt that condoms should be free or more readily available and widely distributed. Lena advocated this approach:

By putting condoms everywhere, maybe people will just grab. Some people, they are shy to go and buy them now. If they just put them free everywhere, I think it is going to help.

Ashley felt that reducing the cost of condoms was one way to make them more accessible in the community:

Yes, they are quite expensive. If they can just reduce the price or have them accessible, anybody have access to those....I mean, if you are trying to protect the community then I would think the prices has to kinda go down so [they] can be more affordable and stuff. Yea, or they can just have them for free....

In addition Ashley and others thought that placing condoms strategically in the community would be another way to facilitate their use and she suggested places where condoms could be, "Picked up anywhere....Everybody goes to the mall, everybody goes to the grocery store. If they could have those in places like that....it would be better."

Given Canadian cultural norms around sexual activity, several participants thought promoting condom use among youth was particularly important, as Jordan commented, "I would say...the young generation who don't have the one sexual partner, I'll advise they use condom every time. The women have to insist on it."

Several community member participants felt that condom use should be promoted together with abstinence for HIV prevention. For example, Peter explained his belief in this dual approach:

With the level of promiscuity in the growing youth population...it is a double protective thing you know, talking about dealing with teenage pregnancy as well as talking about preventing HIV/AIDS.... What I'm saying is like, from my faith, it is said that sex without marriage is not right in the sight of God.... And then generally, I will still say that with the growing...risk of HIV spreading, I would encourage...abstinence until you get married, but...there are people

who still go behind their parents and youth...stay involved in sexual activities, so I will support the idea that condoms should be used, yeah.

Others thought it was important to promote fidelity over condom use. Desailly agreed with this approach to HIV prevention:

One of the methods should be abstinence and some of it should be fidelity. Because sticking to one partner sometime can help you prevent that [HIV] too. Not be floating around. Yea, and some of people by using a condom can also help.

But this view was not universal, as some participants thought that the use of condoms promoted sex. Manjo stated, “My personal view and according to my faith...they [condoms] don’t really help because they encourage people to continue doing...the sexual stuff out there.” Matthew also advocated this approach, though with a strong appeal to men’s moral obligation to their families:

Definitely somebody has to come clear and tell them exactly what is...wrong... some men get it right, some men don’t get it right...by you telling him, “Are these your kids?” Say, “Yea.” “And you love them?” Say, “Yea.” “Why you doing this then? Cause if you really love them, you’d pay attention to them and you’d look after them. But if you don’t really love them you, that’s why you do what you are doing, by going around with other women. One day, if you get in trouble who’s going to look after these children?”

Other advocated the ‘ABC’ approach to HIV prevention –abstinence, be faithful, use condoms- as Lilly did, “It’s to abstain, and if abstinence won’t work, like, safe sex, one partner...”, though Pam felt that abstinence and being faithful to one partner were better HIV prevention methods than condom use:

If I was to talk on this topic, I would encourage everyone to stick with their partner or if you’re not married, don’t have any boyfriends, [and] stay the way you are until you are married. Because you only, the best prevention is abstinence, it’s not even use of condom. Condom could be torn apart.

HIV Awareness

Some community members felt that HIV information was available, like Deng who stated, “We have the information already...how you get the HIV and how you can prevent...not getting HIV.” However, many community member participants suggested it was necessary to increase HIV awareness in order to promote condom use, abstinence and fidelity to reduce sexual transmission of HIV. Lilly, for one, said it was important to address the denial and misconceptions about the disease through direct education and awareness efforts:

The biggest problem is that AIDS is not real yet, in people’s minds it’s not real.... They [are] still saying that AIDS is like a myth.... So if we can increase the awareness of AIDS, like, if people can come out ... we can have all these pictures around, like – this is me then; this is me now – you know with HIV, all those scary

things, I guess people will renew their mind, you know, transform their mind... then you can use a condom.

Ashley who lived with HIV suggested using a personal approach to HIV education with testimonials when she said:

Now I know it's dangerous. You never know who's got it, who doesn't have it. Because it's not written on somebody's face that they're HIV, so y'know, so now I know, and I try to tell a lot of my friends, and a lot of my nephews, nieces, and everything...don't allow anybody to tell you we can have unprotected sex before you get tested...Don't fall for a guy who tells you, "I'll take care of you, I love you, let's do this because I love you," no... Besides education I don't know like, I'm not very sure what can be done to help people. I think first thing they have to understand.

Engage Churches and Community Groups to Promote Awareness

Many community member participants believed that churches could be used as an effective location for promoting HIV awareness and education because of the large numbers of immigrants attending various churches. Lilly elaborated on the need for awareness and education in her community and the role churches could play in addressing many misconceptions:

This thing about AIDS is true.... so you have to change that mentality, [to understand] that they are not going to die if you manage it well, so it's just awareness. And then...another big way of doing this is just through church.... as long as you can increase the awareness of people about AIDS, that it's not just bad people that get it...it's not just about sexual intercourse, you can get it through different means. And maybe even if you don't get it...your sister, your brother, your mom, or your dad can get it, because maybe they don't live a good life, and you know how extended our family is, so it's always going to hit home.... So if we can increase the awareness...to everybody in the community, then you can rest assured that it's going to change...eventually it's going to happen.

Lena noted that in ten years at her church she had never heard anyone talk about sexuality until just recently:

A different pastor, talk about sexuality and everybody was like, *[interviewee gives facial expression]* and he was saying, "I know we never talk about it but we have to!" And he was talking about marriage commitment. And...everybody was waiting to say, oh my [God].... I mean, that's how shock it is.

Others agreed that churches could play a significant role in increasing immigrant communities' awareness of HIV within the context of spiritual and moral messages already taught by the churches. As Josept said:

Through church is an important message. There is a lot of [African] church in Alberta, particularly. If we talk...through every church is really strong message – Because the pastor when they gonna be talk about HIV...it's important that it is the people who...gonna say, oh, this is gonna be a real problem....It's just focus about how...to told the people what is wrong, what is not gonna do....

While there was general discussion of social and community groups that had been formed, only a few community members raised these as possible venues for HIV awareness efforts. Jordan mentioned that two concerts had already been held in the community to raise HIV awareness and funds for services:

We have already have...two concerts already with the HIV group, in (our city) here, just to promote the HIV and let people become aware of it and how to prevent it...and raise funds to support the HIV victims.

However, when the interviewer raised the idea of using community groups as a possibility Jesse agreed:

Yea, of course, of course. We like...for example like you, if you say...we can invite all these people, they gonna come and listen to you... And they're gonna ask you question. And they gonna understand what's...HIV. And what they do...to resist against HIV, to prevent HIV.

Use of Media to Promote Awareness

Community member participants also suggested using various forms of media, such as radio, TV and the internet, to promote HIV awareness with immigrants. Manahsu provided ideas about using various media to raise awareness:

Organize some group of people like all those celebrities or all those actors...or public people. They can use them to do a little jingle. Could be a radio jingle, they play on radio. If you are playing your radio in the car you listen to what they're saying on HIV. It help a lot. If you are watching your TV...and they do a little advice about it, it help a lot....then if you drive on the way you see a billboard...describing all those things, it help a lot.

Lena agreed that TV would be a good medium, “It would be nice if there is someone that can just stand up [on]...the TV and say, ‘Look, I’m your age and I’m positive. Y’know, you gotta be careful.’” Perhaps more tellingly, Lena went for testing for HIV because of an ad she saw on TV. Sylvia thought current ads on TV were very effective:

You gotta tell the women be strong and use a condom and you gotta tell the man, ‘wrap it up or you’re done’. It’s almost like you got to use those words to make them understand.... I know BET uses it, Black Entertainment Television? They tell all the men, wrap it up or lose it....like it’s really catchy, y’know?

Sadikhe pointed out that the Internet was also a very accessible means for promoting HIV awareness and information, and said, "If you have internet, if you just have to click a site you will have many information...[it] is very easy to get information about anything you want to know."

Sex Education for Youth

Another theme evident in the interviews with community members was the importance of promoting HIV awareness through sexual education for immigrant youth. Andrew, a teacher, stated that high school classes provided opportunities for introducing HIV education and awareness:

I'm in a teaching profession, and I get... a lot of immigrant students so... when I teach reproductive system, I get an excuse, that's a very good way for me to explain to my students about the diseases, so that is one way that I can influence my students to have safer sex... to promote, and be more aware of what is AIDS.

As we will see later, however, one of the nurses interviewed felt using schools for reproductive health education and to promote condom use would not go over well in her area, especially in the Catholic schools.

Lena also thought HIV education in schools was important and Manjo suggested several other venues which could be effective for educating youth, "about the HIV/AIDS" such as "in school, in churches, in communities, in youth retreats, talk about these issues."

In terms of HIV awareness and education topics, very few community members discussed the need for information on transmission mechanisms other than sexual transmission, as Sadikhe pointed out:

You have to deal with people to explain them... how to prevent, HIV you can contract the virus by many ways... by sexual transmission, blood transmission and these are too... a child, a baby can get it from his mother too. ...But essentially in the immigrant community we're interested in this two main kind of penetration. The sexual and the blood one....

Visibility of HIV Testing

Lastly, community member participants felt that promoting visibility of HIV testing was an important facilitating factor in HIV prevention. One participant living with HIV described the impact of highly visible ads for HIV testing on her own decision to get tested:

I was about twenty when I went and I did the test because I'm seeing it on TV and I'm seeing it everywhere about HIV wherever you go and they saying... go take the time, go take the test. And they're just pushing y'know? So you just got to get up and do the test.

One participant thought mandatory HIV testing would be an effective HIV prevention method:

So if we can set up a program or encourage something that can make it everybody get tested, that would help a lot too...right now there's nothing forcing anybody to have blood test. So I think that can help eliminate, reduce or get rid of it.... If we can make it something mandatory to your family doctor. To your family doctor. Cause at long last it's the health of the community.

It was evident from the interviews that community member participants recognized the importance of finding effective ways to facilitate HIV awareness and prevention among immigrant communities, as well as the broad range of cultural, social, and health care system barriers to HIV treatment and prevention that would need to be addressed in order for progress to be made in southern Alberta. Policy makers, social planners and service providers have been provided with complex and detailed insight into immigrant communities' barriers and possible facilitating factors as a result of the participants' willingness to engage in this study.

Summary

This section looked at the third research question, *What factors (barriers and facilitators) influence immigrants' use of HIV prevention activities and services?* Some barriers for those living with HIV were logistical: transportation to specialised HIV care, financial hardship due to missed work, and workplace constraints around taking time off regularly for doctor's appointments. Health care professionals agreed with this, saying poverty and job insecurity were huge barriers to HIV care. While there have occasionally been alternative programs to provide transportation, funding for this was usually insecure and at the time of these interviews immigrants had to pay for trips to the HIV/AIDS clinic.

Other barriers to HIV prevention and care included stigma and cultural beliefs around HIV. It was clear that the fear and shame around HIV was so pervasive that even those community members claiming to have love and sympathy for others with HIV had certain ideas about those who lived with it. As one community member said, "maybe even if you don't get it... your sister, your brother, your mom, or your dad could get it, *because maybe they don't live a good life*" (emphasis added). Others would want to support the person with HIV but would not let them near their children, or eat food prepared by them.

There were a variety of beliefs about HIV/AIDS in the immigrant community. Some linked it to promiscuity, and a punishment from God for being promiscuous, or recreational drug use; however, very few community members mentioned homosexuality. Others recognized infection could come from contaminated equipment and more rarely blood transfusions or from mother to fetus, but the cause of HIV infection was primarily associated with sexual activity. Thus, shame and fear of being isolated from the community made it difficult for people with HIV to openly access services, and might have discouraged testing. The very fact that only three immigrants with HIV came forward to be interviewed for this study underscores the stigma and fear around this diagnosis.

While condom use was recognized as one way to reduce risk, negotiating condom use was often difficult for women. Issues of trust, as well as men complaining of decreased pleasure, were frequently cited as reasons for this. The immigrants interviewed felt HIV/AIDS education was lacking and discussion of sexually transmitted disease is not always suitable for general conversation. Therefore, myths about the disease endure. Health care professionals agreed, complaining that sex education in some schools is not allowed. In an earlier section, the closeness of the community was mentioned as a strength; however, the extreme cohesiveness of community also mentioned by health care professionals in an earlier section may have disadvantages because new information has difficulty getting into the network to counteract the myths.

Other barriers included the health care system structure. While some immigrants were positive about health care and thankful that in Canada there were medications to prolong the lives of those living with HIV/AIDS, others found the system disrespectful of immigrants and difficult to negotiate. Some health care providers agreed, saying it could take years for immigrants to learn how to best access care, and when they did access it staff were rude and impatient. Underscoring the immigrant's dilemma, other health professionals pointed out that people who could not communicate in English took much more time than English speaking patients, and that was time they did not have in their already overly busy day.

Other health care system barriers included lack of information sharing within the health care system, lack of institutional support for HIV/AIDS care, a shortage of health care professionals and limited resources in general.

On a more positive note, facilitators included good collaboration among health care programs and stakeholders, open communication between clinics and public health, the language line, some recent training on HIV/AIDS care in the region, support from the local employer in terms of language and general health training for new hires, and the role of public health nurses.

Community members were also asked what would help facilitate HIV testing and care in their community. Their ideas included promoting condom use and providing free condoms, encouraging abstinence, sex education, HIV awareness programs through churches and community groups, and using media to promote HIV testing and safer sex.

Research Question 4: What Services And Strategies Could Address HIV Care and Treatment Among Recent Immigrants?

Recruitment of Health Care Providers

Health care providers cited programs that encouraged physicians to relocate to the area as being one strategy that could address HIV care and treatment. A few mentioned that in addition to the usual competencies, it would be ideal if the physicians had cultural competencies as well, and a good knowledge of HIV. As Jane said, "So I think that if we could get healthcare providers, medical doctors that understood about HIV and understood about culture, because they've lived

it and they've been there, they'd give great care." Having said this, however, she mentioned that some of the immigrants she worked with preferred to see a 'white' doctor.

One physician commented on the need for health professionals to work together collaboratively and address more than just the physical manifestations of HIV, and for the HIV specialists to work more closely with family physicians.

I don't know, maybe (specialists in the HIV clinic) think that the family physician do not have a role that they can play. I'm also thinking that also you know, it's all good and well when we deal with the medical manifestations of the disease, but I don't think we necessarily even begin to touch the social implications, or the psychological implications of dealing with any of this. But I think we don't do a good job dealing with any kind of, in other words I think that they are lacking as far as combining comprehensive, we are maybe getting better at it, then what we were, but still I would see that as a lack.

Family Centred Care

Ideally, treatment for HIV should focus on patient and family to assess how the family was coping with the illness. However, the processes and resources were not in place to provide this holistic family care. Clinics were physician driven and worked on fee for service, and patients were the priority for treatment and care. A primary care clinic that was family centred and not fee for service resulted in better quality care.

Orientation for Newcomers to Health System

A few health professionals saw a need for health professionals that could help new immigrants navigate the health care system. Knowledge that a Canadian may take for granted was not always obvious to a new immigrant, and having a contact such as a social worker who could explain the system would be helpful. As one physician said:

So you have to navigate the bureaucratic system, often without having the tool of effective communication, because you don't speak the language, then on top of that, you feel sick and ill, and you're worried, and you have to deal with a devastating diagnosis like this. Coming back so you know, it's a tremendously difficult situation, and I think that the government should acknowledge that by supplying full time social workers that can assist and help with these issues.

The health care professional participants also mentioned mental health counselling not only to help people cope with their HIV diagnosis but also with other mental health issues they may have. As Jennifer, a sexual health nurse, points out, between language barriers and cultural differences good mental health may be a challenge to deliver effectively: "...how many people are feeling comfortable with using North American standard of what counselling is, to go and talk about it...". Nevertheless, she did rely on other mental health professionals to help her do her job.

I don't mind providing that, but it's not part of my job. If I'm being honest, and you know, at the end of the day I'm sexual health, I'm not mental health, and there is mental health personnel out there so they can deal with it, and they have the time to deal with it. That's taking up time for me that could be, because I'm speciality as well, so, I don't mind at the beginning, but you know, if I feel it's more mental health than HIV, than, we would refer them onto mental health,

The language line was one way to help with communication barriers, but it is a limited tool. Translation is as much an art as a skill, and the translator on the phone is at a disadvantage because he or she does not have the visual cues that are so important in communication, nor does he or she necessarily have the medical background that is helpful in translating medical advice. Perhaps this was why it was mainly the crisis counsellor who used this tool, according to Jennifer. In interviewing the various health providers, there were differences of opinion on how much this tool was used. Some of the providers said the staff did not use it much, other health care providers knew of it and reported having to beg to use it. Because it was a pay per use service, the program that paid for it may feel reticent about lending it out freely.

There was a long wait for individuals to get into see someone in mental health. One health professional stated:

If I have somebody with a major depression, they probably wait 2, 3, 4 weeks before they can get into a mental health consult, and there is once again a shortage because there is not enough funding and there is not enough funding because I think that the government would rather not acknowledge that this is a big problem. Mental health issues, because you cannot quantify it or anything like that does not present itself as a big problem until in communities that we've seen that, you have a slue of suicides, and all of a sudden they say oops, we have a problem, and maybe more money would be, I think as far as mental health issues, I think there is a greater awareness. I think things have improved, but we're not there yet, and specifically with HIV I think the mental health aspect of it is paramount importance, and needs to be addressed.

Health professionals suggested that a way to get the community members involved in their own health care was to have health care providers who understood their culture and who could speak their language. Therefore, the health care providers thought it was essential to recruit immigrants for health care jobs.

And some people are more comfortable with one, other people are more comfortable with another. Right, so, um... it would be nice if we had more immigrants, refugees in the healthcare system.

Cultural Competency

The health care and service providers spoke of the importance of cultural competency, but there was also a realization that true cultural competence in all the different cultures in the area was not realistic. As Lindsay said:

I mean we can't know them all. The secret is to be accepting of anybody with the difference, right? Sounds simple. That's cultural to me. Cultural competency is to be accepting other world and not to stereotype but we are still kind of all hung up in this town on cultural profiles...

Nevertheless, there was a general feeling that education was helpful. John spoke of an education program his wife ran mixing immigrants with Canadian born people. One of the native Canadians was a front office staff person in a clinic, and she reported later:

You know I am the only one out of all the receptionist that can really help the immigrant people, especially the Sudanese, because I spent for a month sitting in the class, talking with them and understanding where they are coming from. And so I can deal so much better with understanding first their accent, second, understanding their fears, their concerns.

Kellie talked about the dangers of over generalizing and stereotyping, but recognized the importance of challenging assumptions and personal biases, not just for immigrants but anyone who was "different".

So that's another part of my job. Is to initiate that, y'know there are people out there who come and talk about cultural competency, get the process started. But I see my job as helping to facilitate ongoing—it's almost like CPR training—ongoing cultural competency, ongoing opportunities to learn about people who are different.

Development of Trusting Relationship

The health care provider/client relationship was very important, especially if both wanted to benefit from learning about each other and establishing mutual respect. This type of relationship building took time, patience and a degree of cultural competency. If trust was to be gained from members of the community, then individual health and service providers, groups and organizations needed to start interacting with people in the community. As one provider said:

And I guess in public health you have, you have more opportunity because you are in people's homes...it's sometimes seeing people outside the hospital walls and seeing them as, seeing them as people not patients. Y'know what I mean?

Accessibility to Health Care Services

Health professionals commented on transportation to services as being a big problem for the immigrant population. Jane commented:

Transportation is an issue for them. Absolutely probably the greatest issue that they face is transportation to access services. Socioeconomic, most of

them are very strapped in that area financially, they can't afford to take days off work and go for help.

As Wilford, who works for an AIDS service organization, pointed out, transportation to and from the HIV/AIDS clinic in the nearest urban centre was viewed as a basic need for immigrants with HIV, and was one way to improve accessibility at a most basic and practical level. Jane disagreed with this approach, however.

And that sounds good, but it's not as good as it sounds, because of course, economically speaking, they'd like to pick up 2 or 3 people and have 2 or 3 appointments on the same day, so it would be economical, but then again, we run into the privacy issue, you don't want to sit in that van with your neighbour, because nobody knows your diagnosis. That poses an issue, childcare poses an issue.

Other health care providers, thought that HIV services needed to be localized to be effective, and that certainly would ease the transportation issue. Kellie was unsure about this, however.

...convenient, I'm thinking convenient for who? Is it more convenient for us as a health region that we don't have to send people out, that we can have people seen here. Is it more convenient for the individual? Maybe, I suppose logistically it'd be more convenient for them to be here. We make that assumption. But since it's a small community, maybe people wouldn't be comfortable seeing somebody here. Because it's too close to home.

While local services may improve access in terms of location, it would do nothing to address the confidentiality issue. Obviously, however, providing service in a confidential manner would be key no matter how the accessibility issue was addressed.

Accessibility to Health Care Information on HIV/AIDS

In order to dispel myths around HIV/AIDS and its prognosis and treatment, some of the health professionals suggested education campaigns, although who should deliver this education and in what form would have to be considered carefully. One suggestion was to survey the population to determine their knowledge about HIV.

One health care professional commented that an area needing more support in the immigrant population was education about women's health issues. Information about all sexually transmitted diseases, including HIV, could be included in a curriculum about reproductive health.

One suggestion was training individuals from different cultures in the community, and perhaps model this training after the project in Edmonton called the Multicultural Health Brokers Cooperative. There are other agencies working separately such as the Global Friendship Center and the Family and Child Care Services. These agencies needed to work together more and possibly create a bigger organization to work with communities more effectively. Healthcare providers indicated that there needs to be more than just information pamphlets available for

people in the community. At the same time, educational efforts would ideally be in the immigrant's native language, with visuals included for those for whom literacy is a problem, taking care that such materials appear to be targeting one group, or immigrants over native Canadians.

Another suggestion was to provide extra training for pharmacists on HIV medications, thus enabling them to adjust medications and dosages with the option to refer the client back to their doctor as necessary. This would reduce the strain in the doctor's office wait room, reduces cost, and would allow the individual with HIV to access responsive care without constant trips to the doctor.

Many of the health care professionals mentioned that they were not at all expert on the subject of HIV/AIDS. Health care providers needed more education about HIV so they could make HIV a more prominent part of their patient teaching and education.

Support Groups

There were no established support groups for people with HIV in the community, although there were some in the cities for people willing and able to travel. While some health care providers spoke of the need for support groups, others did not think they would work given the smallness of the community and the risk of exposure. The community members with HIV expressed no interest in support groups at all, as previously discussed.

Involvement of Key Community Members

Health care providers spoke of involving community leaders from the immigrant groups to spread the word about HIV. Jane spoke of one valuable contact:

We've worked with some churches, there's a church in [urban centre] who has been a tremendous new leader in the HIV world, asked for information about it, got to know some people that have it, now have put a group together to do a mission in another country. People like that are very influential in your community. If you could work with those specific established groups in your community to get this across, I think we'll have success there.

Jane's comment spoke to the need to really know the community and use the resources already there to reach people. Community members agreed with this approach, with some suggesting using local elders or church leaders to help with HIV/AIDS education, and using community gatherings as a way to disseminate information. As Michelle said, "I think an idea that I would have is to go to the leader of the community or someone that a lot of the community members respect and know. Someone like that."

The Newcomer Health Services Coordinating Committee was formed approximately three years ago to try to work together as a group with key players in the community to improve health care access for newcomers. The committee worked collaboratively and included schools, AADAC health region services and others to engage the communities. Through funding from Citizenship

Immigration Canada, the committee was able to hire a cultural navigator for the community called a Newcomer Family Liaison. This person spent time in the community and assisted newcomers access the services, schools and health programs they needed within and outside of the community. People were referred to select centers or programs by the cultural navigator as well as Public Health, Child Family, Global Friendship Immigration Center and the Volunteer Resource Center. Education was an important function for the navigator. Government funding was limited, but a strong case could be made that this service is a wise investment.

Local Employment

As mentioned earlier in this report, the large employer who brought immigrants to the area could help, either indirectly with ESL classes which included health education, or more directly by possibly partnering with health care professionals and organizations to have health care on site.

Summary

This section looked at question 4: *what services and strategies could address HIV care and treatment among recent immigrants?* Health care professionals mentioned recruiting more health care providers and training health care providers from the cultural groups and training for greater cultural competency in Canadian born providers. In addition, recruiting health care providers of all kinds from the local immigrant population would diversify staff and create greater cultural competency in all staff, because health professionals can learn about the diverse groups they serve through both their clients and their colleagues. To ease strain on doctor's offices, pharmacists could have extra training to allow them to make adjustments in medications and dosages without the patient having to visit the doctor's office. Structuring health professional's time to allow for the time it takes to build trusting relationships was important.

A process to better educate and orient new immigrants to the health care system would help in all areas of immigrant health, not just HIV testing and treatment. Health professionals also said more mental health counsellors are needed, although one wondered if western ideas of mental health counselling were appropriate for other cultures. Although the immigrants interviewed did not mention mental health counselling directly as a need, one of the community members with HIV had relied heavily on his social worker to help him cope when he was diagnosed. While a couple of health professionals thought support groups would be helpful, the community members did not want that sort of exposure in their small community.

Accessibility in terms of clinic locations was an issue, but it was not easily resolved. Community members did mention the financial strain of travelling to the larger urban centre to access services, and health professionals echoed this, saying financial help for these trips were sporadic and were non-existent. However, local clinics or group transportation via van threatened privacy and confidentiality.

Both health professional and immigrant participants mentioned involving key community members as a way to get the message out to the community. The local newcomer's association had a liaison position whose principle role was education, and this person could be key in

educating on HIV/AIDS as well. The local employer could help both directly and indirectly through education, language training, and other health promoting activities for its employees.

Research Question 5: What Intervention Strategies Could Promote The Use of HIV Prevention Activities and Early Detection Among Recent Immigrants?

Availability of Medical Information

Given the transient newcomer population moving in and out of Alberta, many health care and service providers recommended increased information sharing between federal and provincial health care systems. This would enhance the effectiveness and timely delivery of health care to individuals as they move around the country, as well as ensuring medical information follows people from clinic to clinic or to the hospital even within one city.

One health care provider, Kelly, talked about the usefulness of having all medical data in a place accessible by professionals.

Do you have med allergies, do you have medications you're on, y'know, what is your immunization status, have you ever had a chest x-ray, do you have underlying health, I mean do you have sickle-cell anemia, do you have thalassemia, do you have some of these illnesses that are endemic to their country, right? And just to have a databank that I can draw on that would have that critical piece of information when they came in.

With three clinics open as well as emergency and the charts not readily transferable between them, medical information could be very hard to access at the hospital unless the patient's family doctor was working in the emergency at that time.

Collaboration

Increased collaboration between health care organizations and local employers, especially companies that employ many immigrants and refugees, would enhance services and reduce overlapping programs. Carol said:

I've seen in the last couple of years that the federal government is recognizing it, the Alberta government is recognizing it, communities recognizing it, so let's make it work, let's have partnerships with other agencies and, you know, so we're not overlapping other services, let's enhance our services...

The health care and service providers all felt strongly that health care at both federal and provincial levels of government need to communicate with HIV/AIDS organizations, the local immigrant organizations, and large employers of immigrant workers to come up with effective care and education strategies.

Wilford, who represented an AIDS service organization, stated: “I wouldn’t think twice about going to the largest employers and beginning to explore the problem in an appropriate way.” While he has had meetings with the human resources department of the large local employer, he said “they’ve shared information and had a chance to ask questions. . . I wasn’t able to gather anywhere near the amount of information to understand the things that I’d like to understand to help us.” However, there was no local office in the area for his organization nor did he have sufficient time or travel funding to travel there as often as he needed to. Ideally, given the number of clients in the area and the need to do community capacity building, create links with the employer and local health programs, and gather information on client and family issues and culture issues, he felt there should be an HIV/AIDS service organization with an office and a staff member working at least part time. “It’s just the way it is that we don’t have that funding,” he stated.

Health providers commented on the need to be actively seek out and understand the immigrant perspective when delivering health care. Kellie said:

So if people come to Canada, identified with HIV/AIDS, identify themselves to a health unit in Alberta. And we then go ahead trying to help them the way that we would anybody else. If we don’t understand their perspective of the disease, we’re gonna be asking them to do things, to answer questions, to take tests, to take pills, to do—and they may not really understand why they’re doing it. . . something as simple as some of the people that I’ve worked with when we talk about Alberta healthcare and getting family doctor, and they, they look at me and they say, why do I need a family doctor? I’m not sick!

Community members also repeated the idea that community members must be consulted. Colin said:

. . . so you need to find out all the things from different communities, from different people, from different points of views to be able to understand in a global way, how you can help the people.

Zena concurred with this view, saying “the government has to listen to all this view and understand what kind of decision is supposed to take in with what immigrant to help. . .” Josept, a community member, went a step further in saying it is not enough for health professionals to ask immigrants their opinion, but to follow through: “If you go and follow what you say, you gonna be really succeed. . . and since you see something, you have to be responsible about that.”

Public Health

A physician working in the local area felt the public health department should have a dedicated department similar to the one developed for tuberculosis. While he acknowledged that HIV/AIDS has a greater stigma than tuberculosis, he felt that such an approach would work well.

Open Attitude

Wilford pointed out that collaborative approaches would be most effective if people examine their own preconceptions of what they feel the community would accept, rather than making assumptions based on what they feel is the culture of the community. As an example, he pointed out the needle exchange program in a small Alberta rural centre.

We just went out and asked and now we have a harm reduction advisory committee [in Urban Centre]... our last meeting [was] attended by ... AADAC, (the health region), the Chief Medical Officer, public nursing supervisor, 911 was there, HIV society was there, BON was there, Salvation Army Family Services was there, the Methadone Clinic was there, Ambulance Services was there, representation from [a small rural centre] was there as well. John Howard's Society was there.

He continued to say that some had thought such a program would be difficult to establish in that area because it was thought to be too conservative. However, he found instead that with a collaborative and open approach the program is moving forward successfully.

The Local Plant Employer

One health care provider mentioned that it might be quite effective if the local plant employer took an active role in the education of their workers, making it part of their orientation. They could include information on where HIV/AIDS services are and reassure newcomers that their information will remain confidential. Barbara adds that private industry could partner more closely with the public sector in promoting and protecting their employee's health. She pointed out that the employer will benefit from their employee's improved health.

Carol, however, sounded a note of caution about relying to heavily on one employer to provide all the resources to educate and treat immigrants, when she said:

Now, we don't have all the answers or questions and sometimes we're not even too sure what next step to take or what direction to proceed in. But y'know, working with settlement agencies like Global Friendship, since they started and helping being a part of that organization and seeing the community agencies really evolve over the last 3, 4 years, in terms of recognizing the community needs and accepting them and then moving forward instead of it being pinpointed as, oh, it's [the employer's] problem, they brought them here, they need to do this, immigration is a reality of our community and of our country. Canada is based on that.

One community member felt that while HIV/AIDS prevention education was the responsibility of the government, a good place to start in educating people would be to go to large employers where a lot of immigrants work.

Access

One health professional pointed out that immigrants would benefit from learning about the health care resources available in the town they move to. She said:

An orientation would be nice, as in, here's the family doctors that are taking, this is the way they would like to do this, this is how you access in, y'know, never giving them the sense that they can't come to emergency but better use of the doctor's time and the resources would be..."

As mentioned earlier in the report, being able to visit a doctor during their time off meant the workers did not lose any pay and did not have to explain doctor's appointments. A number of health care providers mentioned that clinics with extended hours would better serve the community. According to three health care providers, there was a proposal to build a clinic opposite the hospital to ease strain on the emergency department, but it was not passed by the town council due to zoning issues. One participant thought a clinic with diagnostic imaging, lab, and all the charts would be particularly convenient for workers. Another suggested the clinic also provide dental hygienists and language services. One participant thought a clinic right at the plant would be very convenient for workers, but another thought an on site clinic might compromise confidentiality and it would not be well attended.

Another participant, Luise, said that another agency in town that deals specifically with HIV/AIDS counselling would offer another perspective from the hospital based services, giving people with HIV some alternatives. While a physician participant, Dr. Brown, agreed that someone dedicated to counselling people with HIV would be a good idea, he felt the person should be located in the hospital rather than a separate office to provide more anonymity to clients.

Screening

One health care provider, Kellie, mentioned building capacity within the community to do screening. New immigrants often come first to organizations like the immigrant settlement centre and other groups. If these groups did initial screening, another agency can take on more of the ongoing work of intervention.

Research Gaps

One health care provider pointed out that those looking at HIV prevention should investigate the sex trade in the area and how that might be contributing to the problem, and what can be done about that issue. Another service provider thought investigating drug use as it related to HIV/AIDS in the community would also be valuable information.

Another community member, Subsahara, felt more money should go into pharmaceutical research. Deng and Vicky agree that the government should contribute to research in order to find a cure for the disease.

Prevention and Awareness Services: Different Perspectives

Dr. Miller, a family physician, felt that HIV needs to be included in differential diagnoses, since HIV is a “great imposter”.

I think we’ve been comfortable because Canada is not an endemic region, I think we still, there is a lot of denial. Amongst my profession as well.

Carol suggested that interpretive services at prenatal classes would encourage immigrant mother’s attendance and help inform these mothers of risks and treatments for HIV. This would tie in with the point made earlier that some of the immigrant groups need general education on women’s health.

A number of community members mentioned that there is ignorance around HIV/AIDs. Anthony said:

I think people need to get tested and like, especially here in [name of the place], they don’t know ... somebody has to talk about those things and people have to start getting tested you know, and maybe they can get help like after that.

Andrew agreed and said:

A strength for a better health care system would be, as far as AIDS is concerned, they should make people more aware of what is happening, and what is AIDS, people don’t know much about it, they just take it very lightly, but there should be a very serious awareness program...

A number of community members stated that involving community leaders would be a good strategy in informing the immigrant community, which confirmed the view of a number of health providers interviewed. Peter, a community member, was one participant who recommended this strategy and suggested a team of leaders from different communities who could be trained together by a Canadian health care professional and who would in turn disseminate information to their particular community. As Pam said:

If we’re going to get to the individual people we have to get the leaders, individual leaders of this communities. Maybe the immigrant communities. We need to get the contact with the leaders of the immigrant communities. So in that way you can reach the individual. So if tell the leaders what you’re trying to do to prevent the spread of AIDS and we’re organizing such and such program to educate people, I would like all immigrants to be present, such as such day of time, so they will pass that information to the other people.

Luise, a health professional, felt educating and involving elders was a good idea but did not necessarily agree with the approach of inviting people to an information session.

(The) most realistic strategy would be to go, literally, door-to-door or small group. Y'know, if you invite everyone to an information session I don't really think anyone's gonna come. It's integrating in the community, talking to the community and y'know, on a more informal basis, than we're necessarily used to.

Michelle, a community member, agreed with this informal approach, saying she would be more comfortable just talking with a friend. In terms of a large information session, however, she said, "I think, their mentality would be like, well, I don't have it, well, why should I go?" Mathew, a community member, also felt the small group approach is best: "Because in order to win them you got to start them one-by-one, one-on-one, and door-to-door." Mangahsu tacitly agreed with this when he pointed out at the interview, "If you don't come here for the research, I wouldn't know what is going on in this community, I wouldn't know the risk of HIV is going higher... with the immigrants." He went on to say that knew better, and that he would certainly be telling others.

Funding for Awareness and Prevention Activities

Community members mentioned the importance of monetary resources for educational activities. As Deng says, "Money... for the community to spread the word." Anthony stated people who are HIV positive "have to stand up, they have to stand on one voice." Another community participant, Josept, felt that people with status in Canada, such as doctors, can more easily access government support and create educational events such as conferences that way. A couple of community members mentioned the government's responsibility to educate people about HIV/AIDS. Mangahsu felt more communication about HIV/AIDs is needed and the government is responsible for educating people. He felt the campaign against cigarette smoking involving billboards and pictures of diseased lungs on cigarette packages could be applied to an HIV/AIDS campaign, possibly by putting postcards in malls, schools, salons, and other public places. The postcards would warn against the dangers of sharing needles.

A couple of community members mentioned the importance of volunteering in their community and helping both people with HIV and helping with prevention education, although they were not specific about how this would be done. Non government organizations were also mentioned as a possible resource.

Finding Physicians to Practice

One community member, Subsahara, mentioned that foreign doctors have difficulty getting licensed in Canada. She felt if the process for licensing foreign doctors improved it would help increase the number of doctors practising in small rural centres.

Summary

This section looked at question 5: *What intervention strategies could promote the use of HIV prevention activities and early detection among recent immigrants?* Health care professionals tended to look at logistical issues such as better sharing of medical information, more awareness on the part of physicians so that HIV was included in the differential diagnosis as a matter of

course, and having a dedicated public health department dedicated to the issue of HIV/AIDS in the community. They also talked about better collaboration between government, agencies, and local immigrant organizations to reduce duplication, fill gaps and improve efficiencies.

Both health care providers and community members agreed, however, that consultation with immigrant groups was key to providing more effective service. Both groups also agreed on the need for education, although not everyone agreed on approach. Some felt using local community leaders and having gatherings to disseminate information would work. Others, both community members and health care professionals, felt a more informal word-of-mouth approach would be more effective. While some health care professionals felt the local employer had something to contribute to education and support, one health professional cautioned against expecting too much from them, saying high expectations reflected an idea that since the employer brought the immigrants to Canada, they should be the employer's problem.

One provider from an AIDS service organization felt a branch office in the area would provide better service to the population. Such an organization would also serve as an alternative for locals seeking information, advice or possibly even counselling. The same AIDS service organization representative felt research was needed into areas like the local sex trade or drug trade to see how much these activities contribute to the problem, and if something could be done to address that.

Community members felt more funding for education and research was necessary, and that the government was responsible for education campaigns. Another community member thought physician shortages could be addressed by licensing more foreign physicians.

Conclusion and Recommendations

This research was an attempt to gather knowledge and begin to strategize solutions to improving knowledge about HIV, early detection, and prompt appropriate treatment of HIV/AIDS in the immigrant population in Alberta, particularly immigrants who come from HIV endemic countries. The interviews conducted with both local health care providers and immigrants looked at a range of cultural and structural issues that may increase risk for infection, create barriers to testing and treatment, and lead to isolation and stigma experienced by HIV positive people. In addition, the study tried to uncover strengths and resources in existence that are helping this population, both in terms of informing them about HIV/AIDS and helping those who are at risk or already infected.

It is very clear from interviews that stigma around HIV/AIDS was very much present in this community. If any further evidence was needed, we have to look at the fact that only three community members with HIV consented to an interview. The reason for the lack of participation might be related to fear of HIV disclosure, shame, and mistrust. The three participants who had HIV have been very circumspect with their own diagnosis even within their families, and had certainly not told anyone outside select individuals in their family and their health providers. It was plain that the fear and shame connected to HIV/AIDS would be a major barrier to overcome. This finding agreed with other studies (Zuniga, 2008; ACCHO, 2006).

While education could help overcome misconceptions on how the disease is spread, it is reasonable to assume that a disease which could be transmitted sexually or through the use of dirty needles while using recreational drugs would always be prone to more judgment than a disease that is transmitted through airborne means, or a disease with no known aetiology. Of equal importance is the fact that there was a tendency within the wider Canadian society to view HIV as a Black or African disease that was brought to this country by immigrants and spread to the general population, and is associated with homosexuality, which bears its own stigma. It should be noted, however, that even within immigrant groups, people felt that HIV was brought to their country by other racial, ethnic or national groups (ACCHO, 2006). For a person already marginalized in their new country, it was no small wonder that they do not wish any further marginalization as a result of a disease that held such stigma and could result in isolation from their own ethnic group.

The immigrants interviewed for this study did not mention homosexuality or drug use frequently, but they were all aware that the disease was spread through sexual contact. Some mentioned contact with blood as well. However, sexuality and in particular promiscuity was a common theme. Beyond this, however, community members did not know much about the disease, where to go for testing and treatment, or what the treatment would consist of, although many were aware that in Canada medications are available.

Barriers to Accessing the System

Transportation to the nearest HIV clinic was one recurring theme with both community members and health professionals. Access in a rural area for specialty services can be problematic. While at one time funding to help immigrants pay for these trips was available through public health and in one case through a research study, at the time of the interviews sources of funds had disappeared. Immigrants sometimes had to take a day off work to go to the city, which resulted in loss of pay. In addition, frequent doctor's appointments were looked upon suspiciously by work supervisors. While one health service provider was in favour of providing a van to take people to their appointments, it was difficult to see how this could be done without destroying confidentiality. Others felt a local clinic would be ideal, but again, only on the condition that it was not associated with an HIV clinic. Health care professionals were in short supply in the area in general, and addressing this shortage could create health services with extended hours, making it easier for immigrants to attend appointments without missing work.

Lack of knowledge on how the system works, where to go for help, or even not knowing if HIV tests were free are all potential barriers for immigrants. One study done in Toronto pointed out that new immigrants tended to learn about the Canadian health care system through a relative or through newcomer's organizations rather than through the health system itself, meaning their orientation to the system varied in thoroughness and accuracy (ACCHO, 2006). Even something as simple as how the local clinic worked in terms of which patients were seen first could reduce misunderstandings, as the interviews in this study indicated. Access to good and confidential translation services was essential for good care. As Kreps (2008) said, "Communication is crucial for good health care and plays a major role in patient teaching, use of health information, compliance to medical advice, understanding public health messages and other health related interventions." Local translators were not necessarily the answer, because confidentiality could be breached more easily that way. The Language Line could be helpful, but had its limitations as well.

Another barrier for immigrants was having to interact with health professionals who they perceived as racist, impatient and culturally insensitive. Knowledge of different cultures is not an easy thing to acquire, as cultural norms were multi-layered and often subtle. As one health care provider pointed out, cultural competency training was helpful as a first step. However, in the end it was up to health care providers to establish a trusting relationship with the patient and to communicate with them and learn about them as individuals, not just a stereotype of their culture.

Once an immigrant accessed the system, there were still further barriers within it. Health care professionals commented on the inability to access or even locate patient records. In addition, health care providers felt they were not as knowledgeable as they should be about HIV. One doctor felt HIV should be included in the differential diagnosis much more often than it was, and the fact that it often was not, was a sign of denial amongst Canadian doctors. A sexual health nurse commented that her education on HIV/AIDS was limited as well.

Health care professionals mentioned the need for more services for the mental health of HIV positive people. What mental health services would best serve people from different cultures, however, was not clear. Western ideas of psychotherapy might be helpful for immigrants, but

might also be very difficult when both language and cultural barriers existed. However, the participants who were HIV positive spoke highly of the social workers and nurses they encountered. The subject of support groups came up, but it should be recognized that this was a smaller centre and the risk of exposure to one's own community was great. If only three people with HIV agreed to a confidential interview, it was unlikely a support group would garner participation.

One participant from an AIDS service organization mentioned the need for more information on the immigrant community as a whole. As he pointed out, little is known about how much the sex trade or the drug trade may be contributing to the problem.

Cultural and Social Barriers

While most of the community members interviewed were aware that condoms helped decrease the transmission of HIV, they were also aware that condom use was not always easily negotiated in a relationship. This confirmed what other studies mentioned (Weine, 2008; Rois-Ellis, 2007). Men complained that condoms reduced pleasure; women found that men were suspicious and resistant to their suggestions about using condoms. As Organista (2008) pointed out in a study of Latino migrant workers, sexual activity that was mixed with alcohol or drug use was even more likely to be unprotected. Resistance to condom use is not a problem specific to any given culture, and it will not be easy to overcome.

Education

Both the health care providers and the community member groups interviewed, felt education was key to reducing HIV/AIDS transmission, increasing testing, and encouraging people to go for treatment, as well as reducing stigma. This was in line with other research done with immigrant populations (Huang, 2008). Like Huang's study, this study found a gap in immigrants' knowledge about HIV/AIDS. However, how education to address this gap was done might be a point of contention. Any educational program cannot appear to be targeting a certain population apart from the whole population, as this could lead to community censor/backlash, generalization, stereotyping, and increased social discrimination and stigma related to race. In addition, the immigrant population could be more difficult to reach due to language issues, literacy issues and issues of isolation – some immigrants worked and socialized almost exclusively with people from their home country, which limited their exposure to programs in their newly adopted countries, including public health programs.

Both health care professionals and community members felt that education through the community would be one way to increase awareness and understanding of HIV. How this would be done, however, was not completely clear. One community member said an information session on HIV/AIDS might not be particularly successful as people would not go if they felt they were not at risk. A few community members thought a more door-to-door campaign might be effective. Some community members felt elders should be involved; others mentioned that religious norms make it difficult to talk openly about sex. One health care provider mentioned one particularly charismatic community leader who would be an ideal person to involve. Choosing such personalities from an immigrant network would require some intimate knowledge

of the community, or at least connections to someone who would have such knowledge. While involving the community seemed like a good and obvious strategy, Chin (2008) pointed out that in approaching community groups one should keep in mind how likely that group was to either maintain or challenge traditional societal norms or taboos. For example a church group might help in teaching love and acceptance, but might draw the line at providing free condoms or openly discussing sexuality. On the other hand, arts, media, charitable or worker's rights organizations might challenge the status quo and be more likely advocates for HIV/AIDS causes.

A few participants suggested hiring immigrants as health care workers. Carroll (2007) also recommended this in a study on health practises of Somali women. While having an HIV/AIDS outreach worker from one immigrant group would indeed help with language and cultural barriers for one group, there were a number of different groups in the city that were the focus of this study, some of which had old feuds dating back to wars in their countries of origin. While having an immigrant health worker would have a natural advantage because of their familiarity with the immigrant experience, that worker would likely also need support to be culturally competent with immigrants from other areas of the world.

Kreps (2008) felt educators need to embrace open-minded practises that are sensitive to ethnicity, and Rois-Ellis (2007) also mentioned this. In this latter study, Latina women mentioned such ideas as having public service messages before pornographic films. One of the community members in this study suggested putting messages on condom packages, similar to the lung cancer messages on cigarette boxes. It may take a while to generate creative yet suitable ways to reach the community, but by working with the community a variety of approaches could be used to educate people. Media was suggested by several community members as an effective way to promote HIV testing, condom use, and to generally reduce stigma, especially through the use of celebrities.

A recurring theme in the interviews was partnership – between local organizations such as newcomer's organizations, health care, and local employers with a large number of immigrant workers. Regardless of the partnership, it was important to always include community representation. Both health care and service providers agreed that immigrant organizations must be included, and this approach was supported by the literature as well (Kreps, 2008).

Recommendations

Education

Education is needed to inform the general population about HIV/AIDS, to encourage condom use and other practises to limit the spread of HIV, and to encourage those at risk to ask their doctor for an HIV test. In addition, education campaigns that inform people of HIV treatments and help reduce stigma would both encourage people to get tested and help reduce isolation in people who have been diagnosed. Care must be taken that such public service campaigns are culturally sensitive but did not create an impression that immigrants are being targeted, thus reinforcing ideas in mainstream culture that Blacks and Africans were bringing the disease to Canada. Making information available in schools, through work health programs, through newcomer's organizations, through specific communities by way of influential leaders, and

through media, were all ideas that community members and health care providers thought would be effective. In planning these educational campaigns, it is important to involve both community members and health care and service providers.

The findings were also clear that there is a need to address the stigmatization and discrimination felt to exist among health care workers and service providers. Education of health professionals working with immigrant communities and particularly around sensitive health conditions such as HIV/AIDS was not identified by participants in the study but is a recommendation which needs ongoing attention. Changes in attitude and more empathetic interactions would encourage immigrants with HIV/AIDS to seek treatment and care and not feel intimidated and inferior.

Health Care Accessibility

Ensuring those who are HIV positive are supported in treating their disease would ease the burden for these people. In particular participants mentioned stringent attention to confidentiality, education on cultural competency, and finding ways to address language barriers, either through the Language Line or translators (according to what felt comfortable to the person accessing the system). In addition, new immigrants need to know how to navigate the system. Possibly health care professionals could partner with newcomer's organizations, community groups, new mothers' classes or local employers to assist with this task. Classes as well as private consultations could be provided.

Having clinics and labs with extended hours would help immigrants who have difficulty taking time off work or who are financially penalized for taking time off work. Transportation to the HIV clinic in nearest large urban centre could either be subsidized or actually provided, as long as this is done in a way that preserves confidentiality. A family centred care approach, rather than a traditional fee-for-service model, would better serve the complex needs of the person with HIV/AIDS. As a chronic condition, this disease required the involvement and support of a family unit. Care that just looks at immediate physical needs without taking the person's context into account would be inferior care.

Confidentiality cannot be over-emphasised on this issue. Even one slip in confidentiality could destroy access by creating fear that privacy will not be maintained. It was essential that health care workers be keenly aware of the power differential between themselves and immigrants, and realize the importance of taking extra measures to preserve the trust of their patients.

Recruiting more health care workers in areas like public health and mental health counselling, possibly with a funding structure that supports HIV/AIDS work directly, would also improve access. Health care professionals must be given a structure that supports the time it takes to develop trusting relationships with people and their families.

Immigrant Health Care/Out Reach workers

While recruiting more health care workers in general was one suggestion, training immigrants to be health care workers would help with at least some language barriers. While an immigrant health care worker would be no more universally culturally competent than a native Canadian, they would at least have knowledge of their own culture, be fluent in at least their language, and would have a better understanding of the immigrant experience. Setting up scholarships for immigrants might help reduce the financial burden of training and help provide health care workers for rural areas. In addition, such health care providers would bring health knowledge back to their own communities. Having a community member as a health care provider could create confidentiality concerns, however, and this must be addressed.

Hiring an immigrant representative to work in clinics and hospitals as a liaison between hospital staff and immigrant families might also reduce misunderstandings that lead to feelings of unfair treatment, or to feelings of frustration on the part of the staff and the immigrants. While this did not relate to HIV care directly, it did increase trust and understanding of the health care system which led to better all around access and care.

Limitations of the Study

Limitations of this study included a very small sample size for community members with HIV/AIDS. Only three community members with HIV consented to be interviewed, and of those one refused to be taped. These community members reported being adherent to antiretroviral medication regimens, were doing well physically, and could speak English well enough to communicate without a translator. Thus, there was no representation from those with HIV who were not coping well, or those who could not speak English.

The sensitive nature of the topic might have kept community members from being completely honest, either about how they contracted HIV or if they did not have HIV how they would accept people with HIV.

Due to both the small size of the sample and the nature of qualitative research, the results of this study cannot be generalized to be the experience of all immigrants living in rural centers of Alberta. The findings revealed that barriers to seek help for HIV/AIDS and its related problems, and the practice of HIV prevention, were due to many other factors which included not only the individuals' cultural beliefs, values, health-care practices, but also social, political, historical, and economic background.

Challenges Related to Social Stigma – Research Ethics Issues

At the beginning of this study, the lead researcher, Dr. Donnelly, encountered resistance from one ethnic group in the community. Some community members became concerned because the increased incidence of HIV/AIDS in the area was mentioned in the consent form and information letter, along with the names of particular ethnic groups that were being interviewed. One member in particular who worked with the local resettlement centre felt that the researcher was profiling people from his country of origin unnecessarily, and he did not think HIV/AIDS was a problem

either in his country or here in the city. Dr. Donnelly spent some time explaining where the numbers came from and why the research was designed as it was, and also agreed to change any mention of a particular African country to “South Africa” in her documentation. The researcher agreed to meet with him and some members of his community to explain her background and the intent and goals of her research.

In this meeting, it became clear that an unfortunate incident where an article published about the incidence of HIV in this ethnic community in 2005 had devastated the community. The population at that time for this ethnic group was much larger, but since then has dropped significantly due to the negative feelings toward the ethnic community that the article generated. While the researcher had nothing to do with this incident, it was clear that the community is still very angry and to some extent the researchers became a scapegoat for this anger. Fortunately the director of the local immigrant centre defended the research, saying its purpose was to assist, not to harm or stereotype, and researcher re-iterated that every precaution would be taken.

The meeting was a long and painful one, with the researcher getting very little chance to speak. Eventually, however, the community was assured that the research was important enough, and the researcher’s intentions were good, and that every effort would be made to help and not to harm. This story was included in this report to point out the extreme difficulty of doing this sort of research, and the sorts of sensitivities involved.

This story would also be of value to other researchers who may be contemplating conducting research in similar ethnic or immigrant communities, whether concerning HIV/AIDS or other sensitive areas of health and social concerns. There might be various cultural or community-based considerations which researchers might need to spend more time exploring prior to setting up a research project such as this one. Engaging the community in the research project at the outset might not only address any sensitive considerations of the community but could also generate more interest for participation as well as in the outcomes of the study.

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Appendix A: Health Care and Service Providers' Profiles

Participant Title/Positions	Organization	Years of service in the region	Main roles and responsibility
Public Health Nurse	Health Region	7 years	Sexual health educator, counsellor, and program coordinator
Community Liaison	Local employer agency	10 years	Human resource liaison, facilitate housing settlement programs, schools, community questions for new employees. Sits on boards: Newcomer Health, Child & Family Service Council
Public Health Nurse	Region's Health Centre	8 years	Sexual Health Educator; Counsellor; Program coordinator
Dietician	Region's Health Centre	13 years	Nutritional counselling; Provides a wide range of services and gets referrals - (diabetes, pregnancy, cholesterol etc)
Registered Nurse	Region's Health Centre	30 years	Supervisor Acute Care; Pre-employment medicals; Emergency & Home Care: Direct care of immigrants
Executive Director	Immigration Centre	10 years	Provides support & referrals for immigrants to integrate; facilitate immigrants settlement; Program coordinator –developed programs for immigrant resettlement
Pastor	Church and local factory	10 years	Provides spiritual support; helps with immigration papers/ resettlement,
Registered nurse	Region's Health Centre	7 1/2 years	Site manager; Supervises acute care; Public health –worked with immigrants.
Social Worker	Services & Child Protection, Immigrant Settlement Agency	11 years	Investigates concerns reported on child protection. Settlement counsellor-Helped with housing, schooling, medical appointments.

Community Development worker	Employee for a Not for Profit Organization- (funded 80% by Alberta government & 20 % by municipal)	3 years	Works on community initiatives & identify local needs; fund organizations working with immigrants & refugees
Public Health Nurse	Health Region	6 years	Sexual Health Educator Counsellor Coordinator
Registered Nurse-Obstetrics	Region's Health Centre	9 years	Works on Maternity Unit & Preadmissions clinic (prior to labour)
Public Health Nurse	Health Region	3 years	Sexual Health Educator Counsellor Coordinator
Registered Nurse-Obstetrics	Region's Health Centre	27 years	Works on Maternity Unit in hospital
Pharmacist	Region's Health Centre	27 years	Pharmacist in hospital
Assistant Intern to Pastor	Christian Service	1 year	Intern, church administrator Works closely with many immigrants
Safety & Health liaison	Local factory	7 years	Safety issues; also helps with community coordination of immigrant issues, health issues etc,. Experience with social activities & human rights, activists.
Manager of Programming	Immigration Services centre (Settlement Agency)	8.5 years	In charge of programs such as language training, parenting classes to help immigrants adjust to life in Canada
Executive Director of AIDS Service Organization	Regional AIDS Service Organization	4 months	Provide services counselling & advocacy to individual living with HIV
Community Health Nurse	Health Region	24 years	Has worked in Homecare, Public Health; experience in working with immigrants in past 8-10 yrs
Community Health Nurse	Health Region Newcomer Health Consultation Clinic	10 years	Community development; liaison-provides newcomers with basic health care information

Primary Care Physician	Health Region	3years and 4months	Provides family care; assists with deliveries; works with large immigrant population
Primary Care Physician	Health Region	9years	Provides family care, deliveries works with immigrant population (35%) of clients
Primary Care Physician	Health Region	14 years	Provides family care, deliveries works with immigrant population (35%) of clients
Registered Nurse	Health Region & Local factory	25 years	Medical nurse- carries out pre-employment medicals assessment
Service provider in Community	International Church	6 years	ESL children's program; Ladies Teatime; Sewing projects for immigrant women
Health Promotion Facilitator	Health Region	2 years	Works with immigrants & general population; organizes health promotion activities
Registered nurse	Region's Health Centre	25 years	Works in Emergency dept. Works with immigrant population daily for the past 5-6 years)
Community service provider	Region ethnic community	4 years	Women activity groups, schooling
Registered Nurse	Region's Health Centre	25 years	Works in Emergency Dept- has worked with thousands of refugees
Program coordinator	Immigration Centre	10 months	Settlement worker- helps immigrants settle; processed 500 clients in 2006 (1500 services)
Settlement counsellor	Immigration Centre	2 years	Counsel immigrants with process of settlement & integration
Primary Care Physician	Health Region	10 years	Provides family care; works with large immigrant population
Pharmacist	Local Pharmacy	13 years	Works in community setting

Appendix B: Community Members' Profiles

Sex	Occupation	Years living in the region	Ethnic Background
Female	Student	4 years	Ethiopia
Female	Employee at the local factory	4 years	Somalia
Male	Employee at the local High School	7 years	Ethiopia
Male	Employee at the local store and studying part-time at a local college	4 months	Sudan
Male	Employee at the local factory.	13 years	Ghana, Africa
Male	Employee at the local factory	7 years	Liberia
Male	Employee at the local Immigrant Centre	1 year	Congo
Female	Employee at a local hotel	4 years	Sudan
Male	Employee at the local factory	2 ½ years	Liberia
Female	Employee at the local Immigrant Centre	5 years	Ethiopia
Male	Not available	7 years	West Africa
Female	Housewife	2 ½ years	Sudan
Male	Employee at the local factory	4 years	Uganda
Male	Employee at the local factory	4 years	Burundi, Africa
Male	Employee at the local factory	5 years	Sudan
Male	Employee at the local factory	3 years	Liberia
Male	Labor worker	3 years	Africa
Male	Teacher	3 years	
Male	Labor worker	3 yrs in Brooks	East Africa
Female	Employee at the local factory	2 years	Ethiopia
Male	Truck driver	6 years	Ghana
Female	Student	1 ½ years	Cameroon
Male	Self-employed	3 years	Ivory Coast, West Africa
Male	Labor worker	3 years	Sudan

Male	Labor worker	5 years	Sudan
Male	Not available	1 year	Kenya
Male	Quality control worker	2 years	Senegal, West Africa
Male	Machinist	5 years	Cameroon
Female	Self employed	4 years	Cuba
Male	Student	7 years	Kenya
Female	Worker at the local store	1 ½ years	Liberia
Male	Labor worker	4 years	Not available
Male	Labor worker	1 ½ years	Gambia & Senegal
Female	Nursing	6 years	Nigeria
Female	Daycare worker	7 years	Liberia
Female	Student	4 years	Cuba