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**Assessment of the Decision Support Needs of Immigrant and Refugee Women from HIV Endemic
Countries Regarding Voluntary HIV Testing**

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Assessment of the decision support needs of immigrant and
refugee women from HIV endemic countries regarding voluntary
HIV testing

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Title: Assessment of the decision support needs of immigrant and refugee women from HIV endemic countries regarding voluntary HIV testing

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University of Ottawa, Canada

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Objective: To assess the decision support needs of immigrant and refugee women from HIV endemic countries regarding voluntary counselling and testing for HIV (VCT), and the needs of their practitioners with respect to supporting them to make decisions about VCT in a culturally-appropriate manner

Design: Observational study

Methods: Interviews using semi-structured questionnaires based on the Ottawa Decision Support Framework (ODSF)

Setting: Six community health centers, two anonymous HIV testing sites, and an outpatient clinic offering specialized immigrant health services in Ottawa.

Participants: English-speaking, immigrant and refugee women from HIV endemic countries presently living in Ottawa; Practitioners providing VCT at community health centers (CHC) and anonymous testing clinics (AHTC) in Ottawa.

Results: Gaps in the decision making needs of women from HIV endemic countries with respect to VCT exist. Key differences in patient and practitioner perception of these needs were evident, particularly with reference to the target group's knowledge about HIV, and availability access and to resources that support decision making in this context.

Abstract

Objective

The objectives of this study were: 1. To assess the decision support needs of immigrant and refugee women from countries where HIV is endemic regarding voluntary counselling and testing for HIV (VCT) in Canada; 2. To assess the needs of practitioners with respect to supporting the target group in making decisions about VCT in a culturally-appropriate manner; and 3. To evaluate the needs assessment concepts and tools in a cross-cultural context.

Methods

Adapted semi-structured questionnaires based on the Ottawa Decision Support Framework (ODSF) were used to interview practitioners from a variety of clinical backgrounds who provided VCT and adult, English-speaking, immigrant women from HIV endemic countries presently living in Ottawa. Practitioners were purposefully selected from six community health centers, two anonymous HIV testing sites, and the Elizabeth Bruyere Family Medicine Center (EBFMC), an outpatient clinic offering specialized immigrant health services in Ottawa. The patients were recruited at EBFMC.

Results

Results revealed gaps in the decision making needs of women from HIV endemic countries with respect to VCT. Differences in patient and practitioner perspectives on the target group's needs were found. For example, patients identified decision support constructs related to HIV stigma as important obstacles whereas providers emphasized service-oriented barriers. Also, while practitioners expressed concern about the target group's lack of basic knowledge about HIV, patients stressed the need for increased awareness of services in relation to HIV screening and treatment, and the knowledge of the benefits and harms associated with these services. Another difference

between patient and practitioner perspective was that while all patients perceived the target group to be unaware of options around testing, only a few practitioners highlighted this concern.

On the other hand, patients and practitioners offered similar viewpoints on decision support resources. In particular, both groups highlighted the importance of: 1. systems-level supports that could potentially enhance the effectiveness of HIV-related service delivery (i.e. programming considerations for multicultural populations, such as integrated HIV services and multiple formats for the delivery of HIV information); 2. improved availability and access to immigrant health services, particularly language services; 3. public education on HIV; 4. and personalized counselling strategies for VCT.

Conclusions

Study findings emphasize the importance of multiple and multilevel interventions that involve: 1. adapting counselling approaches to address the decision support needs of women from the target group; 2. integrating decision support strategies into practice that facilitate decision making based on the best available scientific evidence and personal values, and in particular, decision aids that increase knowledge and clarify values towards available testing options and their consequences, and offer support to cope with HIV stigma; 3. understanding contextual factors that decrease the effectiveness of VCT in the care context, and; 4. enhancing awareness of broader issues that affect access and availability of healthcare and navigational resources for the target group, and immigrant populations in general.

Practice Implications

Decision support in the context of VCT can improve decisional quality. From a patient perspective, decision support during VCT can be an empowering tool that increases the chance that decisions are based on scientific evidence,

realistic risk perception and personal values. From a practitioner perspective, decision support can supplement existing guidelines on VCT to provide culturally appropriate counselling and support.

Glossary of Terms

ACCHO: African Caribbean Council on HIV/ AIDS in Ontario

AHTC: Anonymous HIV testing clinic

ASO: AIDS service organization

ART: Antiretroviral therapy

CHC: Community health center

CMA: Canadian Medical Association

CPARG: Canadian Paediatric AIDS Research Group

CPG: Clinical practice guidelines

EBFMC: Elizabeth Bruyere Family Medicine Center (Ottawa)

EHPEP: Ethnocultural HIV Prevention Education Program (Ottawa)

HIV/AIDS: Human immunodeficiency virus/ Acquired immunodeficiency syndrome

IDU: Injection drug user

IPDAS: International Patient Decision Aid Standards

MSM: Men who have sex with men

MTCT: Mother-to-child transmission of HIV

OCCA: Ottawa-Carleton Counsel on AIDS (Ottawa)

ODSF: Ottawa Decision Support Framework

PHA: Person living with HIV/AIDS

STD: Sexually transmitted disease

VCT: Voluntary testing and counselling for HIV

VCTES: Voluntary Testing and Counseling Efficacy Study

WHIWH: Women's Health in Women's Hands (Toronto)

CHAPTER ONE: INTRODUCTION

1.1 Epidemiology of HIV/AIDS among Persons from HIV endemic Countries

Persons who emigrate from HIV endemic regions¹ in sub-Saharan Africa and the Caribbean account for the fastest growing proportion of HIV cases in Ontario. In the 2002 report titled "*The HIV/AIDS epidemic among persons from HIV endemic countries in Ontario*", modeled² estimates showed that approximately 2,627 persons from HIV endemic countries were living with HIV or AIDS as of the end of 2002, representing 8.8 % of all 21,453 prevalent cases in Ontario for the same period. This report also indicated that persons from HIV endemic countries accounted for an increasing proportion of incident cases in Ontario, representing 22 % of new HIV/AIDS diagnosis in 2001-2002 in comparison to 4.6 % in 1981-2000. Furthermore, whereas overall prevalence rates among immigrants from these regions may not appear substantial in comparison to injection drug users (IDU) and men who have sex with men (MSM), they are about 20 and 60 times greater than heterosexual, non-injecting persons in Ontario. Analysis of HIV diagnosis by exposure category also revealed that a majority of infections in this group occurred via heterosexual transmission, and that a substantial proportion of the infections occurred post-immigration (30-45 %) (38, 39).

An interesting aspect of the HIV epidemic in Ontario among persons from HIV endemic countries is linked to mother-to-child transmission of HIV (MTCT). A descriptive analysis of data from the surveillance database of the Canadian Perinatal AIDS Research Group (CPARG)³ revealed that the group most affected by

¹ The term HIV endemic refers to populations where the prevalence of HIV infection exceeds 1 %, and where the primary route for exposure is through heterosexual intercourse.

² Methods for data adjustment in this study are open to debate. Modeling estimates vary due to under-reporting or delayed reporting of HIV/AIDS infections, and uncertainty in capturing data on country of origin, as this information is not always disclosed. Voluntary reporting of perinatal cases (i.e. through passive surveillance, for example) and difficulty in assessing exposure category are also further challenges to data quality (28, 34).

³ CPARG is a provincial surveillance system that collects information on HIV-infected women who have delivered since 1992, and includes retrospective cases followed to 1984. The database is based on voluntarily reported data from physicians caring for HIV-infected mothers and their infants (33, 34).

preventable pediatric HIV infections in Ontario was women from HIV endemic countries (31-34, 36). Longitudinal data collected from 1984 to 2001 identified 375 HIV-infected mothers, 105 infected infants (28 %), 202 non-infected infants (62 %), and 39 infants of an unconfirmed status (10 %). Of the 105 infected infants, 56 % were born to mothers from HIV endemic countries in sub-Saharan Africa and the Caribbean. Furthermore, a regional analysis showed that a majority of paediatric infections of this exposure category were confirmed in Toronto and Ottawa at the Hospital for Sick Children (66 %) and the Children's Hospital of Eastern Ontario (26 %), respectively (34, 36, 38).

MTCT rates in women from HIV endemic countries reflect higher maternal HIV seroprevalence in comparison to the general population. For example, the most recent estimate of maternal HIV seroprevalence in Ontario was 3.7 per 10,000 among 78 % of all pregnant women who voluntarily tested for HIV in 2002 (42). In comparison, a few studies exploring maternal HIV seroprevalence in women from HIV endemic countries showed that rates was as high as 2 % in certain sub-groups of this population (40, 41).

MTCT rates in women from HIV endemic countries may not only reflect high maternal HIV seroprevalence but also a lack of timely access to HIV-related services, including reproductive health services. For example, the findings of some studies suggest that the timing for antiretroviral therapy (ART) in pregnancy is sub-optimal in this group. A retrospective study of infants who were perinatally infected by HIV over the 2-year period following the introduction of the Canadian guidelines on prenatal HIV testing⁴ showed that over two-thirds of paediatric infections were linked to mothers from HIV endemic countries (34, 37). Mothers of this risk category revealed that none were aware of their HIV-positive status, and that none were tested during pregnancy (37). These outcomes imply that women from HIV endemic countries face barriers in accessing basic primary health care (34, 37), a conclusion consistent with other Canadian studies that report the underutilization of health services by immigrant and

⁴ These guidelines, which vary by provincial/territorial jurisdiction in Canada, require prenatal care providers to offer voluntary HIV testing to all pregnant women irrespective of risk status (22).

refugee women, particularly preventative screening services such as pap tests and mammography (71-73).

1.2 Key Challenges to Prevention Programming

Local research reveals that one of the major impediments to effective HIV programming for this population may be related to HIV stigma and discrimination. Exploratory research examining the impact of HIV stigma on individual and community level structures in immigrant African and Caribbean communities in Toronto have shown that on an individual level HIV stigma can not only hinder at-risk individuals from getting tested, but adversely affect those who confirm their HIV status through testing. For example, several reports published by ACCHO and WHIWH⁵ highlight the experiences of HIV-positive individuals from these communities, where common consequences of HIV stigma identified include fear of disclosure of HIV status, hesitation to access treatment services, late diagnosis and entry into care, economic marginalization, ostracism from community-and in some cases, gender-based violence and loss of familial and social support (43, 44, 46, 47). The findings of these studies are also consistent with international research on the psychosocial impact of HIV stigma and discrimination (1-17).

On a collective level, the impact of HIV stigma can be more obscure but no less devastating. Reports released by ACCHO and WHIWH have highlighted the association between HIV stigma, lack of community awareness of the problem, and lack of community engagement to address the epidemic. On this subject, findings showed that HIV stigma experienced at the community level can impede the identification of research needs and priorities, and effective provision HIV-related services (43, 44, 46, 47).

⁵ The acronym ACCHO stands for the African Caribbean AIDS Council on HIV/AIDS in Ontario. Please see section 3.6 for more information on this organization. WHIWH is an acronym for Women's Health in Women's Hands. WHIWH is a community health center based in Toronto that is involved in health-related research and advocacy for immigrant and minority women. It is also a member of ACCHO.

Local data also suggest that another barrier to prevention programming may be linked to ineffective service provision. For example, the 2005 report titled *"Planning for an Integrated Response to HIV/AIDS in Ottawa: Progress report on a 5-year service delivery plan for HIV/AIDS-related services"*, published by the Ottawa Carleton Council on AIDS (OCCA), highlighted two key challenges to effective service delivery for people from African and Caribbean communities living in Ottawa. These included: 1. gaps in resource allocation and; 2. lack of sensitization shown by staff at mainstream organizations to contextual issues that affect access to a wide range of HI-related services. The report also made recommendations to meet these gaps. Examples included the distribution of HIV educational materials at immigration/settlement organizations, the implementation of educational programs for immigrants that integrate HIV information within their broader mandate, and extended funding for the Ethnocultural HIV/AIDS Prevention Education Program (EHPEP), a health promotion program for African and Caribbean communities in Ottawa (49). A report published in 2003 by Ottawa Public Health titled *"Priority Goals and Strategies D: Reduce the Rate of HIV Transmission among Immigrants and Refugees by Increasing Use of Effective Prevention Methods"* offered similar recommendations (50).

1.3 The Policy Implications of Prevention

National evidence-based illness prevention guidelines for immigrants and refugees from developing countries are presently being developed to optimize comprehensive, needs-based care. These guidelines, which include the routine offering of the HIV test alongside screening for other infectious diseases prevalent in developing countries (24), will help to meet an important service gap (Aside from tuberculosis screening there are no comprehensive, evidence-based screening guidelines for this group at present) (23, 62, 65). The guidelines will allow immigrants and refugees from developing countries to access appropriate prevention and treatment services. In particular, the introduction of these guidelines has important implications for HIV prevention among immigrants and refugees from HIV endemic countries as

surveillance data from Ontario reveal that a significant proportion of HIV infections in this population occur post-immigration.

Moreover, when established, these guidelines will need to assure that HIV testing occurs with informed consent, a process the Canadian Medical Association (CMA) defines as testing of a voluntary nature that involves a competent individual who understands the “*purposes, risks, harms and benefits of testing, as well as not being tested* (11)”. Challenges to informed consent during routine HIV testing have been documented by several Canadian studies. For example, evaluative studies on the quality of counselling offered during prenatal HIV testing- the only context where the HIV test is routinely offered alongside a standardized group of tests in Canada- have shown that informed decision making is often compromised due to the poor quality of counselling offered by practitioners in this setting. This has not only resulted in poor quality decisions but poor uptake of testing (25-29). In fact, the only Canadian study on the experiences of African and Caribbean women with prenatal HIV testing showed that one of the primary deterrents for testing was related to the lack of information presented on available testing and treatment options during pre-test counselling (46).

Decision support strategies that supplement pre and post test counselling may prove to be an important tool for informed, value-based decision making when the guidelines described above are introduced into practice. The objective of this exploratory study was to assess the decision support needs of immigrant and refugee women from HIV endemic countries regarding voluntary HIV testing in Canada, and the needs of their practitioners to supporting them make decisions in a culturally-appropriate manner.

CHAPTER TWO: THE CONCEPTUAL BACKGROUND

2.1 Decision Aids: Helping People Navigate Care Options

In this age of patient-centred care, decision aids are becoming recognized as an important tool for shared decision making in clinical practice. Often used as adjuncts to counselling, decision aids help individuals make health-related decisions by providing them with information on options and outcomes relevant to their health condition or risk profile, and clarifying their preferences (values) towards these options. More specifically, according to the Cochrane Collaboration, “*decision aids are interventions designed to help people make specific and deliberative choices among options by providing, at minimum, information on options and outcomes relevant to person’s health status*” (62). In addition, decision aids may enable people to:

- understand the probabilities of specific outcomes (i.e. harms and benefits) tailored to their health condition
- clarify their values or preferences towards the benefit and harms of the options
- understand how others decide or recommend
- receive guidance or coaching in the steps of deliberation and communication

Furthermore, it is important to note the distinction between decision aids and general health education materials. While the former enables individuals facing a health decision to make a deliberative choice among personalized options, the latter helps individuals to understand their health condition, screening and/or treatment options in general terms but do not prepare them to make a decision (53, 54, 62).

2.2 The Efficacy of Decision Aids: What does the Literature say?

Decision aids have been developed for a variety of health-related choices, including decisions about disease prevention, screening, treatment, clinical trial entry and

palliative care (62). The latest research on the efficacy of these interventions shows that they improve certain indicators of patient-centered decision making.

In 2003, the Cochrane Collaboration updated a systematic review of trials that explored the efficacy of decision aids (62). This review included studies that met the Cochrane definition of decision aids and were randomized controlled trials (RCT) that compared a decision aid to no intervention, usual care, an alternative intervention or a combination of the above. Results of the meta-analysis under the random effects assumption showed that among the trials that compared decision aids to usual care, decision aids were shown to:

- Increase knowledge of available options (Weighted Mean Difference: 19/100, 95 % CI 13 to 24)
- Create more realistic expectations of the outcomes associated with the options (Relative Risk: 1.4, 95 % CI 1.1 to 1.9)
- Reduce decisional uncertainty (Weighted Mean Difference: -9.1/100, 95 % CI -12 to -6)
- Increase active participation in decision-making (Relative Risk: 1.4, 95 % CI 1.0 to 2.3)
- Reduce decisional conflict scores in relation to feeling informed (Relative Risk 0.43, 95 % CI 0.3 to 0.7)

However, decision aids fared no better than usual care alternatives on outcomes such as satisfaction with decision making, anxiety and health outcomes (62). Moreover, when simpler aids were compared to more detailed ones, results showed that the simpler aids were just as effective as detailed ones in improving knowledge; however, more detailed aids were more effective in increasing knowledge, realistic expectations, and agreement between personal values and choices.

2.3. The Ottawa Decision Support Framework

2.3.1. Description of the Conceptual Framework

The Ottawa Decision Support Framework (ODSF) is an evidence-based, transdisciplinary framework used to assess decisional needs, provide decision support, and evaluate decision quality (52, 54, 63, 64). The framework postulates that decision quality may be sub-optimal because of several unresolved decisional needs of individuals participating in decision making (i.e. women and their health practitioners). Examples include:

- **Decisional conflict:** Personal uncertainty about the best course of action. Manifestations of decisional conflict include: verbalizing uncertainty; expressing concern about undesired outcomes; wavering between choices; delaying the decision; questioning personal values; preoccupation with the decision; showing signs and symptoms of distress or tension during deliberation. Decisional conflict arises from the inherent difficulty choosing among competing options that involve risk, loss, anticipated regret, or challenge to personal life values (70). There are also modifiable factors that can contribute to decisional conflict such as inadequate knowledge, unrealistic outcome expectations, unclear values, and inadequate support and resources for decision making. These are described below.
- **Inadequate knowledge of the facts:** Limited cognizance of the facts regarding options, benefits, risks.
- **Unrealistic outcome expectations:** Unrealistic perceptions of the likelihood of outcomes.
- **Unclear values:** Lack of consideration or insight regarding the personal desirability an individual places on the benefits versus harms of available options. The value of an outcome is difficult to judge without knowing what it is like to experience its physical, emotional, and social consequences. Even if one is familiar with an outcome, its desirability relative to other outcomes may not have been considered.
- **Inadequate support and resources:** Inadequate support for decision making; social pressures to choose among options or disagreement on whose values count in decision making; mismatch between preferred and actual roles in decision making; limited awareness or access to training in shared decision making including structured deliberation, risk communication, values clarification, limited

access to effective education materials, efficient systems for integrating decision support in workflow/care pathways.

- **Unreceptive stage of decision making or predisposition towards options:** Lack of readiness to deliberate about options; strong predisposition that interferes with receptivity to new information of other points of view.
- **Failure to tailor support to personal and clinical characteristics,** including physical, emotional, cognitive, and social functioning that interfere with an individual's capacity to participate in decision making; demographic characteristics that affect attitudes and capacities for participation in decision making, such as age, sex, ethnicity, language, education, literacy, numeracy, and learning style. Practitioner characteristics that affect their ability to support decision making in the care context may include, but are not exclusive to, age, sex, education, clinical specialty, practice locale, experience, and counselling style.

A needs assessment is the first step in the development of a decision support intervention. This stage involves semi-structured interviews using a template based on the ODSF to assess factors that contribute to decisional conflict (Described above; Also please see Section 4.4.1 for more detail). The interviews are conducted with individuals facing a particular health-related decision (known as the target group), and/or others who may possess useful insights into their decision making needs (known as key informants). The latter may include health practitioners, family, friends, or members of a support/ health advocacy group.

The second step to decision support is the implementation of interventions to address the aforementioned needs so that a person can make a 'good decision', one that is informed and consistent with their personal values. Decision support strategies may vary, depending on the decision making needs of a particular individual. Specific strategies may include:

- Providing information to an individual about his/her health situation, options and outcomes, and/or realigning his/her expectations by describing probabilities of options and their associated harms and benefits

- Clarifying individual preferences towards the harms and benefits of options through explicit, value-clarification exercises
- Alleviating social pressures in decision making by helping an individual explore the nature of the pressure (including its source), understand whose opinions matter in decision making, and learn how to cope with the source(s) of pressure through a variety of communication and value-clarification strategies
- Improving an individual's confidence and skills in decision making through structured guidance or coaching in deliberation and communication
- Providing an individual with relevant supports and resources that will help him/her to make the decision, such as access to a health practitioner, family, friends, or a support/advocacy group

According to the ODSF, the above interventions should be tailored to an individual's receptivity or stage of decision making, and demographic/ clinical characteristics. Furthermore, decision support should also take into account an individual's preferred role in decision making (i.e. individual preferences over who guides and gets involved in the deliberation process).

The final step in the implementation of decision support evaluation. This stage involves an assessment of changes in the indicators of decisional quality before and after the intervention. Outcomes used to evaluate the efficacy of decision support generally include knowledge, value and decisional conflict scores. In addition, decision making according to preferred role in decision making, skills and confidence in decision making, match between choice and values towards the harms and benefits, and decisional regret may also be assessed. Evaluation may also be supplemented with an assessment of variables that impact acceptability to decision support, such as preferred language and format of a decision aid.

2.3.2. Rationale for the Application of the Conceptual Framework

The Ottawa Decision Support Framework (ODSF) was selected to guide this study because of its suitability for patients experiencing decisional conflict when facing a

new diagnosis with options that are value-sensitive, such as deciding whether or not to undergo VCT to confirm their HIV status.

The ODSF tailors risk communication and decision support to the type of a decision an individual may face. For example, the ODSF recommends directive counselling strategies for individuals facing decisions that are characterized by outcomes backed by scientific certainty where the harms are minimal in comparison to the benefits (known as effective care decisions). In contrast, the ODSF recommends a more non-directive approach to counselling for individuals facing value-sensitive decisions that involve outcomes that do not have the backing of scientific evidence, or when they do, necessitate value trade-offs between the harms and benefits (known as preference-sensitive decisions). For these types of decisions, the best choice depends on how an individual values known harms and benefits, and the scientific uncertainties associated with the available options (54, 55). Thus, when offering decision support for preference-sensitive decisions, the ODSF recommends strategies that focus on the deliberation (versus implementation) stages of decision making. The routine offering of VCT to the target group is characteristic of a preference-sensitive decision: Although there is clear scientific evidence on the benefits of HIV testing in preventing MTCT, little is known about the perceptions of women from HIV endemic countries regarding the benefits and risks of testing, or the value they place on the outcomes of being tested.

To better explore appropriateness of the ODSF, we must also understand unique features of the framework that support the rationale of the study. The ODSF is a suitable framework for this study due to its intervention focus and broad, gender-sensitive understanding of decision making. Moreover, its analytic focus on decisional quality means that the framework separates the evaluation of the quality of a decision from its outcome. In other words, 'good decisions' can still result in adverse clinical outcomes but are considered good as long as decision makers are informed, act on their personal values, are certain they chose their best option, and perceive that they had personal and external resources in their course of decision making (53-56). This

property of the ODSF is consistent with the study's aim of exploring decisional quality in relation to HIV testing in contrast to uptake rates.

Furthermore, the ODSF has also been used to study the decision making needs of vulnerable populations in cross-cultural settings. This characteristic of the framework will be described in more detail below.

2.3.3. Application of the Conceptual Framework to Cross-cultural Settings

The ODSF has been used to assess decision making needs in two different cultural contexts. In 1999, a decision making needs assessment was conducted with a random household sample of disadvantaged women living in La Pintana, a suburb of Santiago, Chile. In addition, the decision support capacity of front line health practitioners providing primary health care to these women was also assessed. The specific objectives of this project were to: 1. assess the decision making needs of underserved women living in La Pintana, Santiago, Chile; 2. educate practitioners in decision support (including nursing students and faculty at the School of Nursing, Pontificia Universidad Católica (PUC)); and 3. develop strategies to support the decision making needs identified.

For the needs assessment, 650 women and their families in La Pintana were interviewed by faculty and nursing students at PUC. Results showed that the most frequently cited difficult decision was related to health care system navigation (37.7%). Other frequently cited difficult decisions involved decisions about reproduction (12.2%), childcare (7.9%), lifestyle (7.3%), moving (6.3%), employment (5.0%), screening and diagnostic decisions (4.2%), medical treatment (4.1%), surgical treatment (4.1%), retirement (1.9%), immunization (1.2%), and others (8.8%). To address these needs, decision support strategies were developed. They included a telephone line to help women access navigation information about the health care system, an information manual about available services, and health information pamphlets for specific needs. Moreover, several faculty at PUC and practitioners were also trained in decision support. By 2000, 30 faculty at PUC, and at least 20-25

practitioners were trained to provide decision support. Furthermore, the curriculum offered at PUC integrated decision support education materials into several of its courses, and more than 145 students received training in decision support by 2001.

In 2002, Doull et al. used the ODSF needs assessment questionnaires to explore the decision support needs of Thai adolescents and their counsellors regarding sexual health decision making. A purposive sample of adolescents from two secondary schools in Bangkok (n = 18), and counsellors enrolled at a counsellor training program in Chulalongkorn university (n = 10) were interviewed using a cross-culturally adapted version of the ODSF needs assessment questionnaire. All interviews were conducted in Thai. Results revealed significant differences between counsellor and adolescent perception of sexual health decision making needs of the adolescents. When decisions were ranked in order of relative importance, adolescents ranked decisions concerning relationship issues as most important, whereas counsellors ranked decisions involving unwanted pregnancies and sexually transmitted diseases to be most important. Results also showed that adolescents and counsellors shared certain perspectives. For example, both counsellors and adolescents identified peers and parents to have important roles in sexual health decision making. These results were summarized to inform future counsellor training programs in Thailand (61).

And lastly, it must be highlighted that the ODSF has also been applied to research studies on difficult sexual health and reproductive decisions that often fall under the category of preference-sensitive decisions. As described previously, this includes research on reproductive and sexual decision making in cross-cultural settings. Furthermore, some researchers have also applied this framework to preference-sensitive decisions related to pregnancy. Examples include decisions on breech baby presentation, pain management during labour, and prenatal genetic screening (61).

CHAPTER THREE: STUDY RATIONALE

3.1 Preliminary Findings

In the pre-study phase, a systematic literature review was conducted using electronic databases (MEDLINE, CINAHL and EMBASE) and technical reports published by HIV/AIDS EPI Update, the Department of Public Health Sciences at the University of Toronto, and the African Caribbean Council on HIV/AIDS in Ontario (ACCHO). Information was also collected through personal correspondence with practitioners at the Elizabeth Bruyere Family Medicine Center and anonymous HIV testing centers in Ottawa.

The preliminary review revealed that VCT guidelines tailored to support the decision making needs of the target group do not exist. There is a dearth of research evidence on factors that impact acceptability to VCT for this particular population. Moreover, correspondence with practitioners in Ottawa revealed significant difficulties in communicating effectively with women from the target group about VCT in a culturally sensitive manner.

3.2 Study Objectives

The objective of this needs assessment was to:

1. To assess the decision support needs of immigrant and refugee women from countries where HIV is endemic regarding voluntary counselling and testing for HIV in Canada.
2. To assess the needs of practitioners with respect to supporting the target group making decisions about voluntary counselling and testing for HIV in a culturally-appropriate manner.

3. To examine the needs assessment concepts and tools in a cross-cultural context.

3.3 Reasons for the Choice of the Target Group

Reproductive-age immigrant and refugee women from HIV endemic countries were chosen because longitudinal surveillance data from Ontario show that they are disproportionately affected by preventable paediatric HIV infections. This burden is likely reflected by high maternal seroprevalence and lack of timely access to prenatal services that include the offer of voluntary HIV testing (Please see chapter 1.0 for more detail).

3.4 Reasons for the Choice of the Target Decision

3.4.1 Voluntary Counselling and Testing: Entry Point to a Complex Pathway of Care

The rationale for exploring decision making needs around HIV testing is that VCT is the entry point to all HIV-related prevention, treatment and care (85). In other words, VCT allows individuals to confirm their HIV status and enter a complex pathway of care that involves decisions on risk reduction activities for individuals who test negative, and treatment and care options for those who test positive.

Once an individual undergoes VCT, several difficult decisions may emerge depending on his/her test results. Individuals who test HIV negative will usually be encouraged to consider risk reduction practices that keep them and their sexual and/or intravenous drug using partners free from HIV infection. For example, as part of risk reduction counselling, the Canadian Medical Association (CMA) guidelines on VCT mandate counselling regarding safer sex, drug use, and the use of blood products. Furthermore, this process may be accompanied by an assessment of the time interval

between the HIV screening test and the appearance of detectable HIV antibodies in blood and serum (i.e. the window period) and a reminder for repeat testing (21).

In contrast, individuals who test positive for HIV are encouraged to consider decisions about disclosure (“Do I disclosure, and to whom?”⁶), the use of anti-retroviral therapies (“When do I begin anti-retroviral therapy (if asymptomatic)?”; “What type of anti-retroviral regimen do I choose?”), and ancillary supportive care (“What type of psychological and social services do I need?”; “What type of supportive services will I need for my dependants?”) (83). This decision making process is not necessarily systematic and may take place over several post-test sessions following the initial assessment of the tester’s psychological response to the test results (21).

Furthermore, pregnancy may impose additional difficult decisions in the HIV treatment and care pathway (19, 20, 82). For example, pregnant women who test HIV-positive may consider termination (“Do I continue with the pregnancy?”). However, if they choose to continue with the pregnancy, they may have to consider antiretroviral prophylaxis (“Which antiretroviral therapy will be the best for me and my baby?”⁷), safer obstetric practices (“Do I have a caesarean delivery?”)⁸, and appropriate post-natal care (“How do I maintain long-term use of exclusive replacement feeding?”⁹; “How do I care for my children and dependants in the future?”).

While the decisions in the HIV prevention and treatment pathway outlined above vary according to the strength of evidence supporting their efficacy, situational factors that

⁶ Although legal requirements for reporting HIV vary by province, practitioners in Canada are ethically obliged to notify the sexual or drug-using partners of a person diagnosed with HIV of his/her HIV status. Therefore, this may lead to involuntary partner notification, usually through a third party such as public health official. (21)

⁷ The management of HIV treatment during pregnancy is complex. Furthermore, research has shown that this may be overshadowed by conflicting priorities between maternal and foetal risks and benefits (19, 20).

⁸ There may be a range of obstetric interventions to consider when attempting to minimize mother-to child-transmission of HIV during labour, although the evidence on the efficacy of these interventions differ. The ones with the most substantive evidence include: elective caesarean section, reduction in the time between rupture of membranes and delivery, and the avoidance of unnecessary invasive procedures such as episiotomy and suction (86).

⁹ In Canada, breastfeeding is contraindicated for HIV positive women (19, 20). However, in many developing countries, where many do not have access to safe water supplies and there is a high burden of infectious disease, exclusive replacement feeding is generally not recommended (84).

impact their effectiveness, and value-laden harm/benefit ratio of the outcomes, they have one thing in common: they can only be considered after HIV status has been confirmed through testing.

3.4.2. Evidence on the Efficacy of Voluntary Counseling and Testing

The most up-to-date data on the risks and benefits of HIV screening was compiled by the US Preventative Task Force in 2005 (76). This meta-review synthesized scientific evidence on several questions pertaining to HIV screening, including the latest evidence on the efficacy of VCT. Results yielded two systematic reviews¹⁰, both of which explored the relationship between VCT and risk reduction behaviours. The findings of these reviews will be discussed below.

The first systematic review to examine the effects of VCT on risk reduction behaviours was published in 1991 (79). The authors of this review synthesized the results of a broad category of studies that examined the relationship between VCT, knowledge of HIV serostatus and self-reported behaviours. Longitudinal studies comparing behaviour change before and after VCT, and cross-sectional studies comparing populations with different VCT histories (i.e. tested vs. untested, HIV seropositive vs. HIV seronegative) were included. Studies were identified using a database search from 1986 to 1990 (Medline and PsychLit), hand searching of published abstracts and presentations of previous international conferences on HIV/AIDS. Quality assessment, based on predefined criteria on methodological rigor (i.e. sample size, comparator groups, and statistical tests of significance)¹¹ further narrowed the pool of retrieved studies.

¹⁰ A systematic review is a rigorous literature review on a defined health-related question where relevant studies are identified, appraised, summarized and interpreted using pre-specified, explicit, scientific methodology. A meta-analysis, on the other hand, is a statistical technique that summarizes the results of two or more studies in a single weighted estimate (i.e. summary statistic), in which more weight is generally given to the results of studies that demonstrate higher quality. Systematic reviews may or may not use statistical meta-analysis. Generally, a meta-analysis is conducted when the pool of studies included in a systematic review demonstrates limited clinical and methodological heterogeneity (i.e. limited differences among study populations, design, interventions, outcomes and quality) (101).

¹¹ The authors of this review explicitly state their quality assessment criteria, which includes a controversial criterion-the exclusion of studies with small sample size. However, other quality assessment criteria stated by the authors seem consistent with their objective of conducting a meta-analysis (101).

- Overall, fifty studies were included, and results were summarized on the basis of four population groups¹². Descriptive summaries revealed that: Studies on injection drug users (IDU) show that HIV counselling and testing was associated with a reduction in needle using behaviour and some sexual risk behaviours. However, it was unclear whether these effects were due to VCT or a broader constellation of harm reduction interventions applied in concurrence with VCT (N = 12)
- Studies on pregnant women showed that HIV counselling and testing and knowledge of HIV serostatus did not have a significant impact on the decision to terminate pregnancy¹³ (N = 11)
- Studies on “other heterosexuals” were inconclusive due to the extreme variability in study location, intervention type, and population groups. However, the authors reported that a sub-sample of this population (serodiscordant couples) were shown to significantly reduce their risk behaviours (N = 10)

The authors of this systematic review were unable to draw any substantive conclusions on the effect of VCT on risk reduction behaviours across all populations. However, based on their quality assessment criteria, the authors of the meta-analysis concluded that there was good quality evidence supporting the positive impact of VCT on risk reduction behaviours among HIV seropositive MSM and serodiscordant couples in comparison to untested individuals and those who tested seronegative. In addition, when discussing study limitations, the authors made a cautionary note about methodological heterogeneity (i.e. differences in duration and intensity of VCT, and study design), and within group variability in the pooled population groups. Moreover, as most of the included studies were either cross-sectional or longitudinal by design, the authors also highlighted the possibility of bias due to self-selection (i.e. differences between participants presenting for testing versus those who don't, or those who pick up their test results and those who don't) and confounding (i.e. the rise in awareness

¹² These population groups were not defined *apriori*.

¹³ It is unclear why the authors reported on a pregnancy decision not directly related to HIV risk. The use of this measure was inconsistent with the type of outcomes observed in the other population groups. Perhaps the authors were examining studies that dated back to a period when the evidence on the efficacy of antiretroviral therapies was insubstantial.

of HIV/AIDS in gay male communities in the mid-eighties and its impact on risk reduction behaviours) (79).

The only meta-analysis on the effect of VCT on risk reduction behaviour was published in 1999 (78). Like the previous systematic review, the authors of this meta-analysis did not specify eligibility criteria on study design or populations. Instead, they retrieved studies based on a broad description of intervention and outcome variables. Namely, all studies retrieved included: 1. participants who underwent VCT; 2. behavioural data on risk reduction or a proxy measure (such as the incidence of sexually transmitted infections); and 3. summary statistics for within group differences. Study identification involved a database search (MEDLINE, and PsychLit, 1985-1997), a manual search of key journals on sexually transmitted diseases and HIV/AIDS, and reference list checking.

After quality assessment, twenty seven studies were found to meet the prescribed eligibility criteria. The effect sizes among the included studies were grouped according to serostatus groups and risk reduction outcomes. Results showed that:

- When it came to the frequency of unprotected sexual intercourse, the weighted mean effect¹⁴ sizes for those who tested HIV positive ($d = 0.47$, 95% CI = 0.32 to 0.61) and serodiscordant couples ($d = 0.75$, 95% CI = 0.59 to 0.92) showed significant risk reduction in comparison to the untested group ($d = 0.15$, 95% CI = -0.08 to 0.17). However, this association was not significant for those who tested HIV negative ($d = 0.19$, 95% CI = -0.08 to 0.31) (N = 19 trials)

¹⁴ The standardized mean difference (SMD) is a summary effect measure used to pool continuous data measured on different scales in a meta-analysis. It is calculated by estimating the difference between two means of a trial (usually difference in outcomes between treatment and control groups), and dividing by the standard deviation. The SMD has the important property that its value does not depend on the measurement scale. Thus, it can be used to pool similar continuous outcomes measured on different psychometric scales (i.e. pounds and kilos when pooling data on weight) (101). Another advantage of the SMD is that it can be used to compare the relative effects of different interventions. Generally, SMDs of 0.2, 0.5 and 0.8 have been associated with "small", "medium" and "large" effect sizes (105).

- Similar results were observed for data on condom use. Results showed that condom use in those who tested HIV positive ($d = 0.65$, 95% CI = 0.42 to 0.87) and serodiscordant couples ($d = 1.31$, 95% CI = 1.14 to 1.48) was significantly higher than the untested group ($d = 0.24$, 95% CI = 0.17 to 0.30). However, there were no significant differences in condom use between HIV negative persons ($d = 0.05$, 95% CI = -0.02 to 0.13) and the untested group (N = 21 trials)
- When it came to the number sexual partners, the weighted mean effect sizes for those who tested HIV positive ($d = 0.47$, 95% CI = 0.32 to 0.61) and those who tested HIV negative ($d = 0.75$, 95% CI = 0.59 to 0.92) were not significantly different in comparison to the untested group. There were no data for this outcome for serodiscordant couples for this variable (N = 25 trials)

The results of this review were consistent with the main findings of the previous systematic review. Based on their quality assessment criteria, the authors of the meta-analysis concluded that there was good quality evidence supporting VCT as an effective secondary prevention strategy but less on its efficacy as a primary prevention strategy. This conclusion was accompanied by a discussion of the limitations of the review-namely the methodological heterogeneity observed in the effect sizes within the pooled serostatus groups. In particular, the authors highlighted within group differences in intervention type and study design, but failed to analyze these limitations through the use of sensitivity and subgroup analyses (78).

And lastly, it must be highlighted that there is no systematic review level evidence on the impact of VCT on clinical outcomes such as STD and/or HIV incidence (76). In fact, to date there has been only one randomized controlled trial (RCT) that has attempted to examine the effect of VCT on HIV incidence. The results of this trial will be discussed below.

The Voluntary HIV-1 Counseling and Testing Efficacy Study (VCTES) was the largest multi-center RCT on the efficacy of VCT (80, 81). Enrolling over 3120 individuals and 586 couples, this study aimed to measure the efficacy of VCT in reducing unprotected

sexual intercourse and STD incidence. Study participants were recruited from major urban centers in three different countries (Nairobi, Kenya; Dar-es-Salaam, Tanzania; and Port of Spain, Trinidad) and randomly assigned to the treatment or the comparator group, where individuals assigned to the intervention group received VCT based on a counselling framework designed by the *US Center for Disease Control* and those assigned to the comparator group, a health information (HI) session involving a 15 minute video and discussion of HIV transmission and prevention.

Participants were recruited either as an individual or a couple. Data on risk behaviours and HIV status were obtained from all participants at baseline and two consecutive follow-up periods (7 and 14 months). Data on age, sex, level of education, and HIV seropositivity at baseline showed no significant differences between the two treatment groups. However, baseline data showed that HIV serostatus differed significantly by location and gender¹⁵. Results revealed that:

- The proportion of individuals reporting unprotected intercourse with *non-primary* partners decreased significantly more for those assigned to the VCT group than those in the HI group by the end of the first follow-up (VCT vs. HI, Odds ratio, 95 % CI: 0.68, 0.58-0.82). However, decrease in this risk behaviour was only sustained in men by the end of second follow-up (Men, VCT vs. HI, Odds ratio, 95 % CI: 0.86, 0.34-2.14; Women, VCT vs. HI, Odds ratio, 95 % CI: 1.86, 1.12-3.07).
- Significant differences between treatment groups were not observed when it came to unprotected intercourse with *primary partners* at the first follow-up (VCT vs. HI, Odds ratio, 95 % CI: 1.09, 0.92-1.29), and by the end of the second follow-up, more individuals in the VCT group reported unprotected intercourse with their primary partners than the HI group (VCT vs. HI, Odds ratio, 95 % CI: 2.20, 1.38-3.51)

¹⁵ Baseline HIV seroprevalence rates by site were reported as:

- Kenya: Men/ Women enrolling as individuals: 12 % / 27 %; Men/Women enrolling as couples: 19 % / 24 %
- Tanzania: Men/ Women enrolling as individuals: 8 % / 32 %; Men/Women enrolling as couples: 17 % / 23 %
- Trinidad: Men/ Women enrolling as individuals: 4 % / 2 %; Men/Women enrolling as couples: 4% / 4 %

- Couples receiving VCT reduced unprotected intercourse with their enrolment partners compared to couples receiving HI by the end of the first follow-up (VCT vs. HI, Odds ratio, 95 % CI: 0.72, 0.53-0.99)
- Post-hoc analysis by serostatus group revealed that there were no significant differences in unprotected intercourse with primary partners between HIV positive and HIV negative individuals at the second follow-up (Men and women diagnosed as HIV positive vs. HIV negative, Odds ratio, 95 % CI: 1.24, 0.64-2.43). However, significant changes in unprotected intercourse with primary partners were observed at first follow-up (Men and women diagnosed as HIV positive vs. HIV negative, Odds ratio, 95 % CI: 0.60, 0.40-0.89). Moreover, a gender stratified comparison showed that these differences became significant when this variable was compared between HIV positive men and women, and uninfected men. In other words, HIV positive men and women were more likely to reduce unprotected intercourse with primary and non-primary partners than uninfected men but this relationship was not significant for uninfected women (Women diagnosed as HIV positive vs. HIV negative, Odds ratio, 95 % CI: 0.90, 0.49-1.66; Men diagnosed as HIV positive vs. HIV negative, Odds ratio, 95 % CI: 0.19, 0.05-0.81)

Analysis of the secondary outcome, the acquisition of STDs, revealed that:

- Men and women enrolled as individuals who received VCT had a reduced risk of acquiring a STD than the comparison group. However this decline in risk was not significant (VCT vs. HI, Odds ratio, 95 % CI: 0.80 (0.53-1.20))
- Couples who received VCT actually had a substantially increased risk of STD acquisition than the comparison group (VCT vs. HI, Odds ratio, 95 % CI: 2.97 (1.21-7.24))¹⁶

¹⁶ When evaluating these results, please note the rationale the authors provided for not using STD acquisition as a primary outcome: 1. the study was not powered to detect significant differences in STD acquisition between the two treatment groups, and; 2. rate of STD acquisition was actually a proxy for incident HIV infection, a variable that could not be studied due to ethical considerations (i.e. to prevent contamination, the measurement of HIV incidence would entail not providing counselling to participants diagnosed with HIV since enrolment).

Furthermore, outcomes expressed in absolute values showed that the absolute risk differences between the VCT and HI groups for the proportion reporting unprotected sex with their primary partner at first and second follow-up were:

- -2.6 % (26.3 % versus 23.7 %, NS¹⁷) and -5.1 (22.7 % versus 27.8 %, S), respectively, for men enrolled as individuals
- -1.1 % (38.1 % versus 37.0 %, NS) and -1.0 (35.1 % versus 34.1 %, NS), respectively, for women enrolled as individuals

Similar results for those reporting unprotected sex with their non-primary partners at first and second follow-up were:

- -6.6 % (19.8 % versus 26.4 %, S) and -4.3 (16.0 % versus 20.3 %, NS), respectively, for men enrolled as individuals
- -5.6 % (13.9 % versus 19.5 %, S) and -1.3 (10.3 % versus 11.6 %, NS), respectively, for women enrolled as individuals

For those enrolled as couples, absolute risk differences between the VCT and HI groups for the proportion reporting unprotected sex with their non-enrolment partners at first and second follow-up were:

- 5.0 % (15.6 % versus 10.6 %, NS) and 3.2 (13.8 % versus 10.6 %, NS), respectively, for men
- 1.6 % (8.3 % versus 6.7 %, NS) and 3.7 (10.9 % versus 7.2 %, NS), respectively, for women

Absolute risk reduction in the acquisition of STDs was not reported.

Therefore, the latest evidence from the VCTES trial suggests that VCT may reduce unprotected intercourse, and in particular, intercourse with non-primary partners in the short term; However, the impact of the intervention on the long-term adoption of risk reduction behaviours is moderated by gender. In particular, gender appears to enhance HIV risk for women: women in the VCT group did not report significant

¹⁷ Please note that the cited values of significance refer to p-values less than 0.05. Also, please note that differences in absolute risk for all outcomes between the two treatment groups were not significant (NS) at baseline.

reductions in unprotected sexual activity with non-primary partners in comparison to the HI group at second follow-up, whereas men did. Another key finding was that VCT was shown not to impact unprotected sex with primary partners for either sex at both follow-up points. This finding may have important implications for different approaches to risk reduction counselling for risk behaviours shared with primary versus non-primary partners. VCT was also shown not to impact the acquisition of STDs. However, the investigators denoted that this outcome was not a reliable indicator of efficacy as the study was not powered to detect significant differences in STD acquisition between the two treatment groups.

In summary, all the systematic reviews that have been conducted on the efficacy of HIV counselling and testing to date ($n = 2$), including the meta-review completed by the US Preventative Task Force, demonstrate that VCT is more effective in reducing risky behaviours among certain groups (i.e. serodiscordant couples and persons who test HIV positive) than the general population. That said, it is still important to acknowledge that the evidence on the efficacy of VCT¹⁸ will remain inconclusive until existing systematic reviews on VCT are updated, and new reviews that incorporate the impact of VCT on clinical outcomes are published.

3.4.3. Canadian Clinical Practice Guidelines on Voluntary Counseling and Testing

VCT is central to the holistic model of HIV prevention and treatment. It is also a challenging service to offer, encompassing multiple aims and procedures (21, 85). In this section, the Canadian clinical practice guidelines (CPG) on VCT will be discussed in detail to contextualize HIV counselling and testing procedures in Canada.

¹⁸ This section attempts to summarize systematic review level evidence on the efficacy of VCT. Most studies included in the systematic reviews discussed in the previous section evaluate efficacy using behavioural and clinical outcomes, such as the adoption of risk reduction behaviours or the incidence of STDs/HIV. However, from our perspective, we also place importance on assessing decisional quality using outcomes that incorporate the informed preferences (values) of individuals involved in VCT decision making (Please see Appendix A for information on the ODSF).

The third and most recent edition of the CMA's HIV counselling and testing guidelines was published in 1995 (21)¹⁹. The purpose of the guidelines were to provide an opportunity for clients presenting for testing to: 1. understand their risk for HIV, and receive risk reduction counselling; 2. prevent transmission of HIV to others if diagnosed as HIV positive; 3. connect to appropriate treatment and care services if diagnosed as HIV positive, including supportive services that reduce psychological morbidity associated with HIV infection.

The CPG on VCT begin by outlining the principles of HIV testing, including the legal and ethical ramifications of the test. It then details the various stages of the testing and counselling process, and concludes by highlighting special considerations for groups vulnerable to HIV.

At the outset, the guidelines outline that the practitioner should always affirm the voluntary nature of the test and proceed to testing only when full consent is obtained. The practitioner is then encouraged to discuss the confidentiality procedures of testing, and its legal ramifications. This step usually entails an in-depth discussion of the HIV testing options available in Canada, where depending on the province or territory, there are generally three types of options to consider: nominal, non-nominal and anonymous HIV testing²⁰.

Furthermore, the CPG break down the counselling and testing process into two stages: pre and post test counselling. While the CPG on pre-test counselling aim to

¹⁹Please note that since these guidelines are published by the CMA, they are primarily directed towards family physicians and specialists. However, VCT can also be provided by other practitioners, such as nurses, nurse practitioners and social workers (20).

²⁰ Anonymous HIV testing refers to testing that is offered at specialized clinics supported by public health departments. For this type of testing, the test is carried out using a code number that is not linked to any identifying characteristics of the person being tested. The person conducting and ordering the test does not know the identity of the tester, the test results are not recorded on the health record of the tester (unless requested by the tester), and partner notification of HIV status is the responsibility of the tester. Nominal and non-nominal HIV testing, on the other hand, are similar but offer a slight distinction. Both are offered at various clinical locations, including the office of a family practice physician. For nominal testing, the clinician carrying out the test knows the identity of the person being tested, is legally obligated to notify public health officials and the sexual/ drug using partners of the tester if the results are positive, and responsible for recording the test results on the health care record of the tester. Non-nominal testing is similar to the above procedure with the following exception: only the initials of the tester are recorded, and in the case of a positive result, the responsibility of partner notification is delegated to public health officials (21).

help clients prepare for the test procedures, its results and implications, the guidelines on post test counselling offer them an opportunity to understand the meaning of their test results.

Practitioners offering pre-test counselling are recommended to address multiple issues that pertain to testing and its implications. In particular, practitioners are encouraged to:

- Determine their client's reason for testing
- Assess risk based on their client's history, and offer risk reduction counselling²¹
- Explain the test and its limitations, including assessment of the window period, and the mean wait time for results
- Provide information on the test; testing options; the pros and cons of testing; and the meaning of the test results
- Discuss confidentiality and the circumstances under which results must be disclosed by law (i.e. partner notification)
- Assess their client's support network

During pre-test counselling, practitioners are also encouraged to discuss the possible consequences of testing. According to the guidelines, a discussion of the pros of HIV testing may involve talking about the benefits of resolving the uncertainty about one's HIV status, preventing HIV transmission, early detection and treatment, and the ability to make more informed reproductive decisions. In contrast, a discussion of the potential cons of testing may involving talking about the anxiety associated with waiting for the results, the stress of disclosure, and the risks of losing social support, employment, housing, health insurance, and educational/ travel opportunities (21).

Unlike pre-test counselling, post-test counselling may take several visits to complete. According to the guidelines, test results can only be given in a private, face-to-face interview. During this phase, the practitioner is encouraged to help the client

²¹ Risk reduction counselling generally involves counselling on sexual and non sexual activities linked to HIV risk. The latter includes variety of topic areas: safer drug use, exposure to contaminated skin piercing instruments, exposure to blood and blood products, and occupational exposure (21).

understand the meaning of his/her test results. This step may require the practitioner to explain the meaning of a test result (including indeterminate results), provide immediate support, review information on HIV prevention and transmission, and develop a personalized risk-reduction strategy. In addition, if a client is diagnosed as HIV positive, the practitioner is also recommended to:

- Stress the benefits of early detection and treatment
- Further assess his/her psychological and social supports
- Connect the client to appropriate treatment and care resources, including supports that can help him/her cope with the potential negative consequences of testing positive
- Discuss the implications of partner notification

While recommending an individualized approach to VCT, the guidelines advise practitioners to be sensitized to certain contextual factors when counselling. These include sensitivity towards the client's gender, culture, sexual orientation, socioeconomic status, mental and physical disabilities, and capacity to communicate in the two official languages. Furthermore, practitioners are recommended to consider special populations when offering HIV testing. These include individuals living in correctional facilities, individuals diagnosed with STDs, injection drug users, commercial sex trade workers, street involved people, adolescents, Aboriginal people, psychiatric patients and men who have sex with men (MSM) (21).

In Canada, the only scenario in which the medical system intervenes with the routine offer of the HIV test is in pregnancy (22). Since 1998, universal offering of VCT during pregnancy is recommended in all Canadian provinces and territories, although the way the testing is offered varies by jurisdiction. In Ontario, the opt-in approach to HIV testing is recommended. Under the opt-in approach, a pregnant woman can not be given a HIV test by her health practitioner unless she specifically requests to be tested for HIV. This procedure often involves a written consent process. In contrast, under the opt-out option, practitioners must inform pregnant women that a HIV test will be

included among the standard group of prenatal tests but there is no requirement for formalized counselling or written informed consent (22).

3.5 Potential Contributions to Clinical Practice

Decision support in the context of VCT can be an important intervention that improves decisional quality. From a patient perspective, decision support during VCT can be an empowering tool that increases the chance that the decision to test for HIV is based on scientific evidence, realistic risk perception and personal values. From a practitioner perspective, decision support in this setting can supplement existing clinical practice guidelines (CPG) on VCT to provide culturally-appropriate decision support.

The ODSF's concept of a good quality decision (i.e. one that is informed and consistent with personal values) is consistent with Canadian CPG on VCT. For example, the CMA explicitly states that informed consent in the context of VCT involves a competent individual who understands the "*purposes, risks, harms and benefits of testing, as well as not being tested*" (21). Similarly, according to the ODSF, a good quality decision involves the decision maker to understand the options available to him/her, and their associated benefits and harms. Moreover, these guidelines recommend practitioners to help patients presenting for testing to understand the "*meaning of the test results*"-a process that necessitates the valuation of the benefits and harms of testing. This is aligned with the importance the ODSF places on value-informed decision making.

Furthermore, consistent with the ODSF's emphasis on realistic risk perception, the Canadian CPG on VCT recommend practitioners to tailor counselling to the needs of their patients, a process that involves practitioners to assess risk based on their clients' history, and provide personalized risk reduction counselling.

The ODSF also encourages decision aid developers and providers to consider several demographic and clinical characteristics of the decision maker; Likewise, the CMA guidelines on VCT encourage practitioners to be aware of contextual issues when offering counselling to their patients (i.e. gender, cultural background, sexual orientation, socioeconomic status, functional status, and social support) (21) (70).

3.6 Potential Contributions to Policy: Ontario's HIV/AIDS Strategy for Canadian African and Caribbean Communities

The African Caribbean Council on HIV/AIDS in Ontario (ACCHO) is an interdisciplinary body of research affiliates (i.e. Women's Health in Women's Hands community health center; Department of Public Health Sciences, University of Toronto), government agencies (i.e. the Center for Infectious Disease Prevention and Control, Health Canada; the AIDS Bureau, Ontario Ministry of Health and Long Term Care), and ethno-cultural and AIDS service organizations that provide services to African and Caribbean communities in Ontario. Since its inception in 1998, ACCHO has been working to develop and implement a provincial HIV/AIDS strategy for Canadian African and Caribbean communities. The council's primary mandate is *"to reduce the incidence of HIV among people in Ontario from countries where HIV is endemic, and improve the quality of life of those affected and infected by HIV/AIDS."*

In 2003, ACCHO published its provincial HIV/AIDS strategy, a document that was informed by several pilot projects and a two-phased community consultation involving surveys, focus groups and interviews with service providers, researchers, and key leaders/ stakeholders in the affected communities. This document paralleled the Canadian Aboriginal HIV/AIDS strategy in that it was designed to complement the pan-Canadian HIV strategy while highlighting unique areas of concerns for its target population (45).

Rooted in principles of accountability, access, intersectoral partnership, community engagement and equity, the ACCHO strategy outlines mid to long-term objectives in

the following strategic areas (45): 1. Community development and capacity building; 2. Prevention, treatment and support services; 3. Coordination and administration, and; 4. Research needs and priorities. One of ACCHO's directives under the second strategic direction is to *"identify and promote culturally appropriate gender-sensitive HIV prevention, care, treatment and support programs and services delivered within a framework of comprehensive health and social services."*

This research project is consistent with ACCHO's second strategic direction as it aims to identify gaps in culturally-appropriate and gender-sensitive good practices with respect to VCT for women from HIV endemic countries, while addressing the importance of contextual variables that affect the effectiveness of these services.

CHAPTER FOUR: METHODS

4.1 Design

This was an observational study based on standard procedures for a decision support needs assessment (64). The Ottawa Decision Support Framework (ODSF) guided all aspects of study design and methodology. Data collection involved face-to-face interviews using an interview guide adapted for two groups of key informants (Please see section 2.3.1 for definitions). This tool was pilot tested prior to the interviews

4.2 Sample and Setting

In compliance with ODSF methodology, two groups of key informants were selected for the needs assessment interviews. Eligibility criteria for the key informant groups interviewed are described below.

1. Patient informants:

Participants eligible to participate were adult, English-speaking, reproductive-age (18-49 years) immigrant and refugee women from HIV endemic countries in sub-Saharan Africa and the Caribbean who resided in Ottawa. These women were assumed to have important insights into the decision making needs of the target group regarding HIV testing on the basis that they were immigrant women from countries where HIV is endemic, and were willing to speak on the behalf of the target group. The target group was represented by reproductive age immigrant and refugee women from HIV endemic countries in sub-Saharan Africa and the Caribbean who were *presently considering* HIV testing²².

²² We were interested in exploring the experiences of women from HIV endemic countries as a group defined on the basis of country/region of origin data (Please review the epidemiological term "HIV endemic" in Chapter 1). We did not collect any ethnocultural data and examine how participant responses would have varied according to this variable, since from our perspective the semi-structured format of needs assessment tool was not appropriate for this type of an analysis (Please refer to Chapter Six).

Participants diagnosed with acute medical or psychiatric symptoms, including post-traumatic stress disorder, were excluded from the study²³.

Participants were recruited at the Elizabeth Bruyere Family Medicine Centre (EBFMC), an outpatient clinic providing immigrant health and support services primarily to clients of Reception House, an organization responsible for offering orientation services for refugees new to Ottawa. Participants at this site were recruited through practitioner referral. EBFMC was purposively chosen as a recruitment site because it was an outpatient clinic that specialized in meeting the health needs of immigrants and refugees. Furthermore, it provided services to a large proportion of individuals from HIV endemic regions (particularly, immigrants and refugees from Central and East Africa), and was in the process of establishing a program on preventative care guidelines for immigrants from developing countries (24, 99).

2. Practitioners:

A purposive sample of practitioners were recruited from six community health centers (CHCs) and anonymous HIV testing clinics (AHTCs) in Ottawa. Practitioners eligible to participate were providers of VCT from a wide range of clinical specialties (i.e. family physicians, nurses, nurse practitioners, obstetricians, gynaecologists) who primarily worked with immigrant groups. No exclusion criteria were placed on this group.

This informant group was selected from all medical facilities in Ottawa that provided specialized HIV testing services (i.e. AHTCs and CHCs). Incidentally, the sites that offered both specialized and non-specialized testing services (i.e. CHCs) were members of the Coalition of Community Health and Resource Centers, a network of health centers in Ottawa that provide primary health care and health promotion

²³ Practitioners at EBFMC involved with recruitment had access to the participants' medical records, and verified that those recruited from the clinic were subject to these exclusion criteria. However, these exclusion criteria were only verbally verified prior to the interviews by participants recruited through snowball sampling.

services to special populations, including Ottawa's immigrant and refugee communities²⁴. The sites that solely provided specialized HIV testing services (i.e. AHTCs) operated under the directives of Ottawa Public Health. These sites were chosen on the basis of their strong affiliations with CHCs (i.e. such as OASIS, a drop-in AHTC operated by Public Health Ottawa, and Sandy Hill CHC).

4.3 Sample selection and size

Saturation was used to guide sample size. Saturation was defined as *"a point reached during data collection when no new themes or issues arise within a category of data"*. Saturation was assumed to be attained when no new data were gained in the predefined and emergent response coding categories in the needs assessment questionnaires (87, 88). Saturation at both the category and code level was assessed (Please see "Saturation Table" in the appendices).

Based on this criterion, twelve practitioners and eight patients were interviewed, where all patients, with exception to the ones selected via snow ball sampling²⁵ (n = 4), were recruited from EBFMC. Snowball sampling was exercised when it was no longer feasible to recruit eligible participants from EBFMC. To maximize credibility, all those recruited through snowball sampling were required to meet pre-specified eligibility criteria.

4.4 Tool Development

4.4.1 The Needs Assessment Interviews

²⁴ Please see the following website for more information on this network: http://www.coalitionottawa.ca/html/index_e.html.

²⁵ Snowball sampling is a sampling technique employed to reach populations that are difficult to access. It involves developing a research sample where existing study participants recruit future participants from among their acquaintances. Thus, the sample is said to grow like a rolling snowball (88).

The population needs assessment questionnaire used in this study was based on a workbook and semi-structured questionnaire template originally developed by Jacobsen and O'Connor (63, 64). This workbook is a validated tool that has been used to guide several types of health-related decision making needs assessments (i.e. options for end of life care, adolescent and sexual health, breast cancer prevention, hormone replacement therapy treatment) (62).

The needs assessment questions were administered in a face-to-face interview. The interviews explored patient informants' perception of the target group's: knowledge of available HIV testing options and their outcomes (i.e. benefits and harms); personal preferences towards these options and outcomes; preferred roles in decision making about HIV testing; and resources available to make the decision to test for HIV, such as skills and self-efficacy in decision making, social support (or lack thereof), and information on how others in a similar situation decide or recommend (64, 70). Behavioural manifestations of decisional conflict were also assessed in the interviews. This involved assessing whether or not women from the target group displayed uncertainty about decision making regarding HIV testing, were aware of the options for testing, or concerns about the potential consequences of testing; indecisiveness about having to choose among available options for HIV testing, delayed decision making, pre-occupation with the decision, distress or anxiety, or doubts about their importance of confirming their HIV status through testing. These interviews were coupled with demographic data on patient age, level of education, and length of stay in Canada.

Using a similar structured template, practitioner interviews focused on their usual practices in supporting the target group considering VCT, their perceptions of what made decision making difficult for the target group, and what might help. Relevant demographic data were also collected for practitioners (Please refer to the needs assessment questionnaires in the appendices).

4.4.2 Adaptation of the Questionnaires

The interview guides were adapted to the clinical decision making environment for HIV testing and counselling, and the demographic characteristics of the two groups of key informants. Adaptations were based on a literature review, and input from a diverse panel of experts, including three immigrant health specialists (two family physicians and one nurse practitioner from EBFMC), two decision support methodologists (including the author of the ODSF), and a patient informant.

The interview guide was developed in two stages. During the first stage of adaptation, predefined question categories based on the ODSF (i.e. deductive questions) were tailored to the HIV testing decision. In contrast, during the second stage of adaptation, emergent question categories not directly related to the framework (i.e. inductive questions), were integrated into the interview guides, often in the form of probes.

Most adaptations were based on pilot testing interviews. Some adaptations were also made in the post-pilot testing phase, where iterative content analysis based on constant comparison was used to develop some of the inductive questions and/or probes.

The practitioner needs assessment tool was piloted with two practitioners at EBFMC who were a part of the research team. The tool was adapted to the decision for HIV testing, and piloted in a face-to-face interview in English at the workplace of the practitioners. The interviews were audio taped, and feedback from the practitioners discussed in detail during debriefing.

The patient needs assessment tool was piloted in a similar manner. However, during this phase of pilot testing, the interviews were also role played with a patient key informant.

4.4.3 Pilot Testing

The pilot test involved assessing:

- Clarity and appropriateness of the questions
- Logical ordering of the questions
- Time required to complete the interview
- Strategies to effectively introduce basic ODSF concepts in the introduction
- Relevance of certain ODSF constructs to the experiences of women from the target group

When piloting the patient needs assessment, the above considerations were made with particular emphasis on the cultural, linguistic and educational differences between the researcher/interviewer and the participant. Feedback from the pilot testing phase resulted in some changes to the interview guides. Examples of some of the revisions included:

- Adding a question on whether women from the target group perceived HIV testing to be voluntary decision (An example of integrating an inductive question)
- Inserting a table outlining possible HIV testing options women from the target group are likely to consider (An example of adapting a deductive question)
- Highlighting specific examples of informational and supportive resources appropriate to the unique needs of the target group with respect to HIV testing (An example of adapting a deductive question)

4.5 Data Collection and Ethics

4.5.1 Recruitment

Patient informants:

Eligible women were purposively recruited from the patient pool at EBFMC. They were identified by a nurse-practitioner and a family physician at the clinic who were a part of our research team. The practitioners verbally offered eligible women at the clinic with information about the study, and subsequently provided the interviewer with the

contact information of a woman willing to consider participation. A pamphlet describing the study was also made available and provided as an option to women who preferred to have this information in a written format (See appendices for “Patient Recruitment Pamphlet”; See also discussion of considerations made to overcome adverse impact of HIV stigma for participants under “Ethics”).

When participant response rates dwindled during the course of the study, snow ball sampling was exercised at the recruiting clinic to ensure adequate sample size. This was done by requesting individuals from the patient informant group to refer their acquaintances who met the eligibility criteria for participation.

All participants recruited were invited for a research interview at the clinic that began with a formal consent process.

Practitioners:

A purposive sample of practitioners who provided VCT and worked with immigrant populations were recruited from six CHCs and two AHTCs in Ottawa. Practitioner recruitment was coordinated by the Regional Director of Anonymous HIV testing, who was also a member of the project’s advisory committee. Along with a letter of support, the director sent an information package about the study to each site through an email list-serv, requesting each site to release the contact information of at least 1-2 practitioners who agreed to participate in the study (Please see “Letter of Support” in the appendices). The interviewer then contacted interested practitioners to proceed with the interviews

4.5.2 Interviews

Patient informants:

Prior to the interviews, patients were assured that their participation was voluntary and that they could withdraw from the study without compromising their care at the clinic. They were also told that identification numbers instead of names would be used to maintain confidentiality, and that only the research team would have access to the study records. At this stage, the interviewer also described the study purpose, procedures, and potential benefits and risks involved with participation, including specifics about data collection and storage (Please see “Patient Consent Forms” in the appendices).

All interviews conducted were face-to-face, and took on average about thirty to fifty minutes to complete. Patient informants were compensated for their out-of-pocket expenses, such as childcare and transportation costs. The interviews were conducted in English in a private setting at the recruitment clinic by the primary investigator. All interviews were audio taped, and subsequently transcribed.

At the end of the interview, patients had the opportunity to ask questions and offer their feedback. During this debriefing period, patients were offered a two-page, bilingual (English and French) resource list of local organizations that provided language/vocational training, childcare, and housing services.

Practitioners:

A similar process was repeated for the practitioners with the following exceptions: 1. Practitioners were interviewed in a private setting at their own workplace; and 2. Not offered reimbursement, and a resource list during the debriefing period (See “Practitioner Consent Forms” in the appendices).

4.5.3 Data Storage

Verbatim transcription was conducted, except in situations when the participant was

inaudible, or unclear to the transcriber. Transcription involved recording all forms verbal communication in the audio taped interviews. Both overt and latent speech (i.e. hesitation, intonation) was recorded. Memos were made on the transcripts to highlight unrecorded sections, latent speech, and incoherent or unclear speech. Non-verbal cues, on the other hand, were not recorded.

Data in the form of interview transcripts and audiotapes will be stored for a period of five years following the study for follow-up purposes in the Ottawa Health Research Institute (OHRI) database. Data will be kept at a central location at OHRI under lock and key, and not sent to other locations.

The study records will only be accessible to the research team. After five years, the content of the audiotapes containing the interviews will be erased, and the transcripts destroyed.

4.5.4 Ethics

All interviews commenced after the research protocol was approved by the Ottawa Hospital Research Ethics Board (OHREB), and the Sisters of Charity of Ottawa Health Services Research Ethics Board (SCOREB) (Please see “Research Ethics Approval” in the appendices).

The research team recognized the vulnerability of the patient informants. It was noted that potential challenges in applying and interpreting the central tenets of bioethics research, namely-voluntary informed consent, confidentiality, no harm and beneficence- could emerge when working with refugee and immigrant groups. For example, we acknowledged that differences in language, educational background, and social norms could make it difficult to assess informed and voluntary consent (93). Hence, the research team carefully ensured that the manner in which the study was presented, conducted and interpreted would not stigmatize already vulnerable

populations, and this was done by working in close collaboration with practitioners at EBFMC through all aspects of study design and implementation.

Our recruitment methods were also sensitive to the findings of previous research conducted in Toronto with African and Caribbean communities on HIV stigma. This body of literature identified the adverse impact HIV stigma had on mental health, social support networks, and health seeking behaviours (in particular, acceptability to HIV testing, and disclosure of test results) of HIV-infected/ affected individuals. A wide range of concerns about access to health care, employment and immigration were also identified (43, 44).

Therefore, the research team carefully ensured that participants were recruited in a confidential manner, and that practitioners responsible for recruitment were perceived to be trusted and confidential sources of information. Confidentiality was maintained when eligible women were verbally recruited by their practitioners in a private setting at EBFMC. A pamphlet was also designed for women who preferred to have written information about the study but this step in recruitment was offered as a voluntary option since some women could have potentially experienced loss of social support and/or other adverse events if their involvement with this project was disclosed. Similarly, all women who participated in the study, received verbal debriefing after completing the interview, but had the choice to take with them written materials provided during this phase. Furthermore, during the consent process prior to the interview, the potential harms associated HIV stigma were discussed with participants. To maximize confidentiality, participants were given the option of writing their initials (instead of their signature) when providing written consent.

4.6 Data Reduction and Analysis

Descriptive statistics were used to describe the needs of the target group with respect to decision support for HIV testing. These statistics included frequency counts of themes and sub-themes identified in a thematic analysis of the interview transcripts. The frequency counts were contextualized using summary statements, and quotes.

A thematic content analysis was conducted, where responses were coded according to categories that emerged from the interviews. Themes were selected on the basis of their relation to the conceptual framework and frequency of occurrence. The ODSF technique for inductive and deductive coding was applied. As stated previously, the deductive coding system was defined *apriori* and corresponded to constructs of the conceptual framework. In other words, the deductive system of coding emerged out of a process of categorizing responses on the characteristics and determinants of decisional conflict as conceptualized by the ODSF. In contrast, the inductive coding system evolved during the course of analysis when the participants' responses could not be coded using the deductive codes. This latter group of codes were often, although not exclusively, associated with the open-ended questions in the semi-structured interview (88-90).

The analytic technique most frequently used for coding involved "coding up." That is, specific topics or categories were grouped into more pervasive non-overlapping themes or meta-themes. Occasionally, the technique of "coding down" was also employed to explore a topic and break it down to more specific constituents (sub-topics). All coding was developed cumulatively through an iterative process that involved constant comparison of the relationship between emerging topics or categories over time (88-90). Furthermore, the coding process was verified with thesis committee members and a senior researcher at Ottawa Health Research Institute (OHRI) with expertise in both decision support and qualitative research methodologies (Please see "Full definitions of deductive and inductive codes" in the appendices).

Interrater reliability of the coding was also calculated. This involved assessing agreement in coding between two independent coders using a *Kappa* statistic (91, 92).

4.7 Procedures to Ensure Data Quality

4.7.1 Ensuring Rigour in Design

The ODSF not only formed the philosophical basis of the study, but dictated study design and methodology. The rationale for the selection of framework and its compatibility with the multiple aims of the study has been outlined in chapter 2.0. Its limitations will be explored in chapter 6.0.

Rigour in design was also established through the use of appropriate sampling techniques (88-90, 94). Purposive sampling was used to select participants with specific characteristics. These participants, or key informants, were specifically selected because they were assumed to have valuable insights on the decision making needs of the target group regarding HIV testing. Moreover, in the rare case when snowball sampling was employed to ensure adequate sample size, participants were still subject to eligibility criteria described above.

4.7.2 Ensuring Rigour in Methodology and Analysis

4.7.2.1 Credibility/Trustworthiness

The concept of internal validity in quantitative research takes on a different meaning in the qualitative tradition. In the latter type of research, where one often assumes multiple realities, the primary goal of the researcher is to bring to surface the experiences of the participants as accurately as possible. In the following section, the procedures completed to enhance interpretive (i.e. the extent to which the

researcher's understanding accurately describes the perspective of the participants), descriptive (i.e. accuracy of the research process as documented by the researcher) and theoretical credibility (i.e. the degree to which theoretical explanation derived fits into existing data on the study topic) will be discussed (87).

Member checking was used to ensure interpretive credibility (88, 89). During the debriefing period at the end of the interview, the interviewer summarized and reflected the information provided by the participant to clarify his/her interpretation of the responses. Furthermore, a random sample of practitioners participating (n = 3) in the study were also forwarded a summary of the results highlighted in chapter 5.0 to verify whether their overall responses as a practitioner group corresponded to the researcher's understanding of their experiences.

Transcript and audiotape verification was conducted to ensure descriptive validity (88-89). A member of the thesis committee listened to a sample of the audio taped interviews to assess transcript quality. Furthermore, the researcher/ transcriptionist listened to the audio tapes several times to ensure accuracy. Also, as noted previously, verbatim transcription of all overt and latent speech was conducted for maximum credibility.

Theoretical verification with existing literature was conducted in the post-analytic phase. Please see chapter 7.0 for more information.

4.7.2.2 Dependability/ Consistency

A measure of interrater reliability was used to verify the reliability of coding (88, 89). This process involved quantifying coding consistency between two independent coders using a *Kappa* statistic (91, 92). The second coder selected was not part of the thesis committee, but an independent researcher with experience in conducting decision support needs assessments. Furthermore, a random sample of interview transcripts (n = 3) was used to verify interrater reliability.

Conceptual and methodological aspects of the coding process were further verified by members of the thesis committee and a research methodologist. Decision support experts on the thesis committee, including the author of the conceptual framework, provided their feedback on emergent themes related to ODSF, while the immigrant health specialist on the committee shared his perspective on non-ODSF related themes pertaining to health determinants for this group. In addition, the research methodologist, who also had considerable expertise with decision support needs assessments, ensured a rigorous and consistent approach to the content analysis.

4.7.2.3 Confirmability/ Neutrality

A simple project history involving documentation on key phases of the project (i.e. questionnaire adaptation, coding and analysis) was created (88, 89). Furthermore, all key documents were reviewed by the thesis committee to minimize the impact of the personal bias of the researcher on the research.

CHAPTER 5: RESULTS

Eight patients and twelve practitioners were interviewed. Results below are presented according to key ODSF concepts.

PATIENT PERSPECTIVE

5.1.1 Patient Demographics

Most of the patients were between 20 to 39 years old ($n = 7/8$), were enrolled in or had completed post-secondary studies ($n = 5/8$), and were first generation immigrants with variable length of residence in Canada (range: 6 months to 12 years). All patients interviewed, with the exception of those recruited via snow ball sampling ($n = 4$), were recruited at the EBFMC. There were no significant demographic differences between participants from EBFMC and those recruited via snowball sampling, with exception to educational attainment. While all participants recruited via snowball sampling had completed or were completing post secondary schooling ($n = 4/4$), only one participant recruited via EBFMC had done so ($n = 1/4$)

Table 2: Demographic characteristics of patient informants

Variable	Frequency Counts, N=8
Age	
20-29	3/8
30-39	4/8
40-49	1/8
Level of formal education	
Some high school	3/8
College/ University	5/8
Region of Origin	
Sub-Saharan Africa	5/8
Caribbean	3/8
Length of stay in Canada	
< 1 years	3/8
> 1 years but < 5 years	1/8
> 10 years	4/8

5.1.2 Perception of Options

When patients were asked about the types of testing options available to them, none were able to identify any. Thus, the options for VCT were explained, and preferences towards these options recorded. Almost all who responded to this question associated the benefits of anonymous HIV testing with enhanced client confidentiality and control over the consequences of testing (including disclosure). In contrast, the harms frequently associated with anonymous HIV testing were linked to poorer post-test follow-up, poorer continuity of care, and lack of a formal mechanism for partner notification. One individual also identified the lack of an established relationship with practitioners working in AHTC settings to be a disadvantage.

In general, patient preferences towards testing options corresponded to practitioner perspectives (Compare Tables 2 & 7).

Table 2: Patient perspective on options

Variable	Frequency Counts, N=6*
Preferences	
Pros of anonymous testing (cons of non-nominal/nominal testing)	
• enhanced client confidentiality	5/6
• increased client control over the consequences of tes	5/6
Cons of anonymous testing (cons of non-nominal/nominal testing)	
• poorer post-test follow-up	4/6
• poorer continuity of care	4/6
• lack of partner notification	4/6
• lack of established relationship with practitioner providing VCT	1/6

* The question on preferences towards available VCT options was inserted after two interviews. This question was posed hypothetically as none of the women interviewed were aware of VCT options.

5.1.3 Behavioural Manifestations of Decisional Conflict

Patients reported the target group to experience a range of emotions indicative of decisional conflict. Examples of behavioural manifestations of decisional conflict highlighted were: worries about the negative consequences of testing, distress about the decision, and uncertainty about the importance of testing (Compare Tables 3 & 8).

Patients also talked about the target group's concerns and uncertainty about testing. For example, some patients linked concerns about the consequences of testing to employment access issues (*"There is the belief that if you have AIDS there are certain things you are not going to be able to do like get a good job, and things like that. So all those perception also are barriers for all those women. So they would prefer not to know."*). Others talked at length about the consequences in relation to social stigma (*"Most people feel shame when they find out they are HIV positive. So for that reason they wouldn't want to go for a test. Because of the shame it brings to the family, to your children, to the entire family."*; *"Like back home, when you are HIV positive, it's a very big disgrace for your entire family. If you die from HIV, it's a disgrace. So if you are HIV positive or die from HIV, I'm sorry to say that your family won't want to come in the day light."*)

Table 3: Patient perspective on behavioural manifestations of decision conflict

Variable	Frequency Counts, N=8
• worry about the negative consequences of HIV testing	8/8
• feel distressed about the decision	5/8
• question the importance of testing	2/8

5.1.4 Factors Contributing to Decisional Conflict

HIV stigma emerged as a central theme in the patient interviews. As highlighted in the previous section, patients often emphasized the social consequences of HIV stigma in relation to testing. In addition, they also talked about specific characteristics of HIV stigma that paralleled concerns highlighted by practitioners (Compare Tables 4 & 9). In particular, they discussed: 1. social norms and values that propagated negative moral judgement of individuals perceived to be at risk for HIV, or living with HIV; 2. concerns about being negatively labelled in association with HIV; 3. concerns about talking about HIV or a related topic; 4. and worries about loss of confidentiality when accessing VCT or related services, such as ART. These multiple elements of HIV stigma will be discussed in more detail below.

Patients often referred to the moral dimensions of HIV stigma, and its impact on VCT decision making. In particular, patients highlighted negative moral judgement associated with individuals perceived to be at risk for HIV, or living with HIV. For example, when voicing the target group's concern about being approached for testing by their health practitioner, one patient explained, *"It's being identified as a potential person that can have AIDS because AIDS is not really well perceived as a kind of sickness, right? Because if you have AIDS usually that means that you did not have a good life and you were doing all kinds of not so good things and things like that. So when a health practitioner approaches you and asks you to be tested, <you think>, 'What kind of people do you think I am? Why are you even thinking that I can have that?'"* Another shared, *"The way it <HIV> is perceived -like if you have it or if you are asked to get tested-from my point of view it means that you did not have a good life, you had multiple partners, and you were kind of <pause> not pure."*

Patients also highlighted the target group's concerns about being negatively labelled in association with HIV in the care context, particularly in association with ethnicity, country of origin and/or immigration status. For example, one patient, when talking about her experiences of feeling singled out for HIV testing by her practitioners, revealed, *"I would ask myself: 'Why are they asking me? Is it because I am from <county of origin omitted>? Would they ask any other person that?' The kind of perception that you being marked because you are coming from this country versus this other country, or because of because of your <immigration> status also. Because if you are a refugee, you are not so well perceived."* Another patient, who disclosed a similar experience, reflected on the negative impact this facet of HIV stigma had on the practitioner-patient relationship. She shared, *"And the stereotypes, too. Because I would say that it's just really hard. Because the person <the health practitioner> have something, they have thought about you and where you have come from already. It doesn't make it easy for you to make a decision and talk to this person. You just thinking, 'Why would I tell you anything? You already have your answers. You have come to a conclusion about the kind of person I am.'"*

Furthermore, patients expressed that talking about HIV and related topics was linked to HIV stigma. Occasionally (n = 3), this theme was linked to broader issues such as values and norms on communicating about sexuality (*"Back home, where I grew up, it's almost like a taboo. Nobody says anything about sex. People don't talk much about sex. I think it's in a lot of cultures."*). Yet, at times, these concerns were identified to be specifically related to HIV stigma. For example, one patient, when speaking of her brothers who were involved in HIV outreach activities in her home town in East Africa, explained the fear associated with ignorance about HIV and conversely, the ability of educational efforts to dispel the same fear: *"Some are not afraid to talk about this topic <HIV>. But others are afraid. I don't know how to <pause> talk about this topic. When they <her brothers> start the first time, everybody <was> shy, everybody <was> scared. But when they know about that <HIV>, I think they are not because, I don't know, you know, everybody, they teach them. You know, they teach to us."* Another patient explained the silencing associated with HIV stigma from a slightly different angle. Referring to the barriers women from the target group experience when talking about sexually-related HIV risk activities, she explained, *"The other barrier, I think, is about the way the disease is transmitted. Because it's not something that you get, you know, I know that usually that it's sexually transmitted. I know that it can be transmitted also if you have a transfusion and things like that, or if you have a cut or something like that. But the focus is mainly because it's sexually transmitted and it's kind of a taboo."*

In addition, patients discussed the target group's worries about loss of confidentiality during VCT. Sometimes these concerns were linked to some of the characteristics of HIV stigma identified above, such as targeted testing (*"Also, I think because confidentiality will be an issue too because people, as I was telling you earlier, they a bit afraid of being <pause> not targeted but marked. So if they want to keep that for themselves and make sure that it's not something that everyone else will know."*). Other times patients expressed this concern in relation to the target group's preferences for anonymous HIV testing or difficulties with post-test disclosure (*"I would*

say that the one <option> that says that those information can still be shared, would make someone hesitate. When you say, 'You can do it <take the HIV test>. Nobody is going to access to it <the results>', I would see more women readily doing it than if they know that the information can be traced back to them." ; "So maybe if the person <client> is married, don't go to tell the person's husband <the test results>. Maybe try to counsel them. Talk to them, little by little. And maybe ask the person, 'Can I tell your husband? Can I tell your sister? Can I tell your brother or your sister or your child or whomever?' If the person says 'No', you and the person can keep it private.")

Another key finding was that all patients interviewed lacked information on the options available for HIV testing. Therefore, during the interviews, these options were explained to them, and their perspective on their pros and cons assessed. Results showed that patient perspectives were consistent with ODSF's concepts of informed decision making. For example, some patients stated that women from the target group would be better equipped to make informed decisions if they were aware of the available testing options. For example, upon learning about the different testing options, one patient offered, *"Like in my case, I didn't know anything ahead, you know. If I had gone somewhere and there was a session and somebody said something, I'd already know about it-nominal, anonymous, <and then, be able to> choose my thing. That's what I think could be the best because not many immigrants would be informed about these things."* Similarly, when speaking of potential resources for decision making, another recommended, *"By the person <lay health educator> explaining it, they will understand it more. And then when they go to their health practitioner, they will have the information <about the available testing options> already and then they can decide and say, 'I'm going to choose anonymous or nominal or etc.' They would have processed the information before coming in."*

Some patients also expressed that women from the target group were not aware of the options and outcomes of decisions along the VCT pathway, and in particular ART; Others expressed this opinion more implicitly by encouraging VCT providers to educate their clients about ART, and frame HIV as a chronic disease. For example,

one patient who encouraged practitioners to emphasize treatment options during VCT, offered, *"At first people thought that HIV had no cure. We know that HIV doesn't have a cure but it does have treatment that diminishes or that will break it down until you live a certain amount of time. So if you get to know you are HIV positive, and you know there is a cure, I think it's gonna ease the tension up. That's a big change."* Similarly, another voiced, *"Because now they have treatment for AIDS, so suggest them.... So if you have AIDS and they tell you have AIDS, <you> don't feel like the whole world is going to an end."*

Other barriers highlighted by patients were linked to ineffective VCT strategies, such as targeted testing and lack of practitioner sensitization to post-migration integration issues experienced by some immigrants and refugees (See section 5.2.6 for more information). Resource availability and access issues for immigrants were also identified to be a barrier. In particular, lack of language services for non-English and French speakers was a common concern (*"That's another issue....I know in Ottawa I don't see things being translated other than in French and English, the languages where we feel the people of the community speak. "* ; *"As a new immigrant, people don't speak well the two official languages in Canada. So, fearing that nobody can understand them, they will not say anything. So that's a barrier, that's how I see it. "*). Sometimes inadequate funding of organizations that specialize in immigrant services was highlighted as a concern (*"I think community centers, whatever multicultural community centers, help a lot for new immigrants. I think they should be funded more so they can teach their community about what's going on."*)

Table 4: Patient perspective on factors that make the decision difficult

Variable	Frequency Counts, N=8
Knowledge of HIV, HIV testing options, and outcomes	
• lack of knowledge about testing options, their benefits and harms	8/8
Support/Pressure	
• not having support or feeling pressure from others	7/8
Client characteristics and barriers to decision making	
Sociological phenomenon in relation to HIV stigma	
• concerns about being negatively judged in association with HIV risk or status	5/8
• concerns about talking about HIV or related topic	4/8
• concerns about being labelled in association with HIV/AIDS	4/8
• concerns about loss of confidentiality when accessing care	5/8
Practitioner/ Practice Characteristics and Barriers	
Practitioners & VCT counselling	
• ineffective VCT strategies	4/8
Resource availability and access	
• lack of language services	5/8
• health care access challenges, including navigational barriers	3/8

5.1.5. Decisional Roles

Patients expressed that the target group preferred to make the decision to test on their own, often anonymously (*"From back home I see <that> some women are afraid to live <like> that. A lot of people choose to make it like that....They don't tell other people."*). In addition, some disclosed that the target group would not involve their family in the decision (*"So they will ask their really, really close friends. I don't think they would ask any family members because you don't want people around you <to> know."*).

When asked to identify significant others involved in decision making, the majority discussed the important role of health practitioners (and in particular, the family doctor) and partners (*"I would say <that> the family doctor should play a big role."* ; *"The <family> doctor would definitely be the number one."* ; *"Maybe their husband. Yes, you live with your husband."*).

While health practitioners were always perceived to be supportive, partners were assumed to offer supportive/shared or dominant roles (*"But to diminish the fear, counselling, or I suggest you intensify counselling. A lot of support from <the> health care worker."*; *"I think my husband <is> in control. Because only me, I will not go to the HIV test. We <will go> together. The main person is my husband and the doctors too."*). Moreover, when patients talked about positive aspects of supportive roles offered by health practitioners, they highlighted the importance of confidentiality (*"For me, if I go to the doctor and the doctor tests me that I have AIDS, I think I trust the doctor because before you become a doctor they give you an oath that you have to keep secret. So I think the doctor tell them <their patients>, encourage them, talk to them nicely..."*; *"Like if you are with a health practitioner, like in a clinic, you are more open. You can ask a lot more questions. You know when you go back home, this person is not there with you."*)

5.1.6 Decision Support Resources

As highlighted in section 5.2.5, patients identified the important role of the family doctor in decision making. They also offered important insights on how these practitioners could tailor the counselling to meet the needs of the target group. Specifically, many encouraged practitioners to: 1. clearly articulate the purposes of VCT; 2. use a non-targeted approach to VCT; 3. detach negative moral connotations associated with HIV risk; 4. emphasize risk reduction and treatment choices and 5. be sensitized to contextual issues experienced by immigrants and refugees new to Canada. These recommendations will be discussed in more detail below.

Patients stressed the important role of practitioners in enhancing acceptability to VCT. Clear articulation of the purposes of VCT was identified to be crucially important in this aspect. Aside from enhancing informed making, this strategy was also perceived to minimize concerns about targeted testing (*"I would recommend that being a very big part of the questionnaires when a doctor explains to patient, 'Okay, I need you to do this test, and this is the reason why I'm asking you to do it. Don't think I am asking you*

to do it because you are of a certain ethnic background, and I am using it for other purposes. I'm just doing it for your own good'....So with this already out of the way, you can get to the point and you can do your job. And, it's much easier for the patient to open up because they know why <they are testing>”). Moreover, as mentioned in section 5.2.4, patients encouraged practitioners to couple information about the objectives of VCT, with information on testing options and outcomes (“I guess, if I were a health practitioner who is going to talk to a new immigrant about HIV testing, I would first of all try to explain the reasons for why I am asking for this testing. Very clearly, and very <cut off, inaudible>...Like you went through all the steps. You let me know what is anonymous test, nominal and non-nominal. I didn't have this education. I wasn't told what the differences were, and what the implications were if I did whichever one.”). Also, some recommended practitioners to talk to the women presenting for testing about a non-targeted, universalized approach to VCT (“And some people feel like they have been selected, you know, because of their ethnic background, and that not everybody is being tested. The person has to be made aware that this is not just you who has been tested, that it's a general thing that everybody is doing to get better health.”).

Additionally, patients underlined the instrumental role practitioners could take in diminishing the impact of HIV stigma through counselling. In particular, they highlighted the importance of dissociating negative moral connotations associated with HIV risk, and emphasizing risk reduction and treatment choices during VCT. For example, one patient expressed that a practitioner offering VCT should emphasize: “That it's <HIV/AIDS> not something bad to have. It's just a disease like any other disease that can be treated. So I think the approach will be that there are different kinds of disease. As you can get tested for cancer, breast cancer. It doesn't mean that you're bad and that you are doing bad things. It's just that it's a disease that you have to get tested <for>. So I think that this is the approach: you have to make women understand that it's not because we want to stigmatize you, but just a disease and it is something that can be treated.” Similarly, another francophone speaker disclosed, “Just to dematisse. Like have it less dramatic, that the sickness <HIV/AIDS> is not

that you're a bad person. That's the first thing. The second thing is to explain to them the reason why <it's important to test>: 'It's not because we want to just put you aside, but because we want to help you to get treatment and also to prevent it.'”

Lastly, when it came to adaptive counselling strategies, patients also encouraged practitioners to be aware of contextual issues experienced by immigrants and refugees new to Canada (*“Just making sure that the health practitioners are aware that as an immigrant you already have issues to deal with: you know, a new culture, a new government. ...So if they are aware of this, then they are more informed about how to handle a patient. They can get more. They can get to know their patients and get them to trust them more.”*)

Patients also recommended a wide variety of other types of decisional support resources. These included: 1. public education on VCT using a variety of venues (i.e. educational workshops at clinics, door-to-door peer outreach, media advertisements, information pamphlets through immigration services, educational sessions at faith-based organizations and schools); 2. the use of written educational materials in adjunct to counselling; 3. the integration of HIV education into (broader) health, educational and vocational services; 4. and the availability of appropriate language services at the point of care.

When speaking about effective outreach programs, patients often reflected on their own experiences with such services “back home”. For example, one patient, when speaking of her brothers who were involved with HIV outreach activities through a public health agency in her home town in East Africa, expressed, *“They invite a lot of people, and do some get-together. They invite HIV positive persons <speakers>, and they teach them. Back home it's public health, and the schools. Sometimes they come in and teach them. And mass media helps. Yes, sometimes when they have things <information sessions> like that, nobody comes. But TV and radio, everybody has that, everybody sees that.”* Others talked about informal group workshops for women as an effective means of outreach (*“Like women's meetings. Like in Africa where I am*

from, <county of origin omitted>,, sometimes they have workshops. Yes, three day workshops in the military hospital for both men and women. Yes, sometimes three days, sometimes one week. They tell you how to use a condom and what to do. And they tell you that, 'AIDS is here, AIDS is real. You have to stick to one partner and be aware of your partner, and try to talk to your partner'. And after the workshop, they give you a box of condoms." ; "If the community can organize a group that talks to women about being tested, or counsel women being tested, or maybe writing some booklets. But like what I told you, if you have a special day to meet with the women, because this is what we do back home. We have special days to meet with the women.")

Other recommendations included the availability of written materials in adjunct to counselling, and the promotion of integrated HIV services. Patients encouraged the availability of written educational materials at the family doctor's office ("To have something when you get to office. You don't need to speak to anybody but to have the information there. And you take it if you want. You can evaluate it on your own, or discuss it with your doctor if you like."). In addition, patients also advocated the integration of HIV information into broader topics, such as general women's health, through educational workshops. One patient, when talking about her experiences with such integrated workshops, articulated, "Like back home, we have dates for topics. Really, people might be ashamed individually but the subject of HIV, I think it should be generally taught to people. You ashamed because of the fear, but what about the other people? You understand me? So we have schedules. Like today we are gonna talk about general women's health. Let's say Saturday or Monday we have topics on HIV. And people come to it." At times, patients also provided a rationale for such an approach: "Maybe somebody coming and announce it in the neighbourhood: 'Somebody is coming to speak about HIV' or just a broader theme, a broader subject and include it into it. Because maybe if you just say 'HIV', then people are gonna look at who's gonna go. So they might stay away from it. But if you make it broader and just include it in your topic, people will be more exposed to the information you need them to receive."

Furthermore, patients also talked about the importance of making informational services on HIV and VCT available at places in the community offering specialized services to immigrants. Hence, aside from the family doctor's office, the availability of information pamphlets at community centers were often encouraged (*"I don't see how or where that information would be there for them if it's not with the family doctor or a medical facility. I imagine the life of a woman who just came and doesn't go to school is basically just staying home and going to the community...Maybe a community center, they probably have something. That's the way to reach them."*; *"I haven't been exposed to any community health centers but I go to the community center and it's a place where a lot things can happen, where you touch the needs of the people who are surrounding that center. So it would be good to include what we are talking about here with all of the services that are already available in the community but it won't be like a health center....It would be a center for activities and education."*). Explaining her reasons for supporting the availability of such resources at community centers, one patient explained: *"I will say multicultural community centers play a big role <because> they <the target group> need translators, languages and may be transportation."* Some patients also encouraged the availability of educational pamphlets in collaboration with organizations that offer educational and vocational courses/training workshops to the target group (*"Sometimes they have ESL²⁶ courses and things like that. So all those courses when they give specific courses for women, we can target them there....Yeah, where they go anyways. I think that would be helpful because these are different places where they are going to get the information because there are in a learning environment."*). Others highlighted the important role of ethno-cultural associations in the delivery of educational materials, particularly for individuals with limited access to healthcare services (*"Their own community because new immigrants first go to their community, does not matter what. First thing I do when I go in another state, I will look up <county of origin omitted> community association, and I'll call that number, or an <county of origin omitted> restaurant, and then I'll know. So their own community will play a good role..... So I believe their own*

²⁶ An acronym for courses where English is taught as a second language.

community will play a big role for people who do not have a lot of access as new, new immigrants.”)

Lastly, patients identified language services at the point of care as an important resource for the target group. Some encouraged the availability of informational pamphlets in diverse languages (*“Well, I think the language would be something. If they can have all those information in their own <language, then> that would be something really helpful. Then they can understand better”*). Others encouraged the use of translators during counselling (*“I would say that it’s probably the best way of communication ever... And it makes the person <the client> feel more open. You can give more information to this person. Even if there’s another health professional there, if you have another person translating, you can give information more.”*). Moreover, the use of practitioners and lay health educators who spoke the first language of the patient was perceived to enhance acceptability to informational services on HIV (*“If the person has a problem with understanding what you are saying, find the right person that understands the language that the person is more comfortable with.....Let’s say we are in Chinatown. You know it’s a Chinese community, for instance. We need at least one Chinese counsellor, somebody who is around that is a health practitioner as well but speaks the language, and can communicate with this person, and are comfortable enough to talk to you and give information. That way, everybody can get educated on HIV.”*; *“So basically, I am trying to put myself in the shoes of someone who has just come to Canada, who did not have the opportunity to go to school, to know all these things ahead of time. The only way for me to get that information is that is if somebody from my community, preferably speaking my own language, comes out and I can relate to this person. I know where they are coming from.”*).

Table 5: Patient perspective on decision support resources

Variable	Frequency Counts, N=8
Practitioners & VCT counselling	
• adaptation of VCT to needs of the target group	7/8
Macro-level programming & service delivery	
• integrated HIV services	6/8

• use of written educational materials in adjunct with counseling	4/8
Resource availability and access	
• public outreach on HIV	
• increased funding/ availability of immigrant health and support services	7/8
• improved access to health care	7/8
• availability of resources at sites frequented by target group	2/8
	5/8

PRACTITIONER PERSPECTIVE

5.2.1 Practitioner Demographics

Twelve practitioners were interviewed. A descriptive analysis revealed that most practitioners were between 30 to 59 years old, female, and worked at a community health center (CHC) or a specialized anonymous HIV testing clinic (AHTC) in Ottawa. The practitioners came from a wide variety of clinical backgrounds (family physicians (n = 3/12), nurses (n = 4/12), nurse-practitioners (n = 2/12), social workers (n = 2/12)²⁷ and had varying length of work experience as a VCT provider (Range: greater than 2 to less than 20 years). Only 3 of the 12 practitioners interviewed worked at sites where anonymous HIV testing services were offered exclusively (i.e. AHTCs). The rest worked at sites where HIV counselling and testing services were offered through specialized appointments, and family medicine practice (i.e. CHCs).

Table 6: Demographic characteristics of practitioners

Variable	Frequency Counts, N=12
Age	
20-29	2/12
30-39	5/12
40-49	3/12
50-59	2/12
Sex	
Male	1/12
Female	11/12
Clinical Background	
Family physician	3/12
Nurse	4/12
Nurse Practitioner	2/12
Social Worker	2/12
Other	1/12
Location of practice	
Community health center	9/12
Specialized anonymous testing site	3/12
Mean years of experience with VCT	
< 5 years	2/12
> 5 years but < 10 years	7/12
> 10 years	3/12

²⁷ A health promoter working at a community health center in Ottawa who was not a practitioner who provided VCT was also interviewed at the request of several practitioners who worked at the same site.

5.2.2 Perception of Options

When asked about HIV testing options, all practitioners highlighted anonymous, nominal and non-nominal testing. Furthermore, they shared common perspectives on the pros and cons of these options. Several highlighted the pros of anonymous HIV testing, such as greater client confidence in confidentiality and control over the consequences of testing. Others perceived AHTCs to offer more comprehensive counselling in comparison to family medicine practices due to the scope for longer consultations, and the multidisciplinary care environment of the specialized sites. Commonly cited cons for anonymous HIV testing were poorer post-test follow-up and continuity of care, and a lack of a mechanism for partner notification.

The question on options also prompted practitioners to talk about the target group's usual entry point to HIV testing. Examples included: general visits to a health practitioner, annual physical examinations, access to prenatal care, and the immigration medical examination. Furthermore, some perceived the target group to be unaware of anonymous HIV testing (*"This group is most familiar with testing through a family doctor. They find out about anonymous testing later."*). Others highlighted that women were usually in a more advanced stage of decision making when seeking anonymous testing (*"Usually, clients have made the decision <to test for HIV> before coming in to test <anonymously>."*)

Table 7: Practitioner perspective on options

Variable	Frequency Counts, N=12
Preferences	
Pros of anonymous testing (cons of non-nominal/ nominal testing)	
• enhanced client confidentiality	8/12
• increased client control over the consequences of testing	8/12
• more time for VCT	3/12
Cons of anonymous testing (cons of non-nominal/ nominal testing)	
• poorer post-test follow-up	6/12
• poorer continuity of care	6/12
• lack of partner notification	2/12
• lack of established relationship with practitioner providing VCT	2/12

5.2.3. Behavioural Manifestations of Decisional Conflict

When asked about how the target group felt about the decision to test for HIV, practitioners highlighted a range of emotions indicative of decisional conflict. The target group was perceived to worry about the possible negative consequences of testing, feel distressed or upset about the decision, question the importance of knowing their HIV status, and delay making the decision to test.

Many practitioners linked decisional conflict to HIV-related stigma that women feared to experience from their social network ("*<There is> the fear of the negative consequences of testing: fear of alienation and ostracism. Women fear that their partners may leave if they find out they tested. Also, they may be isolated from the community. Once you lose that, you have nowhere to go.*"). Others linked HIV stigma to institutional discrimination, noting the target group's fear of "*how their test results will affect their immigration status*" or "*burden of treatment, affording medication if they don't have a health plan.*"

Practitioners also expressed that the target group questioned the importance of knowing their HIV status ("*Many don't want to know, cannot cope with knowing, and do not have the resources to cope.*"; "*A lot of these women will not go for either*

<forms of testing> because they do not believe it will happen to them, and because they don't want to face the consequences. They would rather just not know.”), while others talked about their delayed entry into the health care system for HIV screening (“After they are here, I think they are dealing with so many other things that HIV testing is low priority unless they get pregnant, which becomes the medical system’s priority, if it’s not theirs, or they themselves get sick to the point they can’t perform <their> normal roles.” ; “Usually it <HIV testing> comes up when they are either pregnant or coming in with certain symptoms.”)

Table 8: Practitioner perspective on behavioural manifestations of decision conflict

Variable	Frequency Counts, N=12
• worry about the cons of HIV testing	12/12
• feel distressed about the decision	11/12
• question the importance of testing	8/12
• delay making the decision	3/12

5.2.4 Factors Contributing to Decisional Conflict

Practitioners identified a broad number of determinants of decisional conflict. In particular, they stressed the target group’s lack of support in decision making, and knowledge deficit concerning general facts about HIV transmission and available testing options. Moreover, the target group was perceived to fear pressure or loss of support from their social network, and this concern was often associated with HIV stigma. One practitioner articulated, *“There is a huge fear-and I don’t know how justified it is, I think it probably is- of ostracism from the community if some people were to find out about <their> HIV positive status. I have yet to have someone from that community who has tested positive and been open in their community about it.”* Other barriers related to HIV stigma were also identified, such as the target group’s fears of being judged and labelled in association with HIV, or talking about topics related to HIV (*“People feel labelled. Africa in the media is linked to HIV. People need to dissociate from this image and therefore don’t go for HIV information.”*; *“<The women> may have strict religious norms to live by and if deviating from these norms, then it becomes difficult <for them> to disclose about HIV risk in a not completely*

confidential, safe environment”; “It was inconceivable she that she was sexually active...She had to get over the barrier to admitting <to her practitioner that> she had <extramarital> sex.”)

Practitioners also perceived the target group to have limited knowledge about HIV transmission and prevention. In particular, they highlighted misconceptions and myths among the target group with respect to the prevalence of HIV/AIDS in Canada (*“Clients feel like they left HIV back home”; “They don’t feel that HIV is here in Canada, especially after being tested during immigration.”*). Moreover, practitioners perceived the target group to be unaware of certain outcomes in the VCT pathway, particularly antiretroviral therapy (ART) (*“The women don’t come from a place where the economy and the medical system has allowed for treatment. They feel better off not to know. But once they know that there is a possibility of getting free treatment for themselves and their children, then I think they are motivated to find out their HIV status.”*). A few expressed that this knowledge deficit was associated with the unavailability of ART and lack of resources for public education on the epidemic in endemic regions (*“In endemic areas, it’s <VCT> very often not well publicized. It’s not well told to the public. There is no public education regarding HIV/AIDS.”*)

Client, practitioner, and practice characteristics were also perceived to be a source of decisional conflict. Client barriers identified were linked to healthcare access issues faced by some immigrants. They included language related barriers and other concerns. While former included factors such as communication barriers during counselling and confidentiality limitations imposed by the use of translators, the latter group of client specific barriers included things such as the target group’s lack of knowledge about the health care system or community resources, and limited use of preventative screening services.

Language related barriers were a common theme identified by the practitioners. When talking about comprehension problems posed by a language barrier, one practitioner

disclosed, *"Women may not be able to tell providers what they want, or providers may not understand their requests and communicate to them appropriately and they may not understand the options <for HIV testing> offered."* Similarly, another practitioner, when talking about language barriers, expressed, *"Language, of course. For those who don't speak English, they would be cut off if they couldn't understand."* Some also pointed to how language barriers could potentially perpetuate misinformation about HIV/AIDS (*"I think all of their background would come forward with them in <their> fears of moving forward to testing. Yeah, <their> home country's attitudes or <their> lack of knowledge. And then you add on to that, they are often dealing with a second language which can cause misinterpretation, myths, and misinformation."*)

Practitioners also talked about barriers posed by translators and cultural interpreters during VCT. Although considered an useful resource at CHCs, many practitioners voiced concerns about their use (*"Certainly I find <that> cultural interpreters can be a cultural barrier because of the norms of their culture and being interpreted by someone from their culture who maybe judgmental on their lifestyle, or maybe judgmental on their family system."* ; *"There are interpreters we use, sometimes from the Interpretation Services of Ottawa. But then you bring in another person into the equation. They are very good and very confidential but I think the patient is more worried."*) At times practitioners also worried about the use of family or friends for interpretation (*"I think the language barrier is a huge thing. And we get a lot of people that need to come in with their <own> translator. And we always worry that we are not giving as much information as we can."*)

Other types of client barriers identified were related to the target group's lack of knowledge and familiarity with the health care system, including public health initiatives such as anonymous HIV testing (*"They <new immigrants> are scared. It's a new country and they are not aware of the health care system, and not sure of the consequences of testing positive."*). In addition, one practitioner also talked about the limited use of preventative screening services by immigrant women as a barrier. For

example, when explaining her involvement with *Mujer Sana*, a local association for immigrant women from Latin America, she stated, *"We found that often <immigrant> women would not come for STI²⁸ screening"*. Then drawing a parallel to breast cancer screening, she explained, *"These women declined mammograms because they would rather not know if they had breast cancer, even though you explained the benefits of early detection."*

In addition, practitioner and practice characteristics were also perceived to decrease the effectiveness of VCT. Specific examples of these types of barriers identified were related to: 1. VCT and cultural sensitization issues; 2. macro-level programming barriers, such as the conceptual issues in programming for multicultural populations, non-integrated HIV services, and time restraints for VCT in family practice; 3. health care access issues faced by the target group; 4. and the availability of immigrant health services.

Practitioners addressed a range of concerns when talking about cross cultural adaptation of VCT. For example, one practitioner, when providing an example of how she adapted pre-test counselling in a cross-cultural setting, expressed, *"The other thing is that I am careful with my language with these women when I'm going through the risk factors."* Another expressed: *"To adapt to that specific population, I think you need to get to know their culture.... It's a complete adaptation from one culture to another. It does not work the same. I don't use the same language. It takes more time sometimes."* Sometimes practitioners linked language to client acceptability. For example, drawing on her experience with a successful outreach program in Ottawa for immigrant women that employed lay health workers for sexual health promotion activities, one practitioner expressed, *"My experience with this study was that lay health workers would go to their homes and explain in very basic language, having the*

²⁸ An acronym that refers to sexually transmitted infections.

empathy for the same culture and speaking in their own language <so> that they could understand. Not only just understand but have better acceptance of what was <said>.”

When talking about macro-level programming barriers, practitioners shared a broad range of concerns. Some challenged conceptual issues related to VCT programming for multicultural populations (*“Most resources are stereotypically stigmatized and defined by who the major risk groups have been in the pastMost resources are for white, gay men and multicultural HIV-positive women clients never feel quite comfortable in places like the Ottawa Hospital HIV clinic.” ; “Not many women will go to the Sexual Health Center because it has a drug users and gay man’s face and immigrant women do not fit in there.”*). Others noted specific gaps in service delivery, with particular reference to the questionable effectiveness of existing HIV educational materials for multicultural populations (*“People have their own culture of doing things. For example pamphlets have been used but <there are> many language barriers. Also, people are not used to this format.”; “What I am saying that one of the barriers for diversity <groups> are that maybe the information is not delivered in their own way of understanding.”*)

Some practitioners also highlighted concerns about non-integrated HIV services, as women from the target group were perceived to be largely unaware of their risk, and therefore unable to relate to these services (*“You are not going to get people showing up. It’s like you: you wouldn’t go to an information session that was being offered in your community for something that you did not think you needed. Why would you go? And that’s they way the feel.”*). Moreover, women aware of their HIV risk status were perceived to not seek these services due to issues around confidentiality. For example, several practitioners stressed the importance of integrating HIV education into broader health programs so that the women *“are not going to be identified as seeking HIV services”* or *“don’t feel that they are singled out”*. Furthermore, some stressed the importance of *“information in a non-threatening environment”*, a *“kind of a context where it would be a very non-threatening, non-targeted way about just*

generally taking care of yourself” or a “kind of context where it’s just part of health, it’s not like a big deal off on its own.”

Some practitioners identified lack of time for VCT in family practice to be a major barrier to effective VCT. For example, a family physician who worked at a CHC disclosed, *“The reality is that we are too busy to do any <thorough> counselling.”* Similarly, when talking about the challenges she faced in completing pre-test counselling in the prenatal care context, one family physician expressed, *“And I think that’s part of the fact that it’s part of the prenatal exam and I’ve only got twenty minutes to do a huge form and a bunch of other stuff around it. So HIV becomes like Hepatitis B, one of the things that’s part of it, as opposed to just the HIV test itself.”*

Furthermore, practitioners talked about the lack of availability of resources and/or funding for specialized services for the target group. For example when highlighting inadequate funding for translation services, one practitioner expressed: *“And the other thing is: money for education. We all talk about educating our youth, about HIV prevention, about anonymous HIV testing. You know, all those things we talk about. But do we have enough resources for it? I don’t think so. When it comes to diversity, whenever you talk about translation and language issues, then it becomes complicated and we say, ‘Ah, no money.’”* Similarly, when talking about the availability of resources for post-test referral, another practitioner shared, *“Yes, there are very few resources for these women after <they have tested positive for HIV>. I think they would feel very, very isolated because I don’t feel like they can go back to their communities and share this with their friends and family. And a lot of the resources we have in town have been set up by gay men.”* A few practitioners also highlighted limited funding for institutions that specialize in providing immigrant health services to be a barrier (*“There are structural issues, like funding for community health center programs.”*)

Table 9: Practitioner perspective on factors that make the decision difficult

Variable	Frequency Count, N=12
Knowledge of HIV, HIV testing options, and outcomes	
• lack of basic information about HIV transmission and prevention • lack of knowledge about testing options, their benefits and harms	7/12 3/12
Support/Pressure	
• not having support or feeling pressure from others	12/12
Client characteristics and barriers to decision making	
VCT & language related barriers for immigrants • basic comprehension barriers • translators & confidentiality barriers	4/12 5/12
VCT & non-language related barriers for immigrants • lack of knowledge about the health care system, or community resources • lack of use of screening services by immigrant women	3/12 1/12
Sociological phenomenon in relation to HIV stigma • concerns about being negatively judged in association with HIV risk or HIV • concerns about talking about HIV or related topic • concerns about being labelled in association with HIV/AIDS	8/12 10/12 3/12
Practitioner/Practice characteristics and barriers to decision making	
Practitioners & VCT counselling • challenges with cross cultural counselling	8/12
Macro-level programming & service delivery • conceptual issues in programming for multicultural populations • non-integrated HIV services • time restraints for VCT in family practice settings	4/12 8/12 5/12
Resource availability and access • lack of access to health services, particularly identified entry points to VCT • limited availability or funding of immigrant health services	4/12 10/12

5.2.5 Decisional Roles

The family doctor was identified to have a key role in decision making. Several practitioners also noted the important role of allied health care workers such as health promoters, outreach workers, multicultural workers, and crises support workers in CHC settings. These allied health care workers were perceived to offer outreach services and make referrals to HIV/STD testing.

Practitioners, supportive workers, and close friends were generally perceived to provide support, or advice so that women could make the decision on their own (*"I think usually there is someone, a supportive person that has either told them or accompanied them or told them about a service that they could have confidence in it. But there is rarely more than one.They have maybe one supportive person. Usually, more often, <it is> a worker other than someone from the community or a friend. Sometimes a sister if they were very close."* ; *" I don't think I have had somebody saying, 'My partner tells me that.' I find that sometimes girl friends or friends, not necessarily partners, will be the ones encouraging the client to be tested."*).

On the other hand, partners were perceived to offer both support, and hinder decision making through the threat of withdrawing support (*"Sometimes the husband has been involved directly and encouraged testing but also sometimes the husband doesn't want anyone to be tested and the woman feels as though she's kind of sneaking around. She has her own fears, <and> worries."*; *"I think by her saying, 'I do want HIV testing', he <the woman's spouse> was feeling like that means, 'You think I fooled around on you.' So there is definitely spousal influence."*)

5.2.6 Decision Support Resources

Practitioners highlighted several resources that could potentially enhance effectiveness and access to VCT and related services. For example, they stressed the importance of culturally acceptable VCT strategies, although respective opinions varied in detail (*"Practitioners would benefit from knowing about culturally-appropriate support sources that are in the community for post-test referral."* ; *"<It is> important to understand the differences in communicating about sexuality in different cultures."* ; *"I would like to know how immigration law impacts acceptability to testing for this group."*). Furthermore, many encouraged contextual changes to VCT. Examples included: 1. integrating VCT education into a broader curricula of services (i.e. prenatal care packages, women's health booklets); 2. increasing time for VCT in

family practice; 3. increasing the availability of immigrant health services, particularly outreach and language services; and 4. improving the target group's access to health care services.

Practitioners often encouraged the integration of HIV information into a broader package of services to overcome patient worries about confidentiality. Examples of such "integrated services" at the point of care were brochures on prenatal care and general women's health topics available at clinics (*"The health department did a 'Passport to women's health' once. A little booklet, and it went through osteoporosis, menopause, one thing after another. Cervical cancer was maybe slipped in there too ...And if HIV prevention was slid into something like that with very simple pictures and simple messages, that I think is the best."*). Practitioners also encouraged the integration of HIV information into educational/health promotion programs offered by CHCs and social service organizations attended by the target group (i.e. breastfeeding clinics, "Fun and Fitness" programs, vocational and language training programs). Such integrated programs were considered to be effective because they were perceived to:

- Create a supportive environment (*"Informal group meetings where women can hear other women's concerns, struggles...Hearing other people normalizes the issues for them"*)
- Package HIV information in a non-threatening way while maintaining confidentiality (*"This way the women can go to the group without <the> fear of being identified."*)
- Provide an opportunity for the target group to receive information on a topic they would otherwise not identify with (*"You have to integrate the information in programs like 'Fun and Fitness' where you throw in a little HIV information. Otherwise, with HIV specific programs you are not going to get people showing up because they do not think it has anything to do with them."*)

Practitioners perceived public education and outreach on HIV/AIDS to be another important resource. Potential venues for outreach involved stakeholders within and outside the formal health care system (i.e. educational pamphlets at the point of immigration, community outreach clinics, high school drop-ins for youth,

advertisements on public transportation, ethno-cultural newspapers and radio programs, anonymous telephone hotline, and public health “*posters celebrating cultural diversity*”). A few practitioners also recommended partnerships with the “*diversity business*”. When probed further, these practitioners identified ethno-cultural associations and businesses serving ethno-cultural communities to be key stakeholders to effective HIV outreach interventions (i.e. ethno-cultural hair salons, grocery stores and restaurants). Two practitioners mentioned the success of a HIV outreach program with Ottawa’s ethno-cultural communities called “Operation Hairspray”, a program operated by Ottawa Public Health that trains barbers and hairdressers in ethno-cultural barbershops to provide HIV/AIDS education to their clients through peer education (50). Practitioners also mentioned the importance of outreach through the “*shakers and movers*” in the faith-based communities because “*they are well respected*”. Some even encouraged the engagement of youth groups through faith-based communities (“*Like if the religious body -if it’s a church, for example- is doing things amongst the youth. If they are putting it <HIV information> out in the open, then that would be terrific.*”)

In addition, practitioners emphasized the importance of appropriate language services at the point of care. On the availability of language services at CHCs, one practitioner commented, “*We have funding for cultural interpretation. All community health centers have funding for it. I think it’s the responsibility of the community health center to know its population. I mean, almost everything we have in English here we also have in Somali because we have a high percentage of Somali folks that utilize our services and we cater to that.*” Although many practitioners articulated that CHCs were offering more language services than mainstream health care organizations, they did not always perceive these resources to meet the needs of their catchment’s populations. On this subject, one practitioner disclosed, “*There are a lot of women from Haiti <and> it’s wonderful because we can speak French with them and we can reach them*”. However, the same practitioner also cautioned: “*We <still> get a lot of people that need to come in with their <own> translator. And we always worry that we are not*

giving as much information as we can.... <We need> more written information in the different languages. I have lots of information in French and English. But those posters for anonymous testing, I don't have any in Arabic or in Somali." Other practitioners based at CHCs voiced similar concerns.

When talking about resources that enhanced the effectiveness of VCT, practitioners stressed the benefits encompassed by the multidisciplinary nature of care provided at the CHCs (*"We have meeting places, informational sessions, crises workers who they <clients from the target group> can go to for anything. We have multicultural workers who would probably had some encounters with these people in their own struggles to stay in Canada"; "Well, as I was saying to you, the outreach program that we have and the health promoters we have go into the community. Sometimes the nurse practitioners will do presentations and stuff. And sometimes we have the youth workers involved as well, with youth presenting to youth. So those are the resources within our building."; "Our nurses are very, very big proponents. And you know, we have crises workers, outreach workers, lactation consultants, mum and baby groups and the message about HIV/AIDS is coming out loud and clear at these levels. And a lot of the programs are offered out here".*)

Furthermore, practitioners offered their perspectives on the relationship between the duration and quality of VCT. For example, contrasting the experiences of practitioners who worked in capitation versus fee-for-service settings, one practitioner explained, *"In my experience, the family doctor has the least time and the least experience with giving pre and post test counselling. And that's a function of the fee-for-service system and how busy their practices are. In the community health centers or another set up where doctors are salaried, it's less of an issue."* Another, articulating the benefits of longer consultations at specialized testing sites, shared, *"And also, <with> the shortage of doctors and the pressure of doctors now, many will not take the half or three-quarters of an hour in pre-test counselling because they simply can't afford to, whereas in the anonymous program, it's part of the package."* Some practitioners also talked about the relationship between duration of counselling and the quality of risk

assessment in the two types of settings (*"And <the clients> may disclose to one of the <allied health> workers their need to be tested. But I would say that it's in a more trusting environment that this happens. I am not sure it happens as much- to be sure- in a family practice, fee-for-service system. And I hate to say that but there's so much more <needed> to give <the clients> the comfort level and the time to actually discuss the issues."*)

And lastly, practitioners perceived health care access be an important resource for the target group. In particular, they emphasized the importance of access to common VCT entry points discussed earlier, such as preventative screening services, and annual health exams. For example, one practitioner explained, *"And the things that would affect their decision <to test for HIV> would be their access to periodic health exams and PAP tests because that leads to questioning around life habits and sexual behaviours and so on."* Others talked about the importance of access to a family doctor: *"I think the <family> doctors are the ones who have the license to raise this topic, really."* Some practitioners also highlighted the importance of making informational services about VCT accessible, particularly for those with concerns about confidentiality issues (*"All this information should be done in a way that can reach people"; "<Resources> should be made more easily available so that they do not have to come out for information. Certainly this group can go to a community health center to acquire that information but that's kind of coming out in the open for some, isn't it? And telephone hotlines... I would make them available in health centers or in universities. But I would stress the hotline because it's more readily available, more private"*).

Table 10: Practitioner perspective on potential decision support resources

Variable	Frequency Counts, N=12
Practitioners & VCT counselling	
• adherence to CMA guidelines on VCT	10/12
• adaptation of VCT to the needs of the target group	10/12
Macro-level programming	
• integrated HIV services	9/12

• multidisciplinary care environment of CHCs	9/12
• scope for longer VCT consultation at specialized sites	4/12
• public outreach services	11/12
Resource availability and access	
• improved access to primary health care/entry points to VCT	10/12
• availability of resources at sites frequently accessed by the target group	7/12
• increased availability/ funding of immigrant health services	10/12

CHAPTER 6: DISCUSSION AND CONCLUSION

6.1 Discussion

Patient and practitioner perspectives converged on several issues. First, both groups revealed similar preferences for HIV testing options. The advantages for anonymous testing were associated with increased client control over disclosure of test results and their consequences; the disadvantages were linked to poorer follow-up, continuity of care, and partner notification.

Secondly, both groups identified the relationship between HIV stigma and VCT decision making for the target population. In fact, stigma variables were identified to have a cross-cutting effect on all domains of the ODSF. For example, findings revealed that the target group had concerns about the consequences of HIV stigma in their personal lives (i.e. loss of social support associated with the negative labelling of HIV-positive individuals), when accessing health services (i.e. loss of confidentiality when seeking HIV-specific services; the use of translators during VCT), and in the broader context (i.e. institutional discrimination, jeopardizing access to health care, immigration, or employment). Consequently, preferred decisional roles (i.e. preference for anonymous decision making, or with a confidential and trusted source) and recommended resources also reflected this concern (i.e. integrated HIV services, a non-targeted approach to VCT, and public education on HIV).

In addition, both patients and practitioners encouraged the availability of educational resources through health care access points, and places in the community frequented by the target group. While the former often identified sites such as immigration service organizations, ethno-cultural and faith-based associations, and schools, the latter cited CHCs and family physician offices. Moreover, both groups encouraged a wide variety of formats for these types of resources.

And finally, both groups stressed the need to adapt VCT to the needs of the target group. For example, both patients and practitioners advocated practitioner role in increasing knowledge about testing options and their consequences, and minimizing the impact of HIV stigma through education and counselling. In addition, both groups displayed concerns for improved availability and access to immigrant health services, particularly, language services.

Results also revealed key differences in patient and practitioner perspectives. Patients tended to emphasize barriers at the level of practitioner/patient interaction, whereas practitioners focused on barriers that moderated the context within which VCT was delivered. This result is likely linked to different patient/practitioner perspectives on VCT, and may in part also reflect the patients' relative unfamiliarity with the health care system, as implied by demographic data collected as a proxy for this variable (i.e. years of residence in Canada). Also, while the patient group as a whole did not express concerns about the target group's lack of basic knowledge about HIV (In fact, some made statements to the contrary), practitioners did. The former, when talking about knowledge deficit, solely expressed it terms of the need for increased awareness of HIV services, and their benefits and harms, particularly ART. This finding may highlight an actual gap, or an artefact of volunteer bias, as most patients who chose to participate in the study were interested and informed about the topic.

Interesting too were differences in patient/practitioner perspectives on potential resources, particularly with reference to concepts of access and availability. While both had similar views on the types of resources that would benefit the target group (i.e. public education, availability of written materials etc), they had distinct conceptual ideas on how these resources ought to be made available to the target group. Specifically, patients reflected on intersectoral approaches to resource distribution, whereas practitioners tended to highlight the importance of supportive structures within the formal health care system. For example, patients generally expressed the need for resources in the community involving sectors broader than the formal health care system (i.e. language and vocational schools, community centers, ethno-cultural

associations and businesses), and emphasized the important role of these organizations to act as knowledge brokers, particularly for individuals with barriers in accessing health information and services. Practitioners, when talking about access, tended to emphasize the need for the target group's to access primary health care, particularly perceived entry points to VCT. Moreover, when referring to knowledge brokers, practitioners highlighted the importance of allied health workers at CHCs (i.e. cultural interpreters, health promoters, outreach workers, and multicultural workers)-resources that were generally accessible to individuals with access to the formal health care system.

Furthermore, while all patients perceived the target group to be unaware of options around testing, only a fraction of the practitioners highlighted this as a concern. While this is an important finding, it is difficult to ascertain the extent of practitioner concern on this issue, as previous studies show that implementation of VCT guidelines, which mandate practitioners to inform their clients about VCT options, depend on practitioner knowledge and attitudes (16, 20), outcomes which were not studied. Furthermore, the nature of the questionnaires also made it difficult to establish this issue with certainty, as the question on the target group's knowledge of testing options was not posed directly.

Also, a far greater percentage of patients identified their family doctor to be an important player in decision making than the practitioners. Moreover, unlike the practitioners, none of the patients identified other allied healthcare workers as important to decision making. Recruitment methods may in part explain this finding as all patients were recruited from a single site (a family medicine practice), whereas the practitioners were selected from several CHCs and AHTCs, where roles of different clinical disciplines may vary.

6.2 Conclusion

In summary, the needs assessment interviews revealed that patients were unaware of the options available to them for VCT. Furthermore, when informed about these options, patient preferences towards them were observed to be aligned with practitioner preferences. These included shared perspectives on the pros and cons of the anonymous testing (i.e. enhanced confidentiality and control over testing consequences versus poorer post-test follow-up and continuity of care). Both groups also highlighted the issue of stigma and negative outcomes associated with testing that created barriers or contributed to delays in women receiving testing. The target group was perceived to prefer anonymous testing, and both informant groups recommended that information and decision support regarding HIV testing be provided via non-targeted strategies, and integrated within a broader package of health and educational services. In addition, patients and practitioners also recommended the importance of adapting VCT strategies to the needs of the target group, and encouraged increased availability and access to immigrant health services, including resources that help the target group to navigate the health care system. However, while patients tended to encourage intersectoral approaches to resource distribution (i.e. partnerships with immigration, education, business, and NGO sectors), practitioners emphasized supportive structures within the formal health care system (i.e. allied health care workers).

6.3 Study Limitations

These findings must be interpreted in consideration of some of the limitations of this study. The small sample size restricted sub-group analysis using hypothesized confounders related to patient and practitioner characteristics. That said, it must be noted that sample size required for saturation was consistent with sample size used in other needs assessments based on the ODSF (60, 97, 98), and expert opinion on sample size requirements for this type of study design (i.e. study guided by a dominant framework, semi-structured interviews, and a relatively homogenous sample of key informants) (95, 96).

Also, volunteer and sampling bias may have influenced some findings. As highlighted, self selection of participants may have limited the interpretation of the results. For example, patients who participated in the study tended to be informed about facts about HIV risk and transmission, and this variable may be correlated to certain ODSF outcomes. Similarly, the implications of eligibility criteria (i.e. access to health care, ability to speak English) may also pose this problem. Self-selection may have also attributed to non-response bias. As discussed previously, individuals affected by HIV stigma may have been less inclined to participate in the study, as may have individuals less acquainted with the Canadian health care system, or those with negative attitudes towards research in general (cross-cultural differences in how the term “research” is interpreted may also have important implications here). It is difficult for us to confirm the reasons for non-response bias as we did not collect any descriptive data on women who declined to participate, or withdrew from the study. We did, however, collect quantitative data on recruitment: Of the eleven women recruited, one was lost to follow-up (due to relocation), one withdrew from the study after accepting to participate (reason not known), and one was excluded because she did not fully meet the eligibility criteria (ability to speak English at the level of the questionnaires).

In addition, the possibility of recall and investigator bias cannot be overlooked, although steps were taken to minimize these limitations. Furthermore, the semi-structured format of the tool was not designed to investigate some emergent themes that merited in-depth analyses. In the future, an ethnographic or phenomenological approach is recommended for exploring the relationship between socio-cultural variables, HIV stigma, and HIV testing for this population²⁹. However, before such

²⁹ Examples of questions researchers could investigate using phenomenological or ethnographic methods in the future are:

- Do social determinants of health (i.e. race, culture, gender, socioeconomic status etc.) place women from HIV endemic countries at increased risk for HIV infection? And if so, why?
- What barriers do women from HIV endemic countries face when seeking HIV-related information and care, including testing? How can these be overcome?
- How do attitudes, beliefs, and socio-cultural norms impact acceptability to HIV testing for this population?
- What types of micro (individual), meso (family or household) and macro (community and broader) level interventions would be effective in combating HIV stigma and discrimination?

research is undertaken, the development of research ethics that address the psychosocial harms of HIV stigma need to be considered. For this purpose, research methodologies created for vulnerable populations that frame ethical issues outside the scope of post-positivist research (i.e. feminist, or Aboriginal research methodologies) may have important insights since they raise questions about values, objectivity, beneficence, knowledge paradigms, ownership, cultural competency, and transparency in research (87).

And finally, we must acknowledge an important limitation related to generalizability, and representativeness. Since the framework allows for the selection of key informants, it is important to reflect on the representativeness of the informants chosen for this study³⁰. In our study, pilot testing revealed that we had to consider tradeoffs between ethical issues and representability. The outcome was that women from the target group were not interviewed because practitioners involved in the pilot tests showed concerns about the risk of disclosure of sexual violence/ trauma by the participants (the rate, which according to the practitioners, were “very high” among refugee women). These practitioners argued that if participants were asked questions about HIV testing from a third person perspective, they would be less likely to talk about their personal experiences in relation to testing, and hence, less likely to disclose any personal information about sexual history and HIV risk. In addition, pilot testing also revealed that interviewing informants instead of the target group would enhance data quality and yield higher recruitment rates (due to the relative ease with which women could talk about a stigmatized topic from a third person perspective). For this purpose, we conducted our interviews with the informant groups.

Moreover, the generalizability of this study could have been enhanced by maximum variation sampling, a type of purposive sampling technique employed to enhance

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- Does HIV stigma impact men and women from HIV endemic countries in different ways? And if so, how?

³⁰ According to the ODSF, the target group refers to individuals facing a difficult decision, and key informants, individuals who have important insights into the decision making needs of the target group, and is willing to share that information (70). In our study the target group was presented by reproductive age immigrant and refugee women from HIV endemic countries living in Ottawa who were facing the decision to test for HIV. The informant group, on the other hand, was represented by a slightly broader sample: reproductive age immigrant and refugee women from HIV endemic countries living in Ottawa who were facing or had faced the decision to test for HIV, or knew others who had, and were willing to speak on their behalf.

diversity in study samples (88, 89). In our case, we could have selected patient informants from the same sites as the practitioners. However, due to the low response rates we experienced during recruitment (once again, related to HIV stigma), we used a more pragmatic sampling approach.

6.4 Implications for Practice

Study findings emphasize the importance of multiple and multilevel interventions that involve: 1. adapting counselling approaches to address the decision support needs of women from the target group; 2. integrating decision support strategies into practice that facilitate decision making based on the best available scientific evidence and personal values, and in particular, decision aids that increase knowledge and clarify values towards available testing options and their consequences, and offer support to cope with HIV stigma; 3. understanding contextual factors that decrease the effectiveness of VCT in the care context, and; 4. enhancing awareness of broader issues that affect access and availability of healthcare and navigational resources for the target group, and immigrant populations in general.

6.4.1 Adaptations to Counselling to Address the Decisional Support Needs of the Target Group

As highlighted earlier, both informant groups advocated supportive counselling strategies that increased information about available testing options and their consequences, and minimized the impact of HIV stigma. Moreover, patients offered specific directives for adaptive counselling strategies; they encouraged practitioners to: 1. articulate the purposes of VCT; 2. use a non-targeted approach to VCT; 3. detach negative moral connotations associated with HIV risk; 4. emphasize risk reduction and treatment choices and 5. be sensitized to contextual issues experienced by immigrants and refugees new to Canada.

6.4.2 Supplementing VCT with Tailored Decision Support

Gaps in the decision making needs of the target group with respect to knowledge, value clarification, and support may also be met through a decision aid that supplements pre and post test counselling. In particular, a decision aid that provides information on available testing options, and their pros and cons, clarifies values towards these options (i.e. through simple, explicit valuation exercises), and offers support to cope with social pressures (i.e. with the help of a trusted family doctor, lay health worker, or a peer support group) may be especially relevant for this group.

Furthermore, special attention ought to be paid to developing a decision aid that is acceptable to the target group, since a majority of the patients interviewed (and practitioners to a lesser degree) stressed the crucial importance of culturally relevant/appropriate information delivery and packaging. Some of their key recommendations included the use of culturally acceptable channels for information delivery (i.e. access to knowledge brokers through intersectoral partnerships, availability of lay health workers, appropriate language services), and information dissemination strategies that addressed the social consequences of HIV stigma (i.e. peer-facilitated women groups, the integration of HIV information into a wider package of health and education services, public education on HIV). Given these recommendations, a health coach model³¹ for decision support may be most appropriate for this group.

6.4.3 Understanding Contextual Factors that Decrease the Effectiveness of VCT for the Target Group in the Care Context

Both informant groups talked about factors they perceived to affect the effectiveness of VCT in the care context. When speaking of barriers on this topic, patients tended to focus on ineffective counselling strategies (linked to lack of cultural competency of the practitioners, or approaches that exacerbate HIV stigma), whereas practitioners highlighted broader, system-level issues (i.e. lack of practitioner training on cross

³¹ In this context, a health coach is a health professional trained in decision support who uses an evidence base knowledge base to help individuals facing difficult health decisions to make informed, value-based choices. They achieve this by implementing coaching strategies that enable individuals to take more active roles in decision making (70).

cultural counselling, time restraints for VCT in family practice, programming issues for multicultural populations).

Consequently, potential resources reflected on solutions to overcome these barriers. As highlighted earlier, patients provided very specific recommendations on how counselling strategies could be adapted to meet the needs of the target group. While highlighting similar needs, practitioners also discussed system-level resources that helped them better support the needs of the target group (i.e. allied health care workers who referred women to testing or were involved in outreach activities, longer time for VCT/ VCT outside the fee-for-service setting etc).

6.4.4 Awareness of Broader Issues that Affect Access and Availability of Health care and Navigational Resources for the Target Group

Lack of immigrant health services was a concern highlighted by both informant groups. For example, both groups underscored structural issues that limited the availability of healthcare and navigational services for immigrants and refugees, particularly language services. Moreover, results revealed that although these resources were sometimes available, they were not always perceived to be acceptable. Thus, both informants interviewed indicated the importance of delivering VCT and related services in a format that was acceptable to the target group (Please see Sections 6.1 and 6.2, and discussion above on decision aid acceptability).

6.4.5 General Considerations

And finally, to be effective, multilevel interventions highlighted above need to consider the impact of gender, socio-cultural, and economic barriers on the physical and mental health of immigrant and refugee women, and their families (102, 103). These include variables related to age, gender, educational attainment, socioeconomic status, cultural background, ethnicity, and immigration status, to name a few. Moreover, they also include factors related to the immigration experience, and post-immigration stress, factors that have been shown to impact the health seeking behaviours and health status of immigrants and refugees (71, 72). For example, consider the following

barriers that have been shown to adversely impact health of immigrant and refugee women living in Canada: 1. language barriers that restrict access to health/ social support resources, and create a dependency on others for translation; 2. isolation, loss of social support, and social dislocation as result of migration, and ; 3. issues pertaining to poor working conditions that create poor living standards (i.e. excessive workload, low wages, deskilling due to lack of professional accreditation). Hence, this is one of the reasons that the four Canadian Centers of Excellence for Women's Health advocate the need to frame the immigration experience itself as a health determinant, and in particular, the need to develop a framework that describes how gender, socio-cultural, and economic factors intersect with the immigration experience to impact the health of Canadian immigrant and refugee women- a conceptual base that would be most appropriate for developing effective decision support interventions for the target group (104).

CHAPTER SEVEN: THEORETICAL VERIFICATION OF KEY FINDINGS

It is important to evaluate how the findings of this study correspond to local qualitative research on the epidemiology of HIV among persons from HIV endemic countries. As highlighted earlier, there are limited data on this topic. Moreover, where data does exist, they are limited to a few sources (The majority of research studies on factors that impact the HIV epidemic among African and Caribbean communities in Canada have been initiated by ACCHO and its partner agencies, particularly Women's Health in Women's Hands (WHIWH) and the Department of Public Health Sciences at the University of Toronto). However, the sparse body of literature that does exist will be examined below.

Prior to our research, the only Canadian study that had examined factors affecting the quality of decision making among immigrant women with respect to VCT reported important barriers to informed decision making. To study the experiences of immigrant women with Ontario's Prenatal HIV Testing Program, and in particular, their understanding of informed consent during prenatal HIV testing, a researcher from WHIWH conducted focus groups and in-depth interviews with twenty-nine immigrant women of African, Caribbean, South Asian and Latin American descent, and eight prenatal providers. Results showed that most women interviewed did not receive necessary information during VCT to permit informed decisions. In particular, most had limited information on HIV transmission, testing and treatment options. Also, reasons cited for not testing included the failure to be informed or offered testing by their practitioner, lack of self-perceived risk, concerns about the implications of testing on immigration, fears of stigmatization and isolation, and lack of health coverage (46). Albeit the populations interviewed in this study differed slightly from the target group of our needs assessment (the former included immigrant women from different backgrounds, including women from HIV endemic countries, who had undergone prenatal HIV testing in Ontario), our findings are remarkably consistent with this study (Compare with quotes under section 5.1.4).

Furthermore, key themes identified in our study correspond to the findings of research studies undertaken by ACCHO, Public Health Ottawa and local ASOs, such as the Ottawa-Carleton Counsel on AIDS (OCCA). In 2001, a group of researchers from WHIWH conducted in-depth interviews with service providers in Toronto to investigate the social determinants of HIV infection, and underlying gaps in the provision of HIV/AIDS services for African and Caribbean women. The results of this study paralleled some of our findings. For example, this study revealed that some of the factors influencing the spread of the HIV epidemic were:

- the perception that the HIV epidemic was happening on the peripheries of the community; myths about HIV; women not getting tested for HIV or not wanting to know their HIV status; women not disclosing HIV status to their partners
- contextual factors (i.e. economic, socio-cultural, gender, religion etc.) and their role in increasing susceptibility to HIV infection, or limiting the ability of HIV positive women to access treatment and care services

In addition, the service providers in this study highlighted programming barriers that were also identified by the practitioners we interviewed. For example, service providers interviewed outlined that most of the HIV/AIDS prevention and treatment services presently available had been developed to meet the needs of the groups that first emerged into the HIV epidemic in Canada, primarily men who have sex with men. (Compare with quotes under section 5.2.4) (47).

A few research studies with this population also present the adverse impact of HIV stigma on psychosocial health outcomes, and access to screening and treatment services. For example, the findings of two large community consultations conducted by ACCHO (2001- 2002) involving key stakeholders in African and Caribbean communities in Toronto reported some of the multiple dimensions of HIV stigma we observed: *"Stigma was identified as a significant issue that contributed to isolation, depression, substance use, secrecy of HIV status, hesitation or denial of access to HIV related services, ... and ostracism."* ; *"Disclosure is not occurring; people are not accessing testing and treatment which increases disease progression and infection rates."* ; *"Either due to immigration status or illness (or both), those who are HIV*

positive have limited opportunities for consistent employment. This greatly affects their access to financial independence.” (43, 44)

Furthermore, the conclusions derived by an exploratory research study on the barriers to effective HIV/AIDS service delivery for African and Caribbean women were consistent with the views of practitioners and patients we interviewed. In particular, this report highlighted the gaps in:

- culturally appropriate service provision, and in particular, knowledge amongst service providers of cultural practices that increase the risk of HIV transmission and reduce the effectiveness of programs, and the impact the target group’s health-related beliefs, values and norms have on acceptability to these services
- a contextual understanding of factors that exacerbate the HIV epidemic among women from HIV endemic countries, including socio-cultural and economic factors such as poverty, unemployment, discrimination, gender-based violence, harmful cultural beliefs, values, and norms (48) (Compare with quotes under sections 5.1.4 and 5.2.4)

In addition, the types of resources that were encouraged by the informants in our study were also consistent with recommendations outlined in existing literature. For example, a report published by OCCA (2005) concerning HIV/AIDS service delivery planning for African and Caribbean communities in Ottawa listed recommendations that supported the findings of our study. This report concluded that HIV-related programs for African and Caribbean communities in Ottawa should ensure confidentiality, and be delivered in a culturally competent manner. It furthered that written educational information on the HIV-related services should be distributed by settlement organizations to immigrants and refugees new to Canada. Moreover, this report added that staff at mainstream organizations need to be educated about the epidemiology of HIV/AIDS in Ottawa’s African and Caribbean communities, including contextual risk factors associated with HIV transmission in this population (49). Similarly, a report published by Ottawa Public Health (2003) on public health strategies for reducing HIV incidence among immigrants and refugees from HIV

endemic regions, outlined that access to information about screening and treatment HIV services was hindered by the need for confidentiality. Furthermore, this report highlighted the importance of further research with the affected communities on beliefs, practices, values and norms related to HIV prevention, and access to prevention and treatment services (50) (Compare with quotes under sections 5.1.6 and 5.2.6)..

Also, it is important to note that the conceptual underpinnings of some of the resources outlined in our study support the findings of a 2003 report published by the Canadian Centre on Minority Affairs (Health Canada) on health promotion strategies for Canadian African and Caribbean communities (including immigrant populations). The authors of this report conducted a comprehensive literature review and consultations with thirty-two key informants about issues affecting health care access and delivery among Canadian African and Caribbean communities. Results revealed the importance of providing practitioners with information on health-related beliefs and values of the African and Caribbean populations they served, and the use of culturally appropriate outreach strategies to raise awareness about prevention and treatment of a range of health conditions. Furthermore, recommendations specific to HIV programming and service delivery included the development of appropriate guidelines for HIV testing (including guidelines for partner notification), and further research on the psychosocial determinants of HIV transmission among members of the affected communities (100).

CHAPTER EIGHT: STRATEGIES FOR KNOWLEDGE DISSEMINATION

Since the initiation of this research project, plans were made to disseminate the results through several channels, including research conferences, peer-reviewed journals, and training workshops for practitioners who provide VCT at specialized HIV testing sites in Ottawa.

8.1. Completed at the time of write-up

Preliminary findings of this study were presented at a few conferences. At the 5th Canadian AIDS Society Skills Building conference (October 2005), the results of this study were presented to members of ASOs, research institutions and NGOs in Canada working on a variety of HIV-related research and advocacy issues. At the 3rd International Shared Decision Making (ISDM) conference (June 2005) on shared decision making in diverse health care systems and cultures, this study was presented to practitioners and researchers with interests and expertise in health-related decision support (Please refer to appendices M & N).

The results of this study were also submitted to a peer reviewed journal, Patient Education and Counseling (PEC) in January 2006. In April 2006, PEC confirmed that it will publish this study as part of its special series on the ISDM conference in 2006-2007.

8.2. To be completed

We also hope that in the future the results of this study will be presented at the Canadian Public Health Conference (May 2006), and the upcoming international HIV/AIDS conference that will be hosted in Toronto, AIDS 2006 (August 2006).

Additionally, in collaboration with Ottawa's Regional Director of Anonymous HIV testing, the primary investigator will conduct a workshop, where the main findings of

this study will be presented to practitioners providing anonymous HIV testing through CHCs and AHTCs in Ottawa. Both practice implications and methodological limitations will be discussed at this workshop (upcoming in June 2006).

Furthermore, a fact sheet authored by the primary investigator and published by the Interagency Coalition on AIDS and Development will integrate the findings of this study. This fact sheet, which will be targeted to a wide audience of policy makers, will become available online at an open access site on the internet (<http://www.icad-cisd.com/content/pub.cfm?ID=9&lang=e>).

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APPENDIX A

AN OVERVIEW OF THE OTTAWA DECISION SUPPORT FRAMEWORK

Assess Needs	Provide decision support	Evaluate
Perception of Decision: Knowledge Expectations Values Decisional conflict Stage of decision making Predisposition Perception of Others: Perception of others' opinions and practices Support Pressures Roles in decision making Resources to Make Decision: Personal: Previous experience, self-confidence, motivations, skills in decision making External: Support from social networks and agencies Characteristics: Client: age, sex, marital status, education, occupation, locale, culture, medical diagnosis and duration, health status Practitioner: age, sex, education, speciality, culture, practice locale, experience, counselling style	Provide access to decision re: Health situation Options Outcomes Others' opinions & choices Re-align expectations of outcomes Clarify personal values for outcomes Provide guidance and coaching in: Steps in decision making Communicating with others Handling pressures Accessing support and resources	Decision making: Reduce decisional conflict Knowledge Realistic expectations and norms Clear values Agreement between values and choice Implementation of chosen options Satisfaction in decision-making Outcomes of decision: Persistence of choice Improved quality of life Reduced stress Reduced regret Informed use of resources

APPENDIX B

DETERMINANTS OF DECISIONS IN THE OTTAWA DECISION SUPPORT FRAMEWORK

Perception of the Decision	
Knowledge	Knowledge of the health problem, available options and their potential outcomes
Expectations of outcomes	Perceived likelihood or probability of outcomes of the options
Values for outcomes	Desirability or personal importance of outcomes of the options
Decisional conflict	The uncertainty about the course of action to take; Occurs when an individual faced with two or more options is uncertain about which option to choose.
Stage of decision making	1. Pre-contemplation: not thinking about options; 2. Contemplation: considering options; 3. Preparation: close to selecting an option; 4. Implementation: taking steps towards implementing an option; 5. Maintenance: Maintaining an option, or if the decision is reversible, revisiting the options.
Timing	Time pressure in making a choice
Choice predisposition	Predisposition towards certain options
Perception of Others	
Perception of others' opinions and practices	Perceptions of what other decide or recommend
Support	Lack of support in decision making, or mismatch between preferred role and actual role in decision making
Pressure	Social pressure to choose a certain option
Roles in decision making	Actual versus preferred role in decision making
Resources to Make a Decision	
Internal resources	Self-efficacy and skills in decision making; Examples may include personal experience (previous exposure to the situation, options, outcomes and the decision making process), self-confidence (belief in one's abilities in to make a decision) and motivation (readiness and interest in decision making).
External resources	Resources from others that are required to make a decision; Examples may include social networks, professional associations, voluntary organizations, support groups, formal health care, social and education sectors
Participants' Characteristics	
Client/Patient	Age, gender, marital status, education, ethnicity, occupation, locale, culture, medical diagnosis and duration, health status etc.
Practitioner	Age, gender, clinical education and speciality, practice locale, years of experience, counselling style etc.

APPENDIX C

PATIENT RECRUITMENT PAMPHLET

Are you a woman of childbearing age from East or Central Africa?

Then please take a moment to read about this new study on decision support for voluntary HIV testing.

What is the goal of the study?

The goal of this project is to develop culturally appropriate support and educational materials that women and their doctors can use to make informed decisions about HIV testing.

Why is this study important?

HIV testing is the gateway to all HIV prevention, treatment and care. Culturally appropriate decision support for HIV testing may allow women to better understand HIV prevention and treatment options for themselves, their partners and children.

How do I benefit?

You may learn more about HIV prevention and treatment, the Canadian health care system and local organizations that provide job & language training. You will also receive \$25 for your participation.

Who is involved?

This study is being coordinated by investigators at the University of Ottawa and doctors and nurses at this clinic.

How do I learn more about the study?

For more information, please contact Deborah Vira at 613-241-6894.

Who do I contact if I want to participate?

If you are interested in participating, please tell a doctor or a nurse at this clinic during your next visit.



APPENDIX D

LETTER OF SUPPORT FOR PRACTITIONER RECRUITMENT

(Submitted on an e-mail list-serv, February 2005)

To: All Anonymous HIV Testing sites of Ottawa

Hi Everyone,

I am writing to ask for your assistance and support. An Ottawa University student by the name of Debjani Mitra has approached me about a research project she will be doing. This research project will focus on immigrant women and voluntary counselling and testing for HIV. This is a great opportunity for the Anonymous HIV Testing program in Ottawa to show our support to student research while at the same time having these results shared with us to help improve our program.

Debjani is hoping to interview all of you who provide anonymous HIV testing to clients from various ethnocultural backgrounds. This interview will be conducted via phone, or one on one. It will take approx 15-20 minutes of your time. I believe that it is important that we give Debjani our full support on this initiative. If you have any concerns about this, please let me know. Attached is more info on the research that Debjani is working on and the interview questions.

Please contact Debjani (613-241-6894) or myself for more information on this research.

Pascale Hough
Anonymous HIV Testing Program Coordinator
Somerset West Community Health Center

APPENDIX E

PERSONAL INTERVIEW QUESTIONS FOR PATIENT INFORMANTS

Good morning. My name is Debjani Mitra. I am a Masters student at the University of Ottawa conducting interviews with health practitioners and women to learn more about the challenges to involving women who are new to Canada in making informed decisions about voluntary testing for HIV/AIDS.

The information from this interview may be used to develop decision support strategies & educational materials for women about voluntary testing for HIV/AIDS. The interview will take about 30-40 minutes. All information in this interview will be kept private. At the end of the interview, please feel free to provide your feedback.

PERCEPTION OF IMPORTANT DECISION

1. Do you think women perceive options when making the test for HIV?

Probes:

☐ If yes, continue to next question

☐ If no, use hypothetical scenario: "Suppose women felt that had options about HIV testing, what would these options be?"

2. What options do you think women face when making the decision to test for HIV?

3. What do you see as the main good points & bad points of the options?

If talking about someone undecided about testing:

Possible Options	Advantages	Disadvantages
Take the test		
Not take the test		
Defer the test		

If talking about someone who has made the decision about testing but is unsure about testing options:

Possible Options	Advantages	Disadvantages
Nominal		
Non-nominal		

Anonymous		

4. Let us talk about the things that make it hard for women thinking about taking the HIV test. How do they feel when thinking about this decision?

Probes: Do you:

- ☐ Feel unsure about the decision
- ☐ Worry about possible negative outcomes associated with the decision
- ☐ Feel distressed or upset
- ☐ Constantly think about the decision
- ☐ Waver among options
- ☐ Delay making the decision
- ☐ Question whether or not it's important to know your status
- ☐ Other _____

5. What makes this decision more difficult for women?

Probes:

- ☐ Not having information about testing options, their benefits and harms
- ☐ Not having information about the likelihood of the benefits and harms of testing
- ☐ Unclear about what pros and cons are important to you
- ☐ Not having information on how others decide
- ☐ Feeling pressure from others
- ☐ Not having support from others
- ☐ Not having skills or confidence to make this type of decision
- ☐ Other _____

6. Who else may be involved in making this decision with them?

Probes: ☐ Partner or spouse ☐ Relative (specify) ☐ Peer ☐ Other _____

7. What is their (person identified in previous question) role in making this decision?

Probes: They.....

- ☐ Make the decision for the you
- ☐ Share the decision-making with you
- ☐ Provide support or advice you so that you can make the decision on your own
- ☐ Other _____

RESOURCES

8. Let us talk about the resources that may be helpful to women when they are thinking about HIV testing. How would they usually go about making the decision to test for HIV?

Probes: They would:

- ☐ Get information on options & pros and cons
- ☐ Get information on how likely the pros and cons of the options are
- ☐ Consider how important the pros and cons of the options are
- ☐ Get information on how others decide or recommend
- ☐ Find ways to deal with pressure
- ☐ Get support from others
- ☐ Other _____

9. What would help them to make this decision (i.e. the decision to test for HIV)?

10. What would get in the way of women making this decision?

11. What would help to overcome things that get in the way of women making this decision?

12. I will list possible ways to help women making the decision to test for HIV. Which of the choices do you think will be most useful to you?

☐ Counselling from health practitioner/ lay health worker

If yes, specify type of practitioner/ health worker _____

If yes, specify preferred gender of practitioner/ health worker _____

☐ Information materials

If yes, specify type of format

☐ Booklets, pamphlets ☐ Videos ☐ CD-ROMS ☐ Internet ☐ Peer support groups / workshops

☐ Other _____

If yes, specify language _____

If yes, specify location(s) information materials should be made available

☐ Community centers ☐ Schools (specify) ☐ Immigration service organizations ☐ Places in the community (specify) ☐ Family doctor offices ☐ Community health centers ☐ Other _____

PERSONAL CHARACTERISTICS

13. Age category: ☐ twenties ☐ thirties ☐ forties ☐ fifties ☐ sixties or more

14. What is the highest level of education you have completed?

☐ less than grade 9 ☐ high school ☐ college/ university ☐ post-graduate studies

15. How long have you been living in Canada? _____

APPENDIX F

PERSONAL INTERVIEW QUESTIONS FOR PRACTITIONERS

Good morning. My name is Debjani Mitra. I am a Masters student at the University of Ottawa conducting interviews with practitioners to learn more about the decision making needs of immigrant and refugee women from HIV endemic countries in making decisions about voluntary counselling & testing for HIV/AIDS. In particular, I am interested in examining challenges to involving women in making informed decisions in this context. Information from this interview may be used in planning decision support strategies and tools for practitioners who support women facing the decision about voluntary testing for HIV/AIDS.

The interview will take about 20 minutes. All information in this interview will be kept strictly confidential. At the end of the interview, please free to provide additional comments.

PERCEPTION OF IMPORTANT DECISION

1. What options do you think women face when making the decision to test for HIV?

2. What do you see as the main advantages & disadvantages of the options you have outlined?

Possible Options	Advantages	Disadvantages
Anonymous		
Non-nominal (identifier code instead of name)		
Nominal (full name)		

3. Let us talk about the things that make it hard for clients thinking about taking a HIV test. How do they feel when making this decision?

Probes: Do women:

- ☐ Feel unsure about the decision
- ☐ Worry about possible negative outcomes associated with the decision
- ☐ Feel distressed or upset
- ☐ Constantly think about the decision
- ☐ Waver among options
- ☐ Delay making the decision.
- ☐ Question whether or not it's important to know their status
- ☐ Other _____

4. What makes this decision more difficult for clients?

Probes:

- ☐ Not having information about testing options, their benefits and harms
- ☐ Not having information about the likelihood of the benefits and harms of testing
- ☐ Unclear about what pros and cons are important to them
- ☐ Not having information on what others decide
- ☐ Feeling pressure from others
- ☐ Not having support from others
- ☐ Not having skills or confidence to make this type of decision
- ☐ Other: _____

5. In the pre-test counselling context, what is your usual role in helping clients make this decision?

6. What factors make it difficult for you to support your client's decision making regarding HIV testing?

7. Who else besides yourself and the client is usually involved in making this decision?

Probes: ☐ Partner or spouse ☐ Relative (specify) _____ ☐ Peer ☐ Other: _____

8. What is their (person identified in previous question) role in making this decision?

Probes: They.....

- ☐ Make the decision for the client
- ☐ Share the decision-making with the client
- ☐ Provide support or advice for the client so that they can make the decision on their own
- ☐ Other

RESOURCES

Now we will talk about resources that may help women from the target group considering HIV testing.

9. How do clients go about making the decision to test for HIV?

Probes: They:

- ☐ Get information on options & pros and cons they have
- ☐ Get information on how likely the pros and cons of the options are
- ☐ Consider how important the pros and cons of the options are
- ☐ Get information on how others decide or recommend
- ☐ Find ways to deal with pressure
- ☐ Get support from others
- ☐ Other _____

11. What would hinder clients making this decision?

12. What would help to overcome things that hinder clients making this decision?

13. I will list possible ways to help clients making this decision. Which of the choices do you think will be most useful?

☐ Counselling from health practitioner

If yes, specify type of practitioner _____

If yes, specify preferred gender of practitioner _____

☐ Information materials

If yes, specify type of format

☐ Booklets, pamphlets ☐ Videos ☐ CD-ROMS ☐ Internet ☐ Other _____

If yes, specify language _____

If yes, specify location(s) information materials should be made available

☐ Family doctor offices ☐ Community health centers ☐ Anonymous HIV testing centers ☐ Other _____

14. Is there anything else that would help you, as a provider of VCT, do a better job supporting your clients' decision-making?

PERSONAL & PRACTICE CHARACTERISTICS

15. Age category: ☐ twenties ☐ thirties ☐ forties ☐ fifties ☐ sixties or more

16. Sex: ☐ M ☐ F

17. Practice Specialty/ Location: _____

18. For how long have you been offering VCT? _____



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APPENDIX G PATIENT CONSENT FORM

Principal Investigators: Dr. Annette O' Connor (RN, PhD), Dr. Peter Tugwell (MD)

Co-Investigators: MJ Jacobsen (RN, MEd), Debjani Mitra (Masters student), Dr. Kevin Pottie (MD)

Purpose of the Study

Investigators at the *University of Ottawa* and the *University of Ottawa's Family Medicine Center* are interested in learning more about the decision making needs of immigrant and refugee women of childbearing age who are considering voluntary testing for HIV. The results of this study will be used to develop decision support and educational materials that can help doctors and nurses help women make informed decisions about HIV testing.

Study Procedures

A doctor or a nurse at the clinic will give you a short information pamphlet about the study. If you are interested in finding out more about the study, they will ask for your permission to complete a phone follow-up. During the follow-up, the study will be described to you in full detail. If you show interest in participating, you will be requested to return to the clinic for an interview at a time convenient to you.

The interview will take 30-40 minutes. A female interviewer will conduct the interviews in English in a private setting at the clinic. During the interview, you will be asked questions about what makes it difficult for women to make the decision to test for HIV. At the end of the interview you will have the opportunity to ask questions and offer feedback.

Potential Benefits/ Risks

If you participate in the study, you may learn more about HIV/AIDS prevention and treatment. You will also receive information about local organizations that provide job and language training.

There are no known risks to completing the interview. If you experience discomfort or anxiety after the interview, a doctor or nurse at the clinic will be available to help you.

Compensation

For your out-of-pocket expenses, you will receive \$ 25.

Confidentiality

We will keep the information that you provide private. We will record an identification number instead of your name, and your record will be kept in a secure place where only the study team will have access to it. Also, your identity will not be revealed if the study results are published.

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☐ *General Campus Général*
510 chemin Smyrh Road
Ottawa, Canada K1H 8L6

☐ *Riverside Campus Riverside*
1967 prom. Riverside Drive
Ottawa, Ontario K1H 7W9

Voluntary Participation/ Withdrawal

Please note that your participation is completely voluntary and you may withdraw at any point without compromising your care at this clinic. Also, you have the right to not answer certain questions.

If you have any questions or concerns about the study, please contact Debjani Mitra at 613-241-6894. You may also contact the Chairperson of the *Ottawa Hospital Research Ethics Board* at 613-798-5555, ext. 14902 if you are concerned about your rights as a study participant.

I have read the description of the study and understand its goals and methods. I voluntarily consent to participate in this study.

Name of participant

Signature of participant

Date

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The Ottawa L'Hopital
Hospital d'Ottawa

**APPENDIX H
PRACTITIONER CONSENT FORM**

Principal Investigators: Dr. Annette O' Connor (RN, PhD), Dr. Peter Tugwell (MD)

Co-Investigators: MJ Jacobsen (RN, MEd), Debjani Mitra (Masters student), Dr. Kevin Pottie (MD)

Purpose of the Study

Investigators at the *University of Ottawa* and the *University of Ottawa's Family Medicine Center* are interested in learning more about the decision making needs of immigrant and refugee women of childbearing age who are considering voluntary counselling and testing for HIV (VCT). The results of this study will be used to develop decision support strategies and educational materials that can aid practitioners help women make informed decisions about HIV testing.

Study Procedures

The regional coordinator of the anonymous HIV testing sites will forward you an information pamphlet about the study. If you are interested in participating, you will be requested to release your contact information, whereupon the interviewer will call you shortly to schedule an interview.

The interview will take 20-30 minutes. An interviewer will conduct the interviews in English in a private setting. During the interview, you will be asked questions about what makes it difficult for women to make the decision to test for HIV. At the end of the interview you will have the opportunity to ask questions and offer feedback.

All interviews will be taped, and the tapes will be destroyed once the transcription process is complete.

Potential Benefits/ Risks

This study will aid practitioners like yourself develop culturally-appropriate decision support strategies that help immigrant and refugee women make informed decisions about VCT.

There are no known risks to completing the interview.

Confidentiality

We will keep the information that you provide confidential. We will record an identification number instead of your name, and your record will be kept in a secure place where only the study team will have access to it. Also, your identity will not be revealed if the study results are published.

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1967 prom. Riverside Drive
Ottawa, Ontario K1H 7W9

Voluntary Participation/ Withdrawal

Your participation is completely voluntary and you may withdraw at any point during the study. Also, you have the right to not answer certain questions.

If you have any questions or concerns about the study, please contact Debjani Mitra at 613-241-6894. You may also contact the Chairperson of the *Ottawa Hospital Research Ethics Board* at 613-798-5555, ext. 14902 if you are concerned about your rights as a study participant.

I have read the description of the study and understand its goals and methods. I voluntarily consent to participate in this study.

_____	_____	_____
Name of participant	Signature of participant	Date

_____	_____	_____
Name of investigator	Signature of investigator	Date

Thank you for your participation.

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APPENDIX I

RESEARCH ETHICS APPROVAL (OHREB)



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Research Ethics Board
Conseil d'éthique en recherches
798-5555 ext 14146, 14902 or 15072
Fax No. ~ 761-4311
<http://www.ohri.ca/ohreb/>

Friday, June 10, 2005

Dr. Peter Tugwell
Centre for Global Health
University of Ottawa
Institute of Population Health
1 Stewart Street, Room 312
Ottawa, ON K1N 6N5

Dear Dr. Tugwell:

Re: Protocol # 2005281-01H Developing a Decision Support Tool for Immigrant and Refugee Women
from HIV-Endemic Countries Considering Voluntary HIV Testing in
Canada

Protocol approval valid until - Friday, June 09, 2006

I am pleased to inform you that your study (listed above), the English Patient Questionnaire, the English Practitioner Questionnaire, the English Letter to Patients, the English Consent Form (Patients), and the English Letter to Practitioner were given expedited review by the Ottawa Hospital Research Ethics Board (OHREB) and are approved. No changes, amendments or addenda may be made in the protocol without the OHREB review and approval.

The validation dated should be indicated on the bottom of all consent forms and information sheets (see copy attached). Approximately two months prior to the expiration date listed above, a single renewal form should be sent to the OHREB office.

The Tri-Council Policy Statement requires a greater involvement of the OHREB in studies over the course of their execution. You must inform the Board of adverse events encountered during the study, here or elsewhere, or of significant new information which becomes available after the Board review, either of which may impinge on the ethics of continuing the study. The OHREB will review the new information to determine if the protocol should be modified, discontinued, or should continue as originally approved.

Yours sincerely,

Raphael Saginur, M.D.
Chairman
Ottawa Hospital Research Ethics Board

Encl.

rch

APPENDIX J

FULL DEFINITIONS OF DEDUCTIVE AND INDUCTIVE CODES

Table I: Inductive and deductive codes from patient interviews

Identifier #	Original definition	Revised 1	Revised 2
PERCEPTION OF TESTING OPTIONS			
21	Perceived pros of anonymous HIV testing (or the cons of nominal and non nominal HIV testing)	Same	Same
21:211	Client perceives VCT to be more confidential	Same	Same
21: 212	Client has more control over the negative consequences of testing positive	Same	Same
22	Perceived cons of anonymous HIV testing (or the pros of nominal and non nominal HIV testing)	Same	Same
22: 221	Client may not return to pick up HIV test results	Same	Same
22: 222	Client may not return for antiretroviral therapy/prophylaxis after finding out her (HIV positive) status	Same	Same
22: 223	There is no legal mechanism for partner notification	Same	Same
22: 224	Client does not have an established relationship the VCT provider.	Same	Same
MANIFESTATIONS OF DECISIONAL CONFLICT			
32	Worry about the consequences of HIV testing	Same	Same
33	Feel distressed about making the decision to test for HIV	Same	Same
37	Question the importance of testing	Same	Same
FACTORS CONTRIBUTING TO DECISIONAL CONFLICT			

41	Lack of knowledge of testing options and/or their consequences	Same	Same
45	Lack of support in making the decision to test for HIV	Same	Same
46	Perceived pressure in making the decision to test for HIV	Same	Same
48	HIV Stigma: Any measure of distinction among persons depending on their confirmed or suspected HIV serostatus (UNAIDS)	HIV Stigma: A sociological phenomenon characterized by moral judgement, silencing, and negative stereotypes of persons suspected to be at risk for or living with HIV/AIDS. HIV stigma can also be marked by social, institutional and internalized discrimination, as described below.	Same
48: 4811	The association of persons perceived to be at risk for HIV, or living with HIV/AIDS with moral impropriety	Same	Same
48: 4813	Concerns about talking about HIV	Concerns about talking about HIV and/or a related topic, or the perception of HIV as a "taboo" topic	Same
48: 4814	Negative labelling of those perceived to be at risk for HIV or living with HIV/AIDS	Negative stereotypes, or negative social labelling of individuals perceived to be at risk for HIV, or living with HIV/AIDS	Negative stereotypes, or negative social labelling of individuals perceived to be at risk for HIV or living with HIV/AIDS. This may include stereotypes on the basis of someone's country of origin, and ethnicity.
48: 4815	Concerns about the loss of confidentiality	Same	Same

	in the care context		
48: 4821	Social impact of HIV stigma	The social consequences of HIV stigma, which may include a broad range of experiences such as loss of support from family, partner, friends; stigma by secondary association; ostracism from community; fear of seeking treatment services; and the fear of disclosure of one's HIV status.	Same
48: 4823	HIV stigma and institutional discrimination	Discrimination from social institutions as a result of one's HIV status	Same
48: 4824	Internalized HIV stigma	The internalization of outwardly experienced HIV stigma that may manifest itself in self-blame, guilt, or loss of self esteem.	Same
111	Practitioner-level barriers that decrease the target group's acceptability to VCT and related services	Ineffective VCT strategies that <i>may</i> decrease the target group's acceptability to VCT and related services	Same
112	Practice-level and other barriers that decrease the target group's acceptability to VCT and related services	Practice-level and other barriers that <i>may</i> decrease the target group's acceptability to VCT and related services	Same
112: 1122	Barriers faced by new immigrants to access health services	Barriers faced by new immigrants to access health services (i.e. transportation, lack of language services etc)	Same
112: 1123	Lack of resources and/or funding for immigrant health services	Lack of resources and/or funding for immigrant health or navigational services. The latter may reflect the lack	Same

		of funding for services such as outreach, translation, and transportation, or limited funding for organizations that offer the above types of services.	
113	Lack of resources for VCT and related services In HIV endemic countries	Same	Same
ROLE OF OTHERS INVOLVED IN DECISION MAKING			
71	Family doctor	Same	Same
73	Family	Same	Same
74	Partner	Same	Same
75	Friends	Same	Same
76	No one; prefers to make the decision completely or partially anonymously	Same	Same
PREFERRED OR ACTUAL ROLE OF OTHERS INVOLVED IN DECISION MAKING			
81	Make the decision for the woman	Same	Same
82	Share the decision-making with the woman	Same	Same
83	Provide support or advice so that the woman can make the decision her own	Same	Same
DECISIONAL SUPPORT RESOURCES			
101	Practitioner-level facilitators that increase the target group's acceptability to VCT and related services	Effective VCT strategies that may enhance the target group's acceptability to VCT and related services	Same
102	Practice related and other barriers that decrease the target group's acceptability to VCT and related services	Practice related and other barriers that may enhance the target group's acceptability to VCT and related services	Same
102: 1021	Effective programming and service delivery	Effective macro-level programming and service delivery structures, as identified below.	Same

1021: 10211	Public outreach	Public outreach on HIV-related information and/or services using multiple stakeholders and/or knowledge brokers	Same
1021: 10212	Programs/services that integrate HIV education as part of broader curricula	Same	Same
1021: 10213	The availability of resources at sites frequently accessed by the target group	Same	Same
1021: 10214	Use of written educational materials in adjunct to counselling	Same	Same
102: 1022	Improved funding, or availability of immigrant health and support services	Improved funding, or availability of immigrant health and support services (including navigational services)	Same
102: 10222: 10221	Increased language services (i.e. translation services, written materials in diverse language etc)	Same	Same
102: 10222: 10222	Increased access to health care	Improved access to health care services (general)	Same

Table II: Inductive and deductive codes from practitioner interviews

Identifier #	Original definition	Revised 1	Revised 2
PERCEPTION OF TESTING OPTIONS			
21	Perceived pros of anonymous HIV testing (or the cons of nominal and non nominal HIV testing)	Same	Same
21: 211	Client perceives VCT to be more confidential	Same	Same
21: 212	Client has more control over the negative consequences of	Same	Same

	testing positive		
21: 213	More time for VCT consultation.	Same	Same
22	Perceived cons of anonymous HIV testing (or the pros of nominal and non nominal HIV testing)	Same	Same
221	Client may not return to pick up HIV test results	Same	Same
222	Client may not return for antiretroviral therapy/prophylaxis after finding out her (HIV positive) status	Same	Same
223	There is no legal mechanism for partner notification	Same	Same
224	Client does not have an established relationship with the VCT provider	Same	Same
MANIFESTATIONS OF DECISIONAL CONFLICT			
32	Worry about the consequences of HIV testing	Same	Same
33	Feel distressed about making the decision to test for HIV	Same	Same
36	Delay making the decision to test for HIV	Same	Same
37	Question the importance of testing	Same	Same
FACTORS CONTRIBUTING TO DECISIONAL CONFLICT			
48	HIV Stigma: Any measure of distinction among persons depending on their confirmed or suspected HIV serostatus (UNAIDS)	HIV Stigma: A sociological phenomenon characterized by moral judgement, silencing, and negative stereotypes of persons suspected to be at risk for or living with HIV/AIDS. HIV stigma can also be marked social, institutional and internalized discrimination, as described below.	Same

48: 481	The association of persons perceived to be at risk for HIV, or living with HIV/AIDS with moral impropriety	Same	Same
48: 482	Concerns about talking about HIV	Concerns about talking about HIV and/or a related topic, or the perception of HIV as a "taboo" topic	Same
48: 483	Negative labelling of those perceived to be at risk for HIV or living with HIV/AIDS	Negative stereotypes, or negative social labelling of individuals perceived to be at risk for HIV, or living with HIV/AIDS	Negative stereotypes, or negative social labelling of individuals perceived to be at risk for HIV or living with HIV/AIDS. This may include stereotypes on the basis of someone's country of origin or ethnicity.
48: 484	Social impact of HIV stigma	The social consequences of HIV stigma, which may include a broad range of experiences such as loss of support from family, partner, friends; stigma by secondary association; ostracism from community; fear of seeking treatment services; and fear of disclosure of one's HIV status.	Same
48: 485	HIV stigma and institutional discrimination	Discrimination from social institutions as a result of one's HIV status	Same
49	Language related barriers for new immigrants	Same	Same
49: 491	Comprehension barriers during VCT due to client's lack of verbal fluency in English or French.	Same	Same
49: 492	Confidentiality	Confidentiality	Same

	limitations imposed by a third party during VCT (i.e. translators)	limitations imposed by a third party during VCT (i.e. translators, cultural interpreters, family members or friends)	
49: 493	Cross-cultural communication issues	Same	Same
50	Non-language related barriers for new immigrants	Same	Same
50: 501	Target group's limited knowledge of/ familiarity with the Canadian health care system	Target group's limited of knowledge of/ familiarity with the Canadian health care system, and community resources	Same
50 : 502	Limited use of preventative screening services by immigrant women	Same	Same
111	Practitioner-level barriers that decrease the effectiveness of VCT and related services	Ineffective VCT strategies that <i>may</i> decrease the effectiveness of VCT and related services	Same
112	Practice-level and other barriers that may decrease the effectiveness of VCT and related services	Same	Same
112: 1121	Lack of effective programming and service delivery	Same	Same
112: 1121: 11211	Non-integrated HIV services	Same	Same
112: 1121: 11212	Lack of time for VCT in family practice	Same	Same
112: 1122	Lack of access or availability of immigrant health services	Same	Same
112: 11221	Lack of access to primary health care/ identified VCT entry points for the target group.	Same	Same
112: 11223	Lack of resources and/or funding for immigrant health and support services	Lack of resources/ funding for immigrant health services. The latter may reflect the lack of funding for	Same

		immigrant health and support services or lack of funding for health care organizations that specialize in immigrant health (i.e. CHCs)	
113	Lack of resources for VCT and related services in HIV endemic countries	Same	Same
OTHERS INVOLVED IN DECISION MAKING			
71	VCT providers	Practitioners who provide VCT (i.e. family doctor, OB/GYN, nurse, nurse practitioner, social worker)	
72	Allied health care workers	Allied health care workers (health promoters, multicultural workers, crises support workers etc.)	
73	Family	Same	Same
74	Partner	Same	Same
75	Friends	Same	Same
76	No one: prefers to make decision completely or partially anonymously	Same	Same
PREFERRED OR ACTUAL ROLE OF OTHERS INVOLVED IN DECISION MAKING			
81	Make the decision for the woman	Same	Same
82	Share the decision-making with the woman	Same	Same
83	Provide support or advice so that the woman can make the decision her own	Same	Same
DECISIONAL SUPPORT RESOURCES			
101	Practitioner-level facilitators that increase the target group's acceptability to VCT and related services	Effective VCT strategies that may enhance the target group's acceptability to VCT and related services	Same

101:1011	Adherence to CMA guidelines on VCT	Same	Same
101: 1012	Adaptation of CMA guidelines on VCT to provide more tailored counselling.	Same	Same
102	Practice-level and other facilitators that increase the effectiveness of VCT and related services	Same	Same
102: 1021	Effective programming and service delivery	Effective macro-level programming and service delivery structures, as identified below.	Same
102: 1021: 10211	Public outreach	Public outreach on HIV using diverse stakeholders	Same
102: 1021: 10212	Programs/services that integrate education on HIV as part of broader curricula	Same	Same
102: 1021: 10213	Conceptual issues in programming for multicultural populations	Conceptual issues in programming and service delivery for multicultural populations	Same
102: 1021: 10215	Multidisciplinary care environment of community health centers	Same	Same
1021: 10216	More time for VCT consultations in family practice	Same	Same
102: 1022	Improved access or funding/availability of immigrant health services	Same	Same
102: 1022: 10221	Improved access to primary health care	Improved access to primary health care (particularly, VCT entry points for the target group)	Same
102: 1022: 10222	The availability of resources at sites frequently accessed by new immigrants.	The availability of resources at sites frequently accessed by new immigrants	Same
102: 10223	Improved funding of immigrant health services	Same	Same

APPENDIX L

SATURATION TABLE (PATIENT INTERVIEWS)

Patient Identifier			1	2	3	4	5	6	7	8
Category	Sub-category	Code								
Preferences towards VCT options	Client has more confidentiality	211	NA	NA	x	x	x	x	NA	x
	Client has more control over consequences of testing	212	NA	NA	x		x	x	NA	x
	Poor post test follow up	221	NA	NA	x	x		x	NA	
	Poor continuity of care	222	NA	NA	x	x		x	NA	x
	No mechanism for partner notification	223	NA	NA	x	x			NA	x
	Lack of established relationship with practitioner	224	NA	NA		x			NA	
Manifestations	Worry about consequences	32	x	x	x	x	x	x	x	x
	Feel distressed about DM	33		x		x	x		x	x
Determinants	Question importance of testing	37			x	x				
	Lack of Knowledge of Options and Outcomes	41	x	x	x	x	x	x	x	x
	Lack of support in DM	45	x		x	x	x	x	x	x
	Pressure in DM	46	x		x	x	x		x	x
	HIV Stigma variables	48	x		x	x	x	x	x	x
	Ineffective VCT/ counselling strategies	111			x			x	x	x
	Ineffective programming and service delivery	1121		x				x		
	Access issues for immigrants	1122		x				x	x	x
	Lack of resources/ funding for immigrant services	1123		x			x	x	x	x
	Resource limitations in countries of origin	113		x			x		x	
Others involved in DM	Family doctor	511	x	x	x	x	x	x	x	x
	Other practitioners	512			x					
	Friends	55			x					
	No one; Prefers partial or complete anonymous DM	56		x		x		x		x
	Partner	57	x		x	x		x		
Preferred roles of those involved in DM	Make the decision for the client	81	x							
	Share the decision making	82								
	Provide support/advice so that client can make decision on her own	83		x	x	x	x	x	x	x
Practitioner Practice/Other	Effective VCT/ counselling strategies	101	x		x	x	x	x	x	x
	Effective programming and service delivery	1021	x	x	x	x	x	x	x	x
	Improved access to health care services	1022		x				x	x	x
	More resources/funding for immigrant services, including navigational services	1023		x	x	x	x	x	x	

APPENDIX M

POSTER PRESENTATION FROM THE 3RD ISDM CONFERENCE (JUNE 2005)



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Evaluating the need for a decision support tool for refugee women from HIV-endemic countries considering voluntary counseling and testing for HIV (VCT) in Canada

Debjani Mitra¹, M.J. Jacobsen², Annette O'Connor², Kevin Pottie^{3,4}, Peter Tugwell⁴

1. Department of Epidemiology and Community Medicine, University of Ottawa, Ottawa; 2. Clinical Epidemiology Program, Ottawa Hospital, Ottawa; 3. Bruyère Family Medicine Center, Ottawa Hospital, Ottawa; 4. Institute of Population Health, University of Ottawa, Ottawa

For more information, please contact Debjani Mitra at debjanimitr@uottawa.ca

Background:

Persons who immigrate from HIV-endemic countries account for the fastest growing proportion of HIV cases in Ontario, Canada. Longitudinal surveillance data also reveal that perinatal HIV infections are disproportionately high in women from HIV-endemic countries. The purpose of this study is to assess the need for a decision support tool for reproductive-aged refugee women from HIV-endemic countries in preparation for voluntary counseling and testing for HIV (VCT). Specifically, the Ottawa Decision Support Framework (ODSF) will be used to explicate processes in VCT-related decision making to assist women to make informed, value-consistent decisions, and sensitize practitioners to contextual issues involving the decision to test for HIV. This abstract will detail the preliminary stages of the study which explored the feasibility of applying a decision support intervention in this setting and identified current gaps in practice.

Rationale:

VCT guidelines tailored to the decision making needs of the target group do not exist. National evidence-based illness prevention guidelines for immigrants from developing countries are being developed to optimize culturally appropriate needs-based care. These guidelines include directives for VCT. However, questions about how to maximize acceptability and informed decision-making in relation to VCT remain unanswered. Correspondence with service providers in Ottawa revealed significant difficulties in communicating effectively with clients about VCT in a culturally sensitive manner. Therefore, gaps exist in the availability of evidence-based, culturally-appropriate decision making tools for both clients and service providers in this setting.

Methods:

In the preliminary phase of the study, a literature review using electronic databases and technical reports published by various governmental and non-governmental organizations was conducted. Information was also collected through semi-structured interviews with health practitioners at the Bruyère Family Medicine Center (BFMC), an out-patient clinic specializing in immigrant health services, and Anonymous HIV Testing Clinics (AHTCs) in Ottawa regarding current practice. Based on the ODSF, the interviews were used to identify practitioner perception of factors that support and hinder the decision-making of the target group concerning VCT.

Preliminary Results:

Preliminary practitioner interviews (n = 4; 2 nurses, 2 family physicians) revealed that

- Factors that made it difficult for practitioners to support their client's decision-making included: 1. client difficulty in talking about the decision to test for HIV due to stigma and the link of the decision to traumatic life events such as sexual assault; 2. client lack of knowledge about the benefits of testing (in particular, information on access to antiretroviral therapies and supportive care in Canada); 3. client disengagement from decision-making processes in general; 4. conflicting expectations about the role of the practitioner in the decision-making process.

- On the other hand, practitioners perceived that it was easier to support their clients decision-making if they were informed about HIV testing options and their pros and cons, and were supported by their partners in the decision.

- The target group relied heavily on the advice of their practitioners for this decision. All practitioners perceived themselves to share the decision-making with their clients. Partners and family members often played a supportive role but at times were perceived to place pressure on the client to choose a certain option.

- Compared to practitioners at BFMC, those at the AHTCs more frequently attended to women in advanced stages of decision making (i.e. women more inclined to test for HIV) who were better navigators of the health care system. Practitioners at the AHTCs also identified structural factors beyond patient/practitioner interaction that may affect the quality of VCT. For example, practitioners at the AHTCs had significantly more time for pre and post test follow-up than their family medicine counterparts.

Next Steps: Needs Assessment Interviews

The next steps for this project involve completing in-depth needs assessment interviews with service providers (n = 10) and commencing ones with refugee women (n = 8-10). For the client needs assessment, a purposive sample of eligible, English-speaking women will be recruited from BFMC by practitioners on the research team. At present, the needs assessment questionnaires are being adapted with input from a diverse panel of experts (practitioners who specialize in immigrant and refugee health, decision support specialists and client advocates) through one-to-one feedback and role playing sessions. So far, the questionnaire adaptation process has involved: tailoring probes to the specific decision, simplifying language to clients' educational background, paraphrasing using terms used by patient advocates, describing key components of the framework using visual aids, using strategies to create dialogue on a difficult/stigmatized topic (i.e. drawing parallels between HIV testing and another self-defined difficult decision), using strategies to determine HIV testing is perceived to be mandatory, and discussing culturally-appropriate sources of support/resources.

Currently recruitment is underway and interviews are expected to commence in late June 2005 after the pilot testing phase.

APPENDIX N

POSTER PRESENTATION FROM THE 5TH CAS CONFERENCE (OCTOBER 2005)



Assessing the decision support needs of immigrant and refugee women from HIV endemic countries regarding and voluntary counseling and testing for HIV (VCT)

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Background:

Persons who immigrate from HIV-endemic countries in Africa and the Caribbean account for one of the fastest growing proportion of HIV cases in Ontario, Canada. Longitudinal surveillance data reveal that perinatal HIV infections are disproportionately high in women from HIV-endemic countries. For example, HIV surveillance data from Ontario shows that of all the HIV positive infants born between 1985-2000, 65.3 % had mothers from HIV-endemic countries in Africa and the Caribbean. The purpose of this qualitative study is to explore how the quality of VCT, the entry point to all HIV prevention and treatment, can be enhanced to assist women to make informed decisions, and sensitize practitioners to contextual issues involving the HIV testing.

The preliminary stage of the study will aim to identify current gaps in practice.

Rationale:

VCT guidelines tailored to the needs of vulnerable immigrant and refugee women do not exist. National evidence-based illness prevention guidelines for immigrants from developing countries are being developed to optimize culturally appropriate, needs-based care. Along with several screening and treatment decisions, these guidelines include directives for VCT. However, questions about how to improve informed decision-making in relation to VCT remain unanswered. Preliminary interviews with service providers in Ottawa during the pilot testing phase revealed significant difficulties in communicating effectively with clients about VCT in a culturally sensitive manner.

Methods:

A literature review using was conducted to identify local trends in epidemiology, and assess previous and ongoing research on HIV/AIDS in persons from HIV-endemic countries (Broader topics on structural determinants of health and health utilization were also covered). After pilot testing the questionnaire, interviews were conducted with VCT providers to identify practitioner perception of factors that support and hinder informed decision-making concerning VCT in immigrant women from HIV-endemic countries. Data were collected through face-to-face, semi-structured interviews with twelve health practitioners at the Bruyère Family Medicine Center (BFMC) an out-patient clinic specializing in immigrant health services, and six Anonymous HIV Testing Clinics (AHTCs) in Ottawa. All practitioners interviewed were VCT providers who worked with immigrant women. Furthermore, all practitioners represented a wide range of clinical specialties (i.e. nurses, nurse practitioners, family physicians and social workers), and had varying experience with VCT.

Preliminary Results:

Barriers

Personal barriers highlighted were related to clients: 1. Worrying about the negative consequences of HIV testing (n=12/12); 2. Feeling distressed/upset when thinking about testing (n=10/12); 3. Delaying making the decision to test for HIV or getting treatment (n=3/12); 4. Questioning the importance of knowing their HIV status (n=6/12); 5. Not having information about testing options, their benefits and harms (n=4/12) and 5. Not having support (n=9/12) & feeling pressure from others (n=6/12). On the other hand, external barriers were associated with:

- Barriers related to information exchange during VCT, and acceptability to HIV services (n=12/12). This included a wide range of issues: 1. Gender and socio-cultural norms that mediate discourse about sexuality, including STDs/HIV (n=9/12); 2. Fear of being labeled in association with HIV as result of ethnicity and/or country of origin (n=2/12); 3. Lack of basic information about HIV, including myths about HIV (n=4/12); 4. Language related barriers in the care context (n=8/12); and 5. Concerns associated with the sub-optimal utilization of health services by new immigrants (n=4/12), such as the lack of familiarity with the Canadian health care system and supportive services in the community.
- Structural factors related to service delivery & programming (n=11/12). These included provider concerns on the: 1. Effectiveness of existing health promotion activities under the 'multicultural health care' model (n=3/12); 2. Lack of funding for educational activities known to be effective (including the lack of language services such as translation, booklets in different languages/dialects, Somali phone hotline) (n=6/12); 3. Stigma associated with HIV-specific services (n=5/12); 4. Lack of time in family practice for thorough VCT (n=5/12), and 5. Difficulty in the provision of culturally appropriate VCT (n=7/12).

Facilitators

Facilitating factors were linked to the development of acceptable forms of HIV education such as: 1. Outreach through culturally-appropriate venues (n=4/12), and 2. the use of non-HIV specific programs that integrated HIV education (n=4/12). Potential resources for outreach identified were: Pamphlets at the point of immigration, outreach clinics, high school drop-ins for youth, ads on public transportation, the media (ethnocultural newspapers and radio), anonymous telephone, posters celebrating cultural diversity, and outreach through stakeholders in the "diversity business." The importance of non-HIV specific programs that integrated HIV education was repeatedly stressed (i.e. Breastfeeding clinics, "Fun & Fitness" and ESL programs). Providers supported these types of programs because they created a supportive environment, and packaged HIV information in a non-threatening way while maintaining confidentiality.

Other facilitators included the multidisciplinary care environment at CHCs (n=4/12), longer time for consultations at AHTCs (n=3/12), and culturally appropriate provision of VCT (n=8/12). Strategies to improve the latter were numerous & varied: "Working with the comfort level of the women" and asking "culturally-bringing questions"; "Understanding the differences in communicating about sexuality in different cultures. How, and what people are comfortable hearing about, things not to bring up, <and> information specific to sexual taboos..."; "Knowing the key issues immigrant women have and to know how we can make it easier for them to understand the information, and what information is important for them. Also, practitioners would benefit from knowing about culturally-appropriate support sources are in the community for post-test referral"; "Educational workshops, executive summary about the history about some places people come from to get an idea of what people might have gone through before they got here".

Next Steps:

The next steps for this project involve completing interviews with immigrant and refugee women from BFMC.

1. Remis RS, Flett M. The Epidemiology of HIV Infection among Persons from HIV Endemic Countries in Ontario: Update to December 2002. Ontario Ministry of Health and Long-Term Care, Sept. 2004.
2. Ontario Women's Health Council. Ontario Women's Health Status Report (Chapter 3: HIV/AIDS). 2002.
3. Potte K. Prevention Guide for Immigrants and Other Migrants from Developing Countries. 2004 (Unpublished).
4. Please note that the interdisciplinary Ottawa Decision Support Framework formed the basis of this study. This framework defines a good informed decision as one that is informed, consistent with personal values, and in which the decision maker feels supported and satisfied with the decision making.