

**Access barriers to reaching human immunodeficiency virus
testing services in Ottawa: Mixed methods study**

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for the
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Abbreviations

ACB	African, Caribbean, and Black
ANC	Antenatal clinics
ART	Antiretroviral Treatment
AIDS	Acquired immunodeficiency syndrome
CATIE	Canada's Source for HIV and Hepatitis C Information
CES-D	Centre for Epidemiologic Studies Depression scale
COMET	The Core Outcome Measures in Effectiveness Trials Initiative
ED/UC	Emergency department/urgent care
ELISA	Enzyme-linked immunosorbent assay
EPDS	Edinburgh Postpartum Depression Scale
GbMSM	Bisexual and other men who have sex with men
HAART	Highly active antiviral therapies
HIV	The human immunodeficiency virus
HIVST	HIV self-testing
HPPA	Health Protection and Promotion Act
IPV	Intimate partner violence
JBI	The Joanna Briggs Institute
LEP	The Laboratory Enhancement Program
NAAT	Pooled nucleic acid amplification testing
ODSP	Ontario Disability Support Program
OHESI	Ontario HIV Epidemiology and Surveillance Initiative
OMERACT	The Initiative of Outcome Measures in Rheumatology

PEP	Post-exposure prophylaxis
PITC	Provider-initiated routine testing
PLWA (HASI-P)	HIV-AIDS stigma instrument
POC	Point-of-care testing
PrEP	Pre- exposure prophylaxis
PRISMA	Preferred Reporting Items in Systematic Reviews and Meta-Analyses
PWID	People who inject drugs
UHIP	University Health Insurance Plan
UK	United Kingdom
UNAIDS	The Joint United Nations Programme on HIV and AIDS
USA	United States of America
VCT	Voluntary counselling and testing
WHO	World Health Organization

Preface

Ethics approval was obtained to conduct this research from the University of Ottawa Health Research Ethics Board (see Appendix 1). The first phase was a scoping review and did not require ethics approval because secondary data were reviewed. The scoping review was implemented by me, the first author. The second phase had two parts that involved face-to-face interviews conducted by me, the first author, in Ottawa. The first part involved twenty young African migrants from nine African HIV-endemic countries, while the second part involved eight community health service providers. The final compilation of the research findings was done by me, the first author.

Abstract

Barriers to reaching human immunodeficiency virus (HIV) testing prevent Canada from achieving The Joint United Nations Programme on HIV and AIDS (UNAIDS) target of 90 percent of undiagnosed people living with HIV knowing their HIV status by 2020 and receive treatment.⁽¹⁾ Fourteen percent (9,090 of 63,100) of Canadians living with HIV were unaware of their status by the end of 2016.^{(1)(p.9)} Individuals exposed to HIV through heterosexual contact are overrepresented (28%) among the undiagnosed people living with HIV in Canada compared to other groups, such as men who have sex with men (18%) and people who inject drugs (20%).^{(2)(par.15)} The reasons preventing this population to present themselves for testing in Ottawa, Ontario, remain poorly understood in the literature. Most of the literature on barriers to accessing HIV testing focuses on the traditional key groups who are likely to test, and limits analysis of these barriers on one or two levels. Equally, health service providers rarely understand challenges behind HIV testing for particularly young heterosexual African migrant men. These challenges may be contributing key barriers to HIV testing. On other hand, late presentation to treatment remains a global issue. Psychosocial outcomes especially after a new positive diagnosis can delay reaching

early treatment and prevention services. Indeed, all test results negative or positive have consequences. Even those with a new negative test can return to risk taking behaviour if they delay accessing prevention education. Yet no systematic study exists in this area essential for quality improvement. Programming more equitable HIV testing services will require more comprehensive evidence about challenges and barriers behind accessing HIV testing and treatment to achieve UNAIDS target of 90 percent of undiagnosed people living with HIV knowing their status and receive treatment. This research aimed to contribute to this evidence through two phases. Phase 1 used the Joanna Briggs Institute methods to implement a scoping review on psychosocial outcomes and their measurements immediately following a new HIV diagnosis. This review considered all participants who tested for HIV – whether their results were positive or negative, as any test results have consequences, and regardless of age, sex, or setting – reported in published articles between 2007 -to the present date. Paper 1 presents the scoping review. Phase 2 relied on a qualitative methodology using Grounded Theory informed by a socio-ecological framework and a framework of access to healthcare to understand experiences of accessing HIV testing services in two parts: 1) to examine barriers to reaching HIV testing among young heterosexual African migrants, focusing on young men, in Ottawa (Paper 2); and 2) to identify challenges experienced by health service providers who make accessible HIV testing services to this population in Ottawa (Paper 3). There is some ambiguity in the use of the terms “first generation immigrants” and “second generation immigrants” (or children of first immigrants). In this study, the term migrants referred to both. Selecting participants from both groups (first and second generation) was important to include a wide variety of experiences and interpretations that reflect the study population. Furthermore, the term “health service providers” was used to refer to both healthcare providers and frontline service providers. Healthcare providers referred to those who conduct HIV testing in

health facilities, whereas frontline service providers referred to those who provide care and support services needed by members in their communities before and after testing within AIDS organizations and community-based organizations.

Results

Paper 1: Scoping Review

Fifteen studies identified a range of concepts describing outcomes in the mental and social domains among men and women eighteen years of age and above immediately following a new negative and positive diagnosis in both high- and low- income countries. There was no consistency across the studies in the instruments to measure psychosocial outcomes. Our study did not identify a core set of psychosocial outcomes and measurements.

Paper 2: Interviews among young heterosexual African migrants

This study found diverse cumulative interrelated barriers and enablers at three stages of test access: approachability, acceptability, and availability. Participants often were unable to recognize the need for HIV testing, to seek testing and to obtain testing due to various interrelated determinants at the intrapersonal, interpersonal, organizational, community and policy levels. Compared with young women, young men reported a major access barrier at the initial level of approachability due to a lack of outreach HIV testing programs. They were also often unable to obtain information about available HIV testing options.

Paper 3: Interviews among health service providers

This study identified various challenges experienced by health service providers, which contributed barriers to test approachability, acceptability, and availability, where multiple problems arose at intrapersonal, interpersonal, organizational, community and policy levels.

Health service providers reported that young heterosexual African men were less likely to accept offered testing than their women counterparts, perhaps because HIV interventions often target women to get tested during pregnancy for the “good of the baby.” The providers further reported the lack of outreach HIV testing programs as a major access barrier especially among young heterosexual African migrant men. This was consistent with the information provided by the young men themselves regarding their inability to obtain information they needed about available HIV testing options that would enable them recognize the need for testing, seek testing or obtain testing.

Conclusions

Paper 1: Scoping Review

Problems presented by inconsistent measurements of psychosocial outcome domains (concepts) immediately following HIV testing could be addressed by establishing a core set of psychosocial outcomes and measurements. Only then can there be complete documentation of these outcomes crucial to inform health care decisions in public health to achieve universal access to treatment.

Papers 1 and 2:

Unique barriers, challenges and enablers in accessing HIV testing services among both young men and women identified in Phase 2 suggest access inequities in Ottawa.

Paper 2: Interviews among young heterosexual African migrants

Reaching HIV testing more quickly among undiagnosed young heterosexual African migrants, especially men will call for an interdisciplinary approach in translating knowledge into more equitable HIV testing programs that respond to needs and priorities of this population.

Paper 3: Interviews among health service providers

Translating knowledge into HIV testing programs that can be timely reached among young heterosexual African migrants from HIV-endemic countries, especially men in Ottawa will require health service providers to be fully aware of the challenges, which should be addressed in order to deliver culturally competent HIV testing services to reduce access inequities.

We have provided several recommendations to improve access to HIV testing in Ottawa.

Chapter 1: General Introduction

1.1 Introduction

How do disadvantaged groups experience accessing HIV testing services, especially young heterosexual African migrant men from HIV-endemic countries in Ottawa, Canada? The Public Health Agency of Canada defines an HIV-endemic country as: “one having an adult prevalence (ages 15-49) of HIV that is 1% or greater and one of the following: (1) 50% or more of HIV cases attributed to heterosexual transmission; (2) a male-to-female ratio of 2:1 or less; or (3) HIV prevalence greater than or equal to 2% among women receiving prenatal care”.^{(3)(p.7)} HIV-endemic countries are mainly in Africa (Appendix 2) and the Caribbean.⁽⁴⁾ Young heterosexual African migrant men from HIV-endemic countries are particularly affected by HIV especially in Ottawa, Ontario, but are less likely to present themselves for testing.⁽²⁾⁽⁵⁾⁽⁶⁾ Barriers and challenges experienced by this population in accessing HIV testing in Ottawa, Ontario are less understood,⁽⁷⁾⁽⁸⁾⁽⁹⁾⁽¹⁰⁾ yet these experiences should be reflected in planning of more equitable services for these Canadian citizens. Equally health service providers rarely understand challenges behind HIV testing, particularly for young heterosexual African migrant men. These challenges may be contributing key barriers to HIV testing but remain under researched.⁽¹¹⁾ Individual⁽¹²⁾⁽¹³⁾⁽¹⁴⁾ and population benefits⁽¹⁵⁾⁽¹⁶⁾ resulting from HIV testing call for further research about barriers and challenges to inform practice and policy to improve HIV testing.

On the other hand, late presentation to treatment is reported in both high- and low-income countries.⁽¹⁵⁾⁽¹⁷⁾ Harmful psychosocial outcomes immediately following testing can delay timely access to treatment especially for those with a new positive diagnosis. Those with a new negative

test present an opportunity for primary prevention interventions to reduce a return to risk-taking behaviors.(18)Barriers may be experienced at various stages of accessing healthcare,(19) and at multiple levels.(20) Evidence about barriers to accessing testing services across populations at multiple levels of analysis will be required to enable programming more equitable HIV testing services to achieve the UNAIDS target of 90 percent of undiagnosed people living with HIV knowing their HIV status and receiving treatment by 2020 in Canada.(1)

First, there are still lack of systematic studies to date about psychosocial outcomes immediately following testing. To our knowledge, there is also a lack of core set of psychosocial outcomes and measurements immediately following a new HIV positive or negative diagnosis. This is essential for quality improvement based on high quality reports that are complete.(21) Second, a complete assessment of barriers and challenges to accessing HIV testing services among young heterosexual African migrants, especially men from HIV-endemic countries is needed to inform the design of more equitable HIV testing services. This research attempted to contribute to these efforts by examining experiences to accessing HIV testing services in two phases.

Phase 1 conducted a scoping review on psychosocial outcomes and measurements immediately following HIV testing using the Joanna Briggs Institute methods.(22) The review was guided by two related questions: 1) “What types of psychosocial outcomes are reported following HIV testing, specifically in individuals with a new negative or positive diagnosis?” 2) “What measures are used to assess these psychosocial outcomes?” Phase 2 conducted semi-structured interviews to examine HIV testing experiences in Ottawa, relying on Grounded Theory (23)(24) informed by a socio-ecological approach (20) and a framework of access to healthcare (19) in two parts. Part 1

examined HIV testing experiences among young heterosexual African migrants guided by this question: “What are the barriers to reaching HIV testing, among young heterosexual African migrants from HIV-endemic countries living in Ottawa, especially young men?” Part 2 explored challenges behind HIV testing among this population reported by community health service providers from different disciplines using this question: “What challenges are experienced by health service providers in making HIV testing services accessible to undiagnosed young heterosexual African migrants from HIV-endemic countries, especially young men, in Ottawa?”

This study reports two qualitative studies about barriers and challenges behind accessing testing services for young heterosexual African migrants from HIV-endemic countries living in Ottawa, especially young men, informed by a scoping review on psychosocial outcomes and HIV testing. It begins with a literature review providing the background and rationale, followed by the framework and methods used in the study and a general discussion and conclusion.

1.2 Literature review: background and rationale

HIV testing is “a serologic procedure for detecting HIV antibody (or antigen) from an individual person, whether recommended by a healthcare provider or requested by an individual”.(25)^(p.2)

HIV testing is associated with several individual and population benefits. Individual benefits include efficacy of treatment when started early(13)(14) and reduction in risk-related behaviors on receipt of knowledge of positive HIV status.(12)There are also population benefits associated with HIV testing in terms of reductions in health care costs,(15) and prevention of onward transmission.(12)(16) Undiagnosed people with HIV who do not timely reach HIV testing cannot know their status and link early with the HIV care cascade, which may increase health inequities. Health inequities are avoidable and unjust health differences, according to the World Health

Organization (WHO).(26) Redressing such health inequities remains a priority of Canadian provincial health systems that have the duty to ensure access to health services for all citizens following the principles of “universality” and “accessibility” enshrined in the 1984 Canada Health Act.(27)Timely accessing HIV testing services is crucial in reducing health differences. Researchers have demonstrated that those unaware of their HIV serostatus represent a hidden population, which may account for more than fifty percent of new HIV infections, particularly among the newly HIV positive due to high viral loads.(28)

On the other hand, the introduction of highly active antiviral therapies (HAART) in 1996 has made knowledge of HIV serostatus and linkage to prevention and treatment services more important than ever.(29) Yet nearly twenty percent of individuals testing positive for HIV do not enter care within a year following diagnosis in both high- and low-income countries.(15)(17) An unexpected positive result can have harmful personal and social consequences,(16)(30) under existing HIV testing strategies, for instance, provider-initiated routine testing (PITC) or under the emerging HIV testing technologies. PITC is an HIV testing strategy, which is not mandatory, operationalized in the context of routine every day care within health facilities and services.(31) Examples of the most common forms of PITC are ante-natal services where, as a routine part of care, pregnant women are offered an HIV test in addition to antenatal services. Others are TB clinics, emergency departments and primary care facilities. In the above mentioned situations, the healthcare provider will offer the test as a routine part of care and patients need to opt-out if they do not wish to be tested.(31)The implementation of PITC is limited to certain populations, yet there is still a need to broaden access to testing, even in low HIV prevalence countries such as Canada. The individual and population negative consequences of late presentation to care among those living with HIV

unaware of their positive status,(13)(15)makes it critical to increase access to HIV testing especially among minority key groups.

PITC is different from targeted testing, which has been the main testing approach in Canada.(32)Targeted testing is conducted with populations identified as at high risk for exposure to HIV and takes two forms: provider-initiated risk-based testing and patient requested HIV testing. Provider-initiated risk-based testing is where a healthcare provider offers a test based on certain risk factors identified by the provider and ensures that those at risk get service in a range of venues, such as, bathhouses and needle exchange sites.(31)The problem is that providers may not always be able to tell who is at risk of HIV. On the other hand, patient requested HIV testing or voluntary counselling and testing (VCT) is one where individuals at risk of HIV on their own request HIV testing.(31)VCT may be integrated in clinical settings or implemented in a fixed place as a community- based service.(31) Some patients, however, may be unable to evaluate their risk due to fear of stigma and discrimination and, thus, may not ask for an HIV test. It means that targeted testing (provider-initiated risk-based testing and VCT) is inadequate to increase HIV testing due to individual inability of accurately assessing risk.(31)

There are various HIV testing technologies that are emerging including point of care test (POC) or rapid HIV test. POC involves a drop of blood from a finger prick to provide the test result in a few minutes.(33) POC has been promoted for use for several reasons, according to a recent review.(32) These included the feasibility of POC in a variety of venues, increased acceptance of POC and higher preference rates of POC over standard testing among populations.(32) Similarly, POC can have a wider reach not only among those never tested, but also among those

recently tested and the undiagnosed living with HIV.(32) Those with a rapid positive test are also linked to care early and there is reported higher satisfaction with POC than standard testing.(32) The World Health Organization further has recommended HIV self-testing (HIVST) and there are seventy seven countries that already have adopted HIV self-testing policies, while many others are currently developing them in 2019.(34)(35) Thus, more people are now being HIV diagnosed using PITC and other emerging HIV testing technologies than before the introduction of HAART.

Psychosocial outcomes that are harmful immediately following HIV testing can hinder accessing early treatment and prevention services. Despite great research interest especially relating to psychological outcomes after testing at the beginning of the epidemic even before the availability of HAART,(36)(37)(38)there is still lack of higher-level evidence in this area. Absence of higher-level evidence about psychosocial outcomes immediately following HIV testing undercuts quality improvement of HIV testing services required to ally further research to understand, for instance, the association between psychosocial outcomes and delays to accessing treatment among the newly HIV diagnosed. The inability to reach early not only HIV testing, but also treatment and prevention services can be costly,(15)lead to poor health outcomes,(17) and drive HIV transmission.(12) Still certain minority key populations may not be able to reach services in given contexts, despite availability of these services.(16)

Young heterosexual African migrants from HIV- endemic countries, especially young men, who are generally excluded from targeted testing, appear to face additional difficulties in accessing HIV testing in Canada. Although barriers to accessing HIV testing have been well-studied,(39)(40) this population has received little attention in the literature.(7)(8) Health service providers also rarely

understand the challenges behind HIV testing for this population, which may be contributing key barriers to HIV testing. Most of the literature on barriers and challenges to accessing HIV testing, especially in high-income countries including Canada, focuses mainly on the traditional key groups of MSM, PWID and pregnant women who are likely to test.(9)(10)(11)(39) While implementation of HIV testing, for instance, relies heavily on nursing and midwifery staff,(41) little literature exists on challenges that nurses and other health service providers experience in making these services accessible, according to a recent meta-synthesis.(40) Complicating matters further, the analysis of barriers and challenges to accessing HIV testing is often limited to one or two levels: either the intrapersonal and interpersonal or organizational level.(9)(10)(11)(40) Access to healthcare, including HIV testing, however, is influenced by multi-level determinants.(19)(42) Indeed, patients often have to make a myriad of decisions about whether and where to go for HIV testing well before arrival in a testing facility.

Describing fully barriers at multiple levels across populations will require tools able to explore diverse perspectives and uncover relationships that exist between the complicated layers of complex research questions. This is essential to inform translation of knowledge into effective HIV testing interventions that can be timely reached, while responding to the priorities and needs of populations. Although mixed methods can be demanding in terms of resources, they are useful to explore diverse perspectives and uncover complex relationships posed by complex research questions.(43) Probing adequately HIV testing experiences will require, for instance, individual interviews that collect rich, detailed data from the ground or specific contexts to be able to explain these experiences. Glaser and Strauss (1967), suggest a method using comparative analysis with

specific procedures that offer flexibility in developing theories able to explain experiences where little is known about the phenomenon in specific contexts.(23)

This study implemented a scoping review and used a qualitative methodology to examine access barriers to reaching HIV testing services in Ottawa. Young heterosexual African migrants, especially men, may experience additional barriers, yet unknown, to reach these services in certain contexts, such as Ottawa, despite existing HIV testing policy in Ontario.

1.3 HIV testing policy context in Ontario

This section briefly presents an epidemiological overview of HIV. The Ontario policy guidelines are then described, followed by the individual and public benefits of HIV testing.

1.3.1 Epidemiological overview

UNAIDS reported that 36.7 million people worldwide lived with HIV at the end of 2016.(44) Many of the estimated 54 percent of people who needed treatment had not yet been tested for HIV in the same year.(45) Twenty one percent (8.1 million) of all people with HIV worldwide remain unaware of their HIV infection in 2019 at the time of writing this report.(34) In Canada, an increase (5%) in the estimated new infections (2,165) was reported in 2016 compared to new infections (1,960) in 2014.(1)^{p.8}The resulting estimated incidence rate in Canada for 2016 increased (to 6.0 per 100,000 population) from that in 2014 (5.5 per 100,000 population).(1)^{p.6}

As indicated in Table 1 below, an estimated fourteen percent (9,090) of people living with HIV (63,110) remained undiagnosed at the end of 2016, according to Public Health Agency of Canada.(1)^{p.9} Table 1.1 shows HIV incidence and HIV prevalence by exposure category in Canada 2016.

Table 1.1: HIV incidence and HIV prevalence by exposure category in Canada 2016

Category	HIV incidence			HIV prevalence		
	Estimate	Range	%	Estimate	Range	%
gbMSM	1,136	620–1,660	52.5	30,980	26,360– 35,600	49.1
gbMSM +PWID	66	30–110	3.0	1,782	1,410–2,150	2.8
PWID	244	130–360	11.3	9,204	7,640–10,770	14.6
Heterosexual/non-endemic	425	230–620	19.6	11,105	9,300–12,910	17.6
Heterosexual/endemic	294	160–430	13.6	9,438	7,830–11,050	15.0
other	5	0-10	0.2	601	420–780	0.9
Total	2,165	1,200– 3,150	100	63,110	55,500– 70,720	100

Adopted from Public Health Agency of Canada (1)⁽⁷⁻⁸⁾

Of this total(63,110), heterosexual contact among people born in a country where HIV is endemic (primarily countries in sub-Saharan Africa and the Caribbean), represented 15.0 percent, at the end of 2016, as indicated in Table 1. Yet people born in HIV-endemic countries only represented approximately 2.5 percent of the overall Canadian population according to the 2011 Census.(1)^(p.7)

HIV incidence and HIV prevalence in Ontario

In Ontario, the rate of new HIV diagnoses (i.e. number of new diagnoses per 100,000 people) increased (6.5 or 916) in 2017 up from 2013 (5.8 or 784).(46)^(p.9) In 2017, there were also more new HIV diagnoses among men (rate of 10.3 per 100,000 people or 717) than among women (2.7 per 100,000 people or 195) in the province.(46)^(p.9) Younger men (25 to 29 years) in Ontario were more likely to be newly diagnosed with HIV than women (35 to 39 years) in the same year.(46)^{p.9} Even so, gay, bisexual and other men who have sex with men (GbMSM) still accounted for more new HIV diagnoses in the Canadian Population each year (about 60 percent) between 2012 to 2017.(46)^(p.9) (see also Table 1.1) Compared to other health regions in the province, however, the

proportion of new HIV diagnoses was highest among populations who were from African and Caribbean countries in Ottawa at the end of 2017.^{(46)(p.10)} Since these statistics do not include HIV-positive individuals who have not been tested for HIV,⁽¹⁾ the exact number of undiagnosed Canadians with HIV including among African migrants from HIV-endemic countries is not known. Estimations of the number of undiagnosed individuals living with HIV infection are calculated based on the modelling method in Canada.⁽¹⁾ What the available evidence shows is that HIV incidence increased at the end of 2017 and that young Canadian men are particularly affected by HIV in Ontario.⁽¹⁾⁽⁴⁵⁾ But those from HIV-endemic countries are less likely to test.⁽²⁾⁽⁵⁾⁽⁶⁾ HIV testing policies that provide guidelines to making available testing services to populations, in Canada, vary by jurisdiction.

1.3.2 HIV testing policy in Ontario

In Ontario, for example, healthcare providers including doctors, nurse practitioners and midwives commonly offer provider-initiated risk-based testing based on patient risk factors, clinical indicators; and patient requested testing, while frontline health service providers link patients to care and support services.⁽⁴⁷⁾ HIV testing is conducted in two ways in the province: nominal testing or anonymous testing.⁽³³⁾ Nominal testing means that a person is tested using their own name. Ninety five percent of HIV tests in Ontario are done using the name of person.⁽³³⁾ If a nominal test is positive, the name of the person together with date of birth, gender, and contact information will be reported by the testing laboratory to Public Health as required by the Health Protection and Promotion Act (HPPA).⁽³³⁾ The newly diagnosed person will be contacted by the local Public Health unit for counselling and support, and to refer the person to HIV related services. If the newly diagnosed person has sexual and needle-sharing partners, Public Health requires to

notify them of the possibility of having been exposed to HIV, also known as contact tracing, partner counselling, or partner notification.(33) This can be done directly by Public Health or in some cases by the newly diagnosed person or their physician, but Public Health may require proof of the notification. The name of the newly diagnosed person is not disclosed to the partner contacts by Public Health authorities.(33)

On the other hand, anonymous testing means that a person is tested without providing their name or personal information, but will be asked for year of birth and the town or city where they live or simply provide the year of birth if they do not want to give more information.(33) Anonymous testing is only offered at specific facilities listed under the HPPA in Ontario. There are currently thirty-eight active anonymous testing site organizations in Ontario, all of which conduct rapid/point-of-care tests.(33)^(p.5)Informed consent is required before testing, which means that the patient: understands the procedures and the consequences of being tested, including Public Health reporting requirements; receives pre-test and post-test counselling to prepare for the test and test result; and gives permission to be tested.(33) If a rapid test is “reactive”, a second anonymous test or a sample of blood will be taken and sent to the testing laboratory to confirm the test, which will take about two weeks.(33) Physicians and registered nurses at anonymous testing clinics are not required to report the name and contact information of a person newly diagnosed as positive.(33) The testing laboratory will inform Public Health about the positive test result but not the name of the person or contact information. The person tested will be given a code for their positive anonymous test result.(33) Various individual and public benefits can be obtained from HIV testing services.

1.4 Individual and Public Benefits of HIV Testing

HIV testing has individual and population health benefits. Individual benefits include efficacy of treatment when started early leading to better health outcomes that improve quality of life, reduces morbidity, and delayed death.(14) Recently-tested people can also benefit from prevention services, such as, risk-reduction counselling, treatment for other sexually transmitted infections, and treatment for opportunistic infections.(48) HIV testing presents an ideal opportunity to identify people at high risk for infection and refer them for enhanced prevention services, particularly pre- and post-exposure prophylaxis (PrEP and PEP).(48) Awareness of HIV positive status can allow individuals to plan, for instance, by making provisions for dependents, especially children.(49) At the same time, HIV testing opens doors to non-HIV specific services, such as mental health and harm reduction services or housing programs.(50) Moreover, counselling associated with HIV testing may increase individual knowledge and reduction of risk-taking behaviour among those who test HIV negative essential to prevent contracting sexually transmitted diseases including HIV.(18)

Public benefits of HIV testing include averting through treatment costly opportunistic infections that occur among late presenters to testing.(15) HIV transmission is prevented also through adherence to treatment that can suppress viral loads.(12)(13) As well, initiating prenatal treatment lessens the chances of mother-to-child transmission that could be costly.(16) Accurate HIV prevalence data may further improve prevention campaigns at a population level.(51) Barriers to timely accessing testing in certain contexts hinder individuals and the public to take advantage of these benefits in Ontario, calling for evidence about these barriers as the first step in programming more equitable HIV testing services.

Relying on Grounded Theory(23)(24)informed by a socio-ecological framework, (20) and a framework of access to healthcare,(19) this study aimed to examine the experiences of HIV testing services among disadvantaged groups, focusing on young heterosexual African migrants, especially men from HIV-endemic countries in Ottawa, Canada. It was conducted in two phases and reported in three papers. The following section presents the approaches used.

1.5 The study framework

The socio-ecological theoretical framework was used in the two phases of this study. It is a way of approaching issues based on various assumptions in developing new knowledge namely: “interrelationships between persons and settings”; “constructionist premises; collaborative style; and social processes”.(20)^(p.308) This framework was chosen because of these assumptions that put into focus the broader environmental factors affecting health outcomes, which can be useful to identify possible environmental interventions. The socio-ecological framework represents diverse ecological models that emerged as a response to disappointments with some individually-oriented lifestyle change programs within health promotion interventions. Some models of this approach have categorized the environment into multilevel influences, such as intrapersonal, interpersonal, and broader organizational, community, and policy levels(52) defined below in Table 1.2. Table 1.2 presents the definitions of different ecological levels.

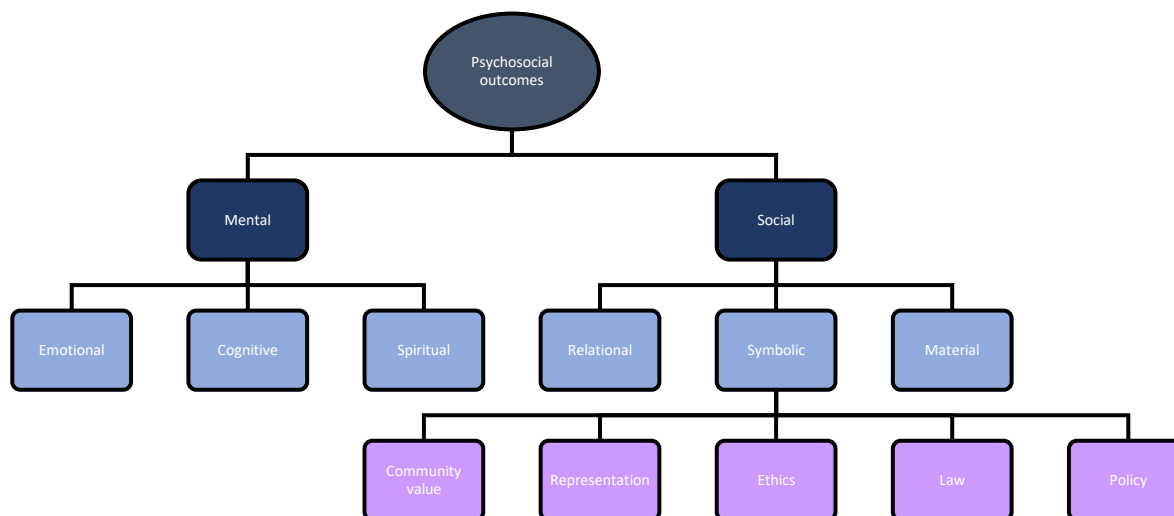
Table 1.2. Definitions of Levels

Multilevel	“numerous planes, echelons, or layers”(20) ^(p.308)
Intrapersonal level	“characteristics of the individual such as knowledge, attitudes, behavior, self-concept, skills, etc”.(52) ^(p.355)
Interpersonal level	“persons and small groups with whom the at-risk people associate (family, friends)”.(53) ^(p.437)
Organizations	“systems with a formal multiechelon decision process operating in pursuit of specific targets (schools, companies, professional associations)”.(53) ^(p.437)
Community	“collectives of people identified by common values and mutual concern for the development and wellbeing of their group or geographic area (villages, neighborhoods)”.(53) ^(p.437)
Policy level	“(political players in) larger systems possessing the means to control several aspects of the lives and development of their constituent subsystems (provinces, states, countries)”.(53) ⁽⁴³⁸⁾

This model was chosen for this study because of its analytical approach that enables full understanding of the inherent complexity of the causal link between determinants and health outcomes at multiple levels. A determinant is “a construct or factor thought to play a causal role in explaining a health behavior or outcome”.(20)^(p.308) Another reason for choosing this framework was because it has been applied extensively to health issues (e.g., (54);(55);(56)) and has also been successfully used to study barriers to accessing HIV testing.(40)

Although there are many levels that must be assessed, the socio-ecological model(20)(52)was a more powerful predictor of the determinants influencing access barriers and provided possibilities to identify interventions at multiple levels than models that focus solely on psychological or structural barriers. Translating knowledge into culturally competent HIV testing services to reduce the large pool of undiagnosed people living with HIV in Canada, especially young men in this study, will require complete assessment of evidence to inform priority setting in programming these services in Ontario. Priority setting in health care is commonly defined as “the process for making decisions over the allocation of population health care resources”.(57)^(p.771)

Knowledge translation is a way of “ensuring that stakeholders are aware of and use research evidence to inform their health and healthcare decision-making”.(58)^(p.2) In this study, stakeholders refer to policymakers, health practitioners and communities affected by HIV. By contrast, cultural competence aims “to balance quality, to improve equity and reduce disparities by specifically improving care for people of color and other disadvantaged populations”.(59)^(p.1282) Improving health equity among disadvantaged groups will call for policies or strategies based on evidence about health inequities in real world conditions.(60) Drawing on empirical studies, a prior scoping review examined HIV testing and psychosocial outcomes.(61) Figure 1.1 below shows a model of post HIV diagnoses psychosocial outcomes developed from the scoping review to accommodate the needs of this study.

Figure 1.1 Model of post HIV diagnoses psychosocial outcomes

The concept “psychosocial outcomes” referred to uncertainties or fears that individuals experience or anticipate immediately following HIV testing at the intrapersonal, interpersonal or broader organizational, community, and policy levels. Three levels relate to mental domains: emotional, cognitive and spiritual. “Emotional” refers to feelings, “cognitive” to thoughts and “spiritual” to higher-level experiences. Three levels relate to social domains: relational, material and symbolic.

“Relational” refers to interpersonal interactions with others and groups. The organizational level was measured at the “material” and “symbolic” levels to accommodate the findings. “Material” refers to available resources/conditions and “symbolic” to values. There are five related values identified in this study: 1. Community values; 2. Ethical values or judgements of right and wrong; 3. Social representations or social values; 4. Legal or laws; and 5. Policy or organizational measures relating to HIV testing and treatment. This model informed the analysis of access barriers in qualitative studies among young heterosexual African migrants and health service providers.

The following section presents methods used in the qualitative studies.

1.6 Methods

Phase 1 implemented a scoping review following the Joanna Briggs Institute method.(22) Two questions guided the scoping review: “What types of psychosocial outcomes are reported following HIV testing, specifically in individuals with a new negative or positive diagnosis?” “What measures are used to assess these psychosocial outcomes?” A scoping review was the appropriate method to examine these questions because existing information about outcomes relating to the mental and social domains in this area was sought. To identify the (sub)-domains and their measurements, this study relied on the Initiative of Outcome Measures in Rheumatology (OMERACT) and the Core Outcome Measures in Effectiveness Trials (COMET) Initiative respectively.(62)(63) Each of these models use a systematic approach to define a “core set” of domains and identify specific measurement tools for each domain. The core set is useful in standardizing outcome measures that can guide production of complete reports to inform health care decisions. The socio-ecological framework(20) was used to classify the concepts immediately following HIV testing identified in the review. That is, according to mental domains (emotional, cognitive, spiritual), and social domains (interpersonal, organizational, community, policy).

Phase 2

Grounded Theory (23) was used to analyse and interpret data through comparative analysis, which enabled to communicate theories (23) about the experiences of HIV testing in our reports, informed by a socio-ecological approach (20)and access to care framework.(19) Using semi-structured interviews between May and October, 2017 in Ottawa two sub questions were examined: “What

are the barriers to reaching HIV testing among undiagnosed young heterosexual African migrants from HIV-endemic countries, especially young men, in Ottawa?” What challenges are experienced by health service providers in making HIV testing services accessible to undiagnosed young heterosexual African migrants from HIV-endemic countries, especially young men, in Ottawa?

1.7 General discussion

This study aimed to fill the gap in the literature about experiences behind HIV testing services focusing on the newly HIV diagnosed and young heterosexual African migrants, especially men using mixed methods: a qualitative research methodology and a scoping review. Understanding the complexity of the experiences to accessing HIV testing services that include testing and prevention services may be useful to inform programming fair and timely HIV testing services crucial in achieving a key UNAIDS global policy to end the HIV epidemic by 2030 based on the 90-90-90 targets.⁽⁶⁴⁾ That is, by 2020 to have 90 percent of all people living with HIV know their status, 90 percent of those diagnosed receive antiretroviral treatment (ART), and 90 percent of those on ART achieve viral suppression.⁽⁶⁴⁾The findings from this study were reported in three papers.

Paper 1: Scoping Review

Fifteen studies were reviewed that examined men and women participants eighteen years of age and above immediately following HIV testing; and before initiating treatment among those testing positive in high-and low-income countries. The broad range of identified concepts describing mostly harmful psychosocial outcomes and inconsistent application of instruments to measure these concepts made it difficult to compare findings across studies. Standardising outcome

measures is needed to facilitate complete documentation and reporting outcomes required for quality improvement.(21) The scoping review also highlighted gaps in primary data about psychosocial outcomes and the absence of studies on indigenous populations, adolescents, prisoners, lesbians, or transwomen. Few studies were also identified about women not in prenatal care. While most of the reviewed studies were carried out in high-income countries, less than a quarter (20% or 3) of the reviewed studies considered populations from HIV-endemic areas such as sub-Saharan Africa. Not only further primary research to fill these gaps is called for, but also higher-level research, such as, on the relationship of harmful psychosocial outcomes to delays in reaching treatment and prevention services crucial for quality improvement.

Paper 2: Interviews among young heterosexual African migrants

This study contributes grounded evidence about interrelated access barriers and enablers at three stages of approachability, acceptability, and availability. Participants often were unable to recognize the need for HIV testing, to seek testing and to obtain testing due to various interrelated determinants at the intrapersonal, interpersonal, organizational, community and policy levels. Compared with young women, young men reported a major access barrier at the initial level of approachability even before reaching testing due to a lack of outreach HIV testing programs. They were also often unable to obtain information about available HIV testing options. This study found that young heterosexual African women participants experienced unique barriers, such as not being taken seriously by healthcare providers.

Paper 3: Interviews among health service providers

This paper contributes empirical evidence about challenges and enablers encountered by health service provider participants. Challenges contributed access barriers at the stages of approachability, acceptability, and availability in making HIV testing accessible among young

heterosexual African migrants. Also, multiple problems faced by health service providers reported at these stages arose at intrapersonal, interpersonal, organizational, community and policy levels. Health service providers reported that young heterosexual African men were less likely to accept offered testing than their women counterparts, perhaps because HIV testing interventions often target women to get tested during pregnancy for the “good of the baby”.(65) Providers further reported the lack of outreach HIV testing programs as a major access barrier, especially among young heterosexual African migrant men. This was consistent with the information provided by the young men themselves regarding their inability to obtain information they needed about available HIV testing options, which made it difficult for them to recognize the need for testing, seek testing and obtain testing. Heterosexual men generally excluded from provider-initiated risk-based testing in Ontario face additional problems, including often being unable to obtain knowledge about the available options in the province. This study further highlighted a variety of HIV testing opportunities at multiple levels.

1.8 Limitations

Paper 1: Scoping Review

It is possible that some relevant studies could have been overlooked. Also, the quality of the studies reviewed was not evaluated, since this was a scoping review. The study was limited to English publications. Despite limitations, the scoping review provides more up-to date information about psychosocial outcomes immediately following HIV testing to help improve care delivery to the target populations in this study.

Paper 2: Interviews among young heterosexual African migrants

A major limitation of the study findings is the focused data from only a few sites in Ottawa. That is, young heterosexual African migrants from the two sites may not represent all young heterosexual African migrants from HIV-endemic countries. This limitation also applies to paper 3 about interviews among providers. Participants from three community health centres and three community-based organizations may not be representative of all health service providers/ community health centres / HIV community-based organizations.

Papers 2 and 3

Despite limitations of Phase 2, this study is one of the very few qualitative studies to do an in-depth and comprehensive ecological analysis with a gender focus. It provided interesting insights for recommendations that may resonate in other Ontario contexts. Also, both phases of the study were supported by a multidisciplinary team with primary care, legal and methods expertise.

1.9 General conclusion

Paper 1: Scoping Review

Problems presented by inconsistent measurements of psychosocial outcome domains (concepts) immediately following HIV testing could be addressed by establishing a core set of psychosocial outcomes and measurements. Only then can there be complete documentation of these outcomes crucial to inform health care decisions in public health to achieve universal access to treatment.

Phase 2 (Paper 1&2)

Researchers, policymakers, health practitioners, communities and patients should be aware of the dimensions of access to HIV testing services and their interrelatedness. Stakeholders should also appreciate how multi-level determinants, including sex and gender, influence the ability of populations to test, or not, both before and after reaching services. Barriers, challenges and enablers to testing have implications for practice and policy that are provided in the reports.

Chapter 2: Paper 1. HIV Testing and Psychosocial Outcomes: A Scoping Review

Abstract

Objective: This scoping review sought to map psychosocial outcomes immediately following HIV testing and their measurements, specifically in individuals with a new negative or positive diagnosis.

Introduction: No systematic study has described psychosocial outcomes and their measurements immediately following a new negative or positive HIV diagnosis. Also, to our knowledge, there is no consensus on a core set of psychosocial outcomes and measurements immediately following HIV testing.

Inclusion Criteria: All study designs were included that considered participants tested for HIV, regardless of sex, age, or HIV status in any setting. Excluded were those in treatment and care.

Methods: The search for this scoping review included databases of Ovid MEDLINE, EMBASE and PsycINFO, and published articles in English between 2007-to the present day and was conducted March 2, 2019. The methods for scoping reviews outlined by the Joanna Briggs Institute Library of Systematic Reviews and Implementation Reports were followed. The data extracted included the author(s), year of publication, country of origin, aims, study population and sample size, methods, study period, outcome (sub)- domains or concepts, measurements and key findings. To identify outcome (sub)- domains and measurements, the models proposed by the Outcome Measures in Rheumatology Initiative and the Core Outcome Measures in Effectiveness Trials Initiative respectively were used. To analyse the data, this study used a multi-level social-ecological model.

Results: Fifteen studies were reviewed that examined men and women participants eighteen years of age and above, newly HIV diagnosed before initiating treatment, in high-and low-income countries. All HIV test results, whether positive or negative, reported harmful and beneficial consequences. A range of psychosocial outcome (sub)-domains and instruments to measure these outcomes were identified. Two approaches of testing were identified: provider-initiated routine testing /opt-out testing and targeted HIV testing conducted at various sites. Testing was conducted at the emergency department/urgent care, HIV local testing sites, antenatal and sexual health clinics, homes, HIV support organization, and outreach programs. Four main domains or broader concepts (mental, relational, material, symbolic) were documented with a total of one hundred and forty-eight (sub)-domains or specific concepts describing mostly harmful (82% or 122/148) and beneficial (18% or 26/148) psychosocial outcomes at the intrapersonal, interpersonal, material, and symbolic levels. This study documented a range of quantitative and qualitative instruments that were inconsistently applied to measure the outcome (sub)-domains.

Conclusions: The broad range of concepts identified describing psychosocial outcomes and the inconsistent application of measurement instruments complicated comparing findings across studies. Researchers need to agree on a core set of psychosocial outcomes and measurements to ally high quality research reports such as on the association of psychosocial outcomes and delays to testing services. This is crucial to improve the quality of treatment and prevention services to enable those just diagnosed HIV positive to timely reach treatment; and those just diagnosed HIV negative to timely reach preventive services to avoid returning to risk behaviors.

2.1 Introduction

According to World Health Organization, HIV antibody testing involves identifying HIV negative or HIV positive individuals through an analysis of blood or body fluids for the presence of antibodies produced in response to HIV.(25) Timely HIV testing carries individual benefits for those who reach early these treatments and adhere to them, which suppresses viral loads improving their quality of life.(13)(14)(66). HIV testing can lead to reduction in risk-related behaviors on receipt of knowledge of positive HIV status.(18) Testing also has population benefits of reductions in health care costs of medical services for late presenters to care,(15) and prevention of onward transmission of HIV.(12)(16) The introduction of HAART in 1996 has added to the urgency of knowing ones HIV serostatus in order to link early to prevention and treatment services.(29) Thanks to the availability of HAART, provider-initiated routine testing is now recommended by the WHO to be offered by healthcare providers to patients at healthcare facilities, unless they decline.(48) This and emerging HIV testing technologies,(48)(71) imply that more people are now being tested than before HAART with a real possibility of benefiting from the available treatment. Nevertheless, sustained antiretroviral therapy that can reduce viral loads is only possible if patients overcome harmful psychosocial experiences after receiving an unexpected positive result.

Psychosocial outcomes, including psychological responses, can delay accepting a positive test, which may reduce the ability of patients to reach early treatment and adhere to treatment. However, there is still lack of higher-level evidence in this area. Research shows that only nearly one-quarter of people access antiretroviral treatment after three months, while almost eighty percent enter care within a year following HIV testing in both low- and high-income countries.(17)(15)(67) While a

recent systematic review reported psychological responses relating to HIV testing, such as knowledge, attitudes, and perceptions, it excluded psychological responses after HIV testing.(68) Yet following especially an unanticipated positive diagnosis, some people, for example, may react in ways that are harmful to self and others due to both stigmatizing psychological and social reactions.(30)(69) Those with a new negative diagnosis present an opportunity for prevention education to avoid a return to risk-taking behaviours and contracting sexually transmitted diseases including HIV, which they can spread to others.(70) Systematically studying psychosocial outcomes following a new negative or positive diagnosis is urgently needed to inform policy and practice able to tailor HIV primary prevention strategies to the increasing numbers of individuals now accessing the various strategies of HIV testing.(48)(71)Also, to our knowledge, no consensus exists on a core set of psychosocial outcomes and measurement immediately following HIV testing to enable standardizing outcomes critical for quality improvement.

The existing literature examines delays to care predominantly relying on analyzing surveillance or medical records,(72)(73)(74) which fail to capture psychosocial outcomes deterring reaching treatment and support services among newly HIV diagnosed people. Other studies focusing on structural barriers, such as poor linkage between HIV testing facilities and ART centres,(72)(74) or on socio-demographic factors to determine behaviour outcomes after testing(72)(74) remain important but under analyze the psychological and other social barriers to timely reaching treatment and prevention services among recently HIV tested populations. Psychosocial outcomes immediately following HIV testing can be experienced at, and between multiple levels, such as the intrapersonal, interpersonal, organizational, community, and policy levels.(20) These outcomes can increase health inequities defined by the WHO as avoidable and unjust health

differences.(26) Overcoming inequities key to achieving the 90 UNAIDS target of viral suppression by 2020 will only be possible through sustained antiretroviral therapy to all people with HIV.(64)

A scoping review is needed to establish the range of available evidence on psychosocial outcomes immediately following HIV testing - whether negative or positive - and their measurements to advance scientific knowledge essential for effective clinical interventions. A scoping review can act as a basic unit of knowledge translation ‘ensuring that stakeholders are aware of and use research evidence to inform their health and healthcare decision-making.’(58)^(p.2) No systematic review on psychosocial outcomes immediately following HIV testing was identified through a preliminary search for existing systematic literature reviews conducted on this topic in Google Scholar, Cochrane Database of Systematic Reviews, the Joanna Briggs Institute Library of Systematic Reviews and Implementation Reports, and Ovid MEDLINE. Instead, there is a growing body of work on outcomes immediately following HIV testing in the mental and social domains. This scoping review sought to fill this gap by providing a range of existing evidence in this area that researchers may find useful to initiate dialogue towards a consensus on a core set of psychosocial outcomes domains and their measurements.

Review questions

Two related questions guided the scoping review:

1. What types of psychosocial outcomes are reported following HIV testing, specifically in individuals with a new negative or positive diagnosis?
2. What measures are used to assess these psychosocial outcomes of HIV testing?

2.2 Inclusion criteria

Types of participants

The current review considered all participants who tested for HIV, both negative and positive, regardless of sex or age in high- and low-income countries.

Concept

The concepts of interest for this scoping review were psychosocial outcomes and their measurements. Psychosocial outcomes referred to the mental and social uncertainties or fears that individuals experience or anticipate immediately following HIV testing. The timeline was one year because recent findings have indicated that eighty percent of newly HIV diagnosed patients enter care within a year of testing.(17) Measurements referred to instruments used to study the concept. Post-test and follow-up counseling were included. Psychosocial outcomes after initiating treatment and care were excluded. Studies on concerns of parents/carer givers relating to psychosocial outcomes of their children were also excluded.

Context

The context of this review included public hospitals, antenatal clinics (ANC), emergency department/urgent care (ED/UC) at health facilities, HIV clinics, HIV support organisations, and sexual health clinics in any country, whether high- or low-income.

Types of sources

This review considered all study designs including qualitative and quantitative studies, reviews, and mixed methods studies in the published articles in English between 2007–up to the present day. Studies before 2007 were excluded, to allow a time lag of 10 years of HAART since it was rolled out in 1996.(29) The need to provide the most recent and relevant data useful for quality improvement justified this timeframe.

2.3 Methods

The Joanna Briggs Institute (JBI) method for scoping reviews was used.(22) The objectives, inclusion criteria, and methods were specified in a protocol.(61)

Search strategy

A three-step search strategy was utilized to find studies published within the last 12 years from 2007-to the present date. An initial search of Ovid MEDLINE, JBI Database of Systematic Reviews and Implementation Reports, and the Cochrane Library was undertaken. The text words contained in the title and abstract, and the index terms to describe the article were used to develop a full search strategy. The search strategy, including all identified keywords and index terms, was adapted across all included databases and a second search was undertaken on March 2, 2019. The full strategies are provided in Appendix 3. The reference lists of all identified reports and articles were screened for additional papers.

Information Sources

The full search was undertaken on the databases of Ovid MEDLINE, EMBASE and PsycINFO. The search terms used were: ‘HIV’ and ‘test’ (diagnosis/anonymous testing/screen) and ‘psychosocial’ (psycho social/psychological/social) and psychosocial adjustment and ‘outcome’ (harm/benefit).

Study Selection

Following the search, Ovid multifile auto search was used to de-duplicate in the Ovid platform across Ovid MEDLINE, EMBASE and PsycINFO. This was followed by hand search for any remaining duplicates. Titles and abstracts were screened for assessment through consultations between two reviewers in an iterative process whereby the selected studies were repeatedly weighed against the inclusion and exclusion criteria. Potentially relevant studies were retrieved in

full and their citation details imported into Zotero data directory. Full texts papers that did not meet the inclusion criteria using the process described above were excluded and reasons for their exclusion are provided in Appendix 4. Divergences between the two reviewers at each stage of the study selection process were resolved through discussion in a review team of six committee members.

Data extraction

Data were extracted from papers included in this scoping review through consultations between two reviewers using a data extraction tool developed by the reviewers.(61) The data extracted included details on the following, which were relevant to the review questions: author(s), year of publication, country of origin (where the study was published or conducted); aims/purpose; study population and sample size (if applicable); methodology/methods; study period; outcome domains (concepts); measurements; and key findings about psychosocial outcomes in newly HIV negative or positive diagnosed individuals. Any disagreements that arose between the two reviewers were resolved through discussion in a review team of six committee members.

Data presentation

The data is presented in a tabular form in a manner that aligns with the objective of this scoping review. A narrative summary follows the tabulated and charted results and describes how the results relate to the review objectives and questions.

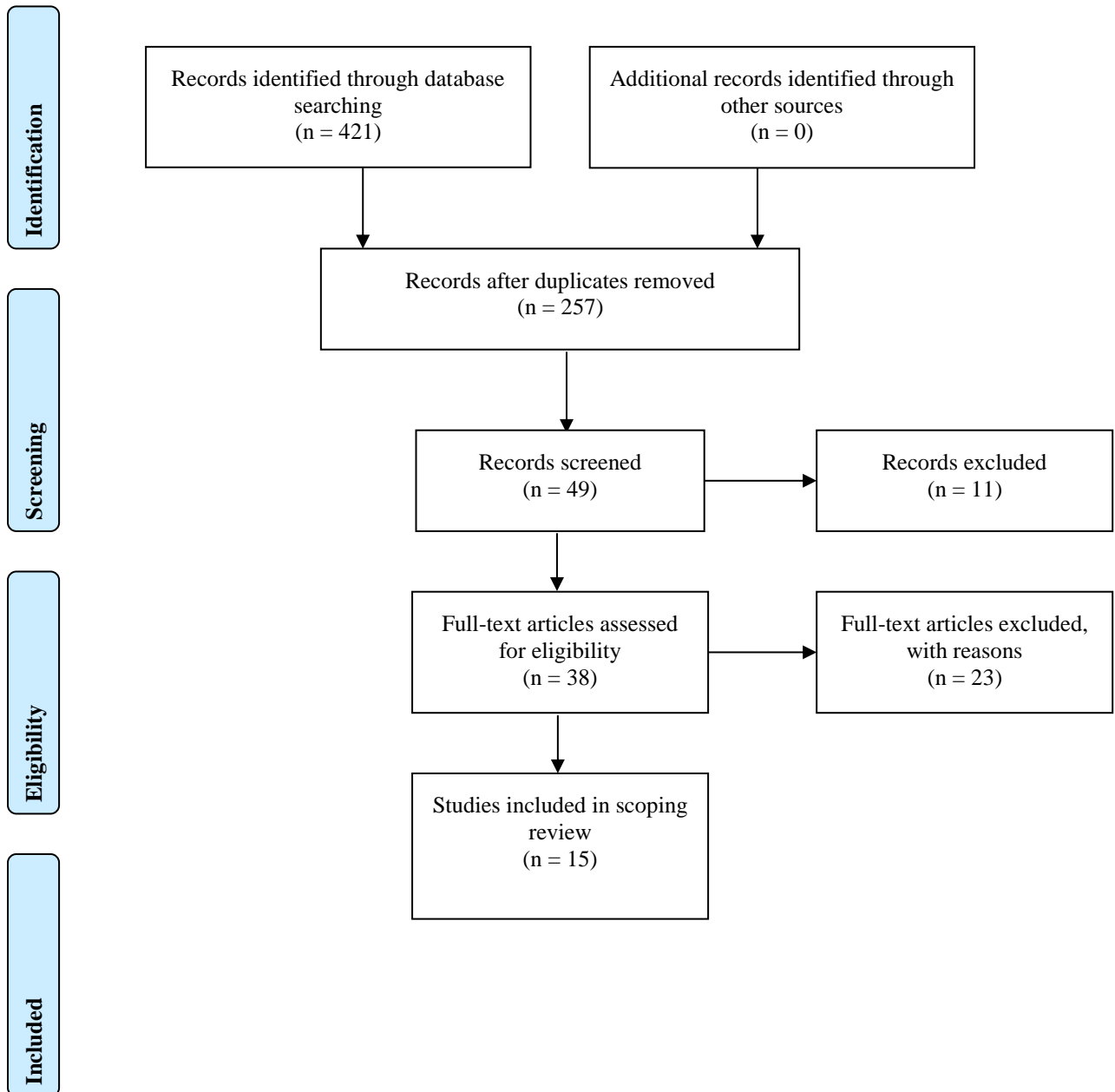
2.4 Results

Study inclusion

The search of three databases yielded two hundred and fifty-seven citations after duplicates were removed, and an additional fourteen citations in the same databases were found via hand searching.

A flowchart showing the number of citations at each stage is detailed below (Figure 2.1), adapted from the PRISMA flow chart,⁽⁷⁵⁾ including reasons for exclusion and study selection.

Figure 2.1: A flowchart showing search results and study selection and process



Source: Liberati et al.⁷⁵

The titles and abstracts for these two hundred and fifty-seven citations were screened, of which two hundred and nineteen papers had irrelevant titles and abstracts, and thus were excluded. The

remaining citations (38) were retrieved in full text and assessed. Of these, twenty-three were excluded either because participants were linked to care, the study was outside of the concept, or the study type was irrelevant (see Appendix 4). The search yielded fifteen citations for inclusion in this review.

Table 2.1 (see appendix 5) presents a summary of author, country, the aims of the reviewed studies, population, methods, study period, outcome domains, instruments and key findings about psychosocial outcomes in newly HIV diagnosed individuals.

2.4.1 Characteristics of the identified sources

2.4.1.1 Context

Table 2.2 below presents the setting of the studies reviewed by author, country and place the testing was conducted.

Table 2.2 Settings of included studies

Author	Country	Clinics/review
Hult et al.(82)	United States of America (n=7)	HIV local testing clinics
Hult et al.(83)		HIV local testing clinics
Moskowitz et al.(81)		HIV local testing sites and clinics
Mustanski et al.(70)		HIV local testing sites and clinics
Christopoulos et al.(84)		Emergency department/urgent care (ED/UC)
Valle & Levy(86)		Project outreach programs
Galletly et al.(30)		Review (ANC and HIV local testing clinics)
Lingen-Stallard et al.(77)	England (n=3)	ANC / HIV support organization
Anderson et al.(85)		HIV local testing sites and clinics
Willcocks et al.(76)		Sexual health clinic
Grace et al.(71)	Canada (n=1)	Sexual health clinic
Kelly et al.(69)	Northern Ireland (n=1)	Homes of women
Kotze et al.(78)	South Africa (n=1)	ANC
Larsson et al.(79)	Uganda (n=1)	ANC
Turan et al.(80)	Kenya (n=1)	ANC

Seven studies, including a review,(30) were conducted in the United States of America,(70)(81)(82)(83)(84)(86) three studies in England,(76)(77)(85) one study in Canada,(71)

and one study in Northern Ireland.(69) Only three studies included in this review were undertaken in low-income countries: South Africa,(78) Uganda,(79) and Kenya.(80) Five studies were conducted in HIV local testing sites and clinics,(70)(81)(82)(83)(85) four studies in antenatal clinics (ANC),(77)(78)(79)(80) two studies at a sexual health clinic,(76)(71) one study through outreach programs.(86) One study was carried out at the emergency department/urgent care (ED/UC),(84) one study at homes of women,(69) one study included HIV support organizations,(77) and one study was a review.(30)

Population size/sample

The population size ranged from four to seven hundred and twenty five participants for the included studies.(69)(70) The types of participants were adult patients eighteen years old and above as indicated in Table 2.1 (Appendix 5). Of the fifteen studies identified, eight conducted HIV diagnosis under a provider-initiated routine testing protocol: seven focused on pregnant women(30)(69)(76)(77)(78)(79)(80)and one at an emergency department/urgent care.(84) Seven conducted HIV diagnosis under a targeted HIV testing protocol often reporting rapid testing: three on gay men,(70)(81)(71) two among mixed population but predominantly gay,(82)(83) one each among people who inject drugs,(86) and immigrants after participants fell ill.(85) Only one study examined participants with a negative test.(70) The rest (13 primary studies and a review) detailed experiences among HIV-positive participants.

2.4.1.2 Methods used in the reviewed literature

Quantitative, qualitative, a review, and mixed methods studies were identified.

Two studies used solely quantitative methods,(78)(80) mainly surveys or structured interviewer administered questions.(78)(80) Eight studies used solely qualitative methods mainly in-depth semi-structured interviews,(76)(77)(79)(83)(84)(85)(86) including one study that used

unstructured conversational style.(69) Four studies used mixed methods,(70)(81)(71)(82): surveys and semi-structured interviews,(81)(82) surveys and focus groups,(70) surveys and qualitative interviews,(71) as indicated in Table 2.1 (appendix 5).

Study period

Four studies did not specify the study period,(76)(78)(85)(86) but were published within the time frame of this study (2008-2019), that is, 2008,(86) 2010,(85) 2013,(78) 2016.(76) The rest took place between 2003 and 2013 and were published within the time frame of this study. All studies described psychosocial outcomes among participants after initial HIV diagnosis within a year before initiating treatment as described in Table 2.1 (Appendix 5).

2.4.2 Narrative summaries of key findings

The aims of the reviewed sources were to measure outcome experiences immediately following a new negative or positive diagnosis using various instruments. HIV diagnosis was conducted under provider-initiated routine testing (8 studies) or targeted HIV testing (7studies) in the reviewed studies. We provide a narrative summary of the key findings.

Review Question 1

What types of psychosocial outcomes are reported following HIV testing, specifically in individuals with a new negative or positive diagnosis? This study identified harmful and beneficial outcomes reported in the reviewed literature after a new positive and negative diagnosis in the mental and social domains and their measurements at the intrapersonal, interpersonal, organizational, community and policy levels. In this study, broader concepts were defined as domains and any specific measured concepts as (sub)-domains. The identified (sub)-domains are presented below by type of testing beginning with a negative test result. Only one study reported on new negative diagnoses under targeted HIV testing.(70)

New negative diagnoses

Only a total of five (sub)-domains were documented at the mental level after a new negative diagnosis using targeted testing. Three beneficial (sub)-domains at the emotional level: relief,(70) reinforced safety,(70) and luck.(70) Two harmful (sub)-domains one each at the emotional and cognitive levels respectively: feelings of immunity(or invulnerability) and reductions in perceptions of personal HIV risk.(70)

2.4.2.2 New positive diagnoses under provider-initiated routine testing

Table 2.3 below presents harmful and beneficial psychosocial outcomes (sub)-domains identified in the eight reviewed studies immediately after provider-initiated routine testing.(30)(69)(76)(77)(78)(79)(80)(84)

Table 2.3. Beneficial and harmful psychosocial outcome (sub)-domains under PITC

Mental domain	Beneficial (sub)-domain	Harmful (sub)-domain
1. Emotional (feelings of)	(n=4) Acceptance,(77) resilience,(77) active coping,(78) self- esteem.(78)	(n=32) Devastation,(30) anger,(77) rage,(30) betrayal,(84) guilt,(30)(76)(84) trauma,(69) chaos,(69) sadness,(84) surprise(84) emotional,(69) extremely traumatic,(84) stressful,(69) worrisome,(69) being different,(69) stressed about starting medication, (76) shame,(71)(76)(84) shock,(77)(84) disbelief,(77) turmoil,(77) internalized stigma,(77)(78) depression,(78)(80)avoidant coping,(78) loss of old- self,(77) erosion of self-worth,(77) feeling isolated,(77)(84) anxiety,(71) fearing harm to the baby,(71) shattered dreams about motherhood,(71) feeling disconnected from the baby,(71) ambivalence about bringing baby into world,(71)feeling inadequate as a mother,(71) delayed emotional processing of HIV diagnosis.(84)
2.Cognitive (thoughts of)	(n=2) Better to know,(69) knowing people living with HIV.(79)(78)	(n=5) Suicide,(30)(69)(77), abortion,(76)(77)losing focus on baby,(71) believed baby would be positive,(77) difficulty accepting HIV-positive status.(84)
Total	n=6	n=37
Social Domain	Beneficial (sub)-domain	Harmful (sub)-domain

1. Relational	(n=4) Positive social support(78) calmed,(84) comforted,(84) by provider; active linkage to care by health care providers.(84)	(n=23) Refraining from sexual activity,(30) risk of intimate partner violence,(30)(80) paternalism by provider,(79) fear of HIV sero-discordance within the couple, if man is negative,(79) stigma,(80) fear of partner notification,(69) abandonment by partner,(79) disruption to their life course,(69) felt separation from family and culture,(69) embodied distress,(69) a sick baby would uncover mother's HIV status,(69) impulsive disclosures of HIV status,(30) fears about HIV transmission to baby,(76) anxiety about fetal death,(76) maternal uncertainty,(76) dislocation from the pregnancy,(76)(77) avoiding disclosure of their own HIV status,(76)(79) confidentiality issues,(77)(84) sought retesting or further assurance,(77) felt forced by the ANC staff to unwillingly disclose HIV status,(79) couple-testing experienced as precarious,(79) loss of desired emotional(84)/social supports.(84)
2. Material	(n=0)	(n=6) Drug use, (30) alcohol use,(30) losses of social,(30) instrumental,(30) and financial support,(30) discrimination at work.(30)
3. Ethics	(n=0)	(n=3) Lack of justice to be HIV positive,(69) unfair testing that allows men to opt-out,(79) morally judged.(84)
3. Social Representation	(n=0)	(n=3) HIV is untreatable, (30)(77) death sentence,(30)(77) Like going to hell and back.(69)
Total	n=4	n=35

This study documented a total number of eighty-two (sub)-domains after provider-initiated routine testing. Of these, the proportion of harmful (sub)-domains (88% or 72) was higher than that of beneficial (sub)-domains (12% or 10). The largest proportion of harmful (sub)-domains was reported at the mental level (51% or 37/72) compared to the social level (49% or 35/72). The largest number of harmful (sub)-domains at the emotional level was more than six times(32) than the number at the cognitive level(5). At the social level, the largest number of harmful (sub)-domains was found at the interpersonal level(23), followed by the material level(6), the social representation

level(3) and ethics level(3). Six beneficial mental (sub)-domains (4 emotional and 2 cognitive) were identified compared to only four beneficial social (sub)-domains.

2.4.2.3. *New positive diagnoses under targeted HIV testing*

Table 2.4 below presents harmful and beneficial psychosocial outcomes (sub)-domains identified in six studies after targeted HIV testing.(71)(81)(82)(83)(85)(86)

Table 2.4. Beneficial and harmful psychosocial outcomes (sub)-domains: targeted testing

Mental domain	Beneficial (sub)-domains	Harmful (sub)-domains
1. Emotional	(n=4) Less stressful than other things,(81) not overwhelmed,(81) (83) relief,(82)(85)(71) acceptance.(85)	(n=18) Shame,(82) guilt,(82) shock,(83)(85) surprise,(83) disbelief,(83) sadness,(83) depression,(83) crying,(83) distress,(85) increased anxiety,(71)(-due to judgmental, overly emotional, impersonal provider or interpretation of results) upset,(81) stressful,(82) internalized stigma,(81) pleasure-seeking,(86) uncertainty,(85) fear,(85) chaos, (85)confusion.(85)
2. Cognitive	(n=3) Determination,(83) readiness to enter treatment,(83) identified medical benefits /treatment.(71)	(n=12) Suicide,(81)(85) self-destructive,(86) denial,(85) loss of their -known self,(85) - present life,(85) -envisioned future,(85) a period of ambiguity,(85) just one among more problems,(86) resignation,(86) minimization,(86) troubled,(71)- about cause for being positive; unable to fully “absorb” unclear testing information.(71)
3. Spiritual	(n=2) Wake-up call,(86) being blessed.(86)	
Total	n=9	n=30
Social Domain	Beneficial (sub)-domains	Harmful (sub)-domains
1. Symbolic Relational	(n=0)	(n=12) Lying about their serostatus,(82) stigma,(81)(82)(85) reluctant to disclose to sex partners(81)(82) confidential concerns,(82) selectivity in disclosing,(82) loss of desired emotional(81)/social supports,(81) blame, (86) vengeance,(86) end of intimate relationships,(85)(71) victim of domestic

		violence,(85) seeking information from online about acute HIV infection.(71)
2. Community	(n=1) Advocacy.(86)	(n=2) Threat to their group identity,(81) difficult to get social support.(82)
3. Ethics	(n=1) Wrong not to disclose.(82)	(n=1) Not right to disclose.(82)
4.Social Representation	(n=2) Living clean,(86) a direct message from a higher power to live differently or die.(86)	(n=3) HIV as -physical death,(81)(86)(85) ontological death, (85) biographical disruption.(85)
Total	n=4	n=18

A total number of sixty-one psychosocial (sub)-domains were documented after targeted testing. Of these the proportion of harmful (sub)-domains(79% or 48) was higher than that of beneficial (sub)-domains(21% or 13). The largest proportion of harmful (sub)-domains(62% or 30) was identified at the mental level and a small proportion of the same at the social level(28% or 18). At the mental level, the largest number of harmful (sub)-domains were reported at the emotional level(18) compared to that found at the cognitive level(12). At the social level, the largest number of harmful (sub)-domains were reported at the interpersonal level(12), followed by the social representation level(3), the community level(2), and the ethics level(1). However, the number of beneficial (sub)-domains documented at the mental level was more than twice (9) that found at the social level (4). Of these, four emotional (sub)-domains were identified compared to only two cognitive (sub)-domains, while at the social level, one (sub)-domain was documented each at the community and ethics level, and the rest were at social representations level(2), and none at the interpersonal level.

Table 2.5. Number of psychosocial (sub)-domains by testing protocol

Testing protocol	Psychosocial (sub)-domains	
	Negative	Positive
Provider-initiated routine testing		82
Targeted testing	5	61
Total	5	143

Table 2.5 above provides a summary of the number of psychosocial (sub)-domains by testing protocol in the reviewed studies. The total of number of harmful and beneficial psychosocial (sub)-domains documented immediately following a positive test (143) and a new negative test (5) were one hundred and forty-eight. Of these, the number of (sub)-domains following provider-initiated routine testing was higher (82) than that after targeted HIV testing (66). Various similarities and differences are observed within the studies and the identified psychosocial (sub)-domains.

All studies except one (70) reported on new positive diagnoses. All studies reported psychosocial outcomes immediately following initial HIV diagnosis before entering treatment. Four studies did so retrospectively, that is, the duration between diagnosis of initial HIV and interview ranged from six to sixty two months,(84) between nine months and 13 years,(85) two to twelve years.(77) In one study, age of first post HIV-diagnosis children varied from 18 months to 4 years.(76)

The number of total harmful (sub)-domains was higher (122 of 148) than that of beneficial (sub)-domains (26 of 148). (Sub)-domains documented at the mental level (87) were overrepresented among all (sub)-domains, with only sixty one found at the social level. Harmful (sub)-domains were also mostly found at the mental level (57% or 69/122) compared to those at the social level (43% or 53/122). At the mental level, harmful emotional (sub)-domains represented the largest

proportion (74% or 51/69) compared to the cognitive (sub)-domains (26% or 18/69). There were only two spiritual (sub)-domains. At the social level, the highest proportion was documented at interpersonal level (66% or 35/53), in contrast to other levels combined (34% or 18/53).

Of all the harmful (sub)-domains, fifty-five percent (or 82/148) were reported following provider-initiated routine testing compared to forty-five percent (or 66/148) under targeted HIV testing. A major difference was that in all cases beneficial (sub)-domains were more likely to be documented following target HIV testing (62% or 16/26) than after provider-initiated routine testing (38% or 10/26). Of these, the mental level represented the largest proportion (69% or 18/26) compared to the social level (31% or 8/26). In addition, differences were also observed at the mental and social levels relating to the categories identified. Targeted HIV testing reported more categories at the mental level (emotional, cognitive and spiritual) compared to provider-initiated routine testing (emotional and cognitive). Equally targeted HIV testing reported more categories at the social level (community, ethics and social representations) compared to provider-initiated routine testing that reported only one category (relational).

Research gaps

This scoping review highlighted gaps in primary data. No data were found relating to the legal domain (such as the effect of fear of non-disclosure prosecutions following a positive outcome) and about certain key populations, for instance, indigenous populations, adolescents, prisoners, lesbians, and transwomen. Few studies were also identified about women who are not in prenatal care and about populations from HIV-endemic regions and heterosexual men. The instruments used to measure the above described (sub)-domains are presented below.

2.5 Review question 2

What measures are used to assess these psychosocial outcomes of HIV testing?

2.5.1 Measurement instruments

Table 2.6. Author, instrument and number of studies per instrument

Instrument Type	Author	Instrument
Mixed (n=4)	Moskowitz et al.(81)	Structured interview questions Open-ended questions
	Hult et al.(82)	Standardized instruments: <ul style="list-style-type: none"> • Combined stigma scale of 12 total items of Perceived and Internalized stigma scales; • 24-item Social Provisions Scale Open-ended questions
	Mustanski at al.(70)	Structured interview questions Open-ended questions
	Grace et al.(71)	Structured interview questions Open-ended questions
Structured interview questions (n=2)	Kotzé et al.(78)	Standardized instruments: <ul style="list-style-type: none"> • Adapted version of the Brief COPE; • An adapted version of the Multidimensional Social Support Inventory; • Internalized stigma and attributed stigma scales, each with 12 items; • The Rosenberg Self-Esteem scale; • The Centre for Epidemiologic Studies Depression scale; • A seven-item scale to measure women's empowerment.
	Turan et al.(80)	Standardized instruments: <ul style="list-style-type: none"> • HIV/AIDS Stigma Instrument–PLWA (HASI-P); • Edinburgh Postpartum Depression Scale (EPDS) Pre/Postpartum intimate partner violence
Open-ended questions (n=8)	Kelly et al.(69) Hult at al.(83) Valle, Levy.(86) Anderson et al.(85) Larsson et al.(79) Lingen-Stallard et al.(77) Willcocks et al.(76) Christopoulos et al.(84)	Open-ended questions
Commentary (n=1)	Galletly et al.(30)	Commentary

Table 2.6 above shows author, instrument and number of studies per instrument. Various quantitative, qualitative and mixed instruments used to measure (sub)-domains were identified in the reviewed articles. These instruments were applied inconsistently to measure outcomes as observed in Table 2.6.

2.6 Discussion

This scoping review documented a broad range of available evidence relating to psychosocial outcomes immediately following HIV testing among individuals with a new negative or positive diagnosis and identified inconsistencies in the way instruments to measure outcome (sub)-domains were applied. At the beginning of the epidemic, there was a lot of interest in research especially relating to psychological outcomes after HIV testing likely due to the need to address the effects of social reactions of stigma and discrimination on people recently diagnosed with HIV.(36)(37)(38) Despite this initial interest in the psychological effects of HIV testing even before HAART became available, no systematic study has described psychosocial outcomes and their measurements immediately after HIV testing. Promising results in this area were revealed in this study that included mostly primary studies (93% or 14) published over a ten-year period. One study was a review.(30) Only one study reported on new negative diagnoses,(70) while fourteen studies reported on new positive diagnoses.

Two approaches of testing were identified: provider-initiated routine testing and targeted HIV testing. Targeted HIV testing can take two forms: provider-initiated risk-based testing and patient requested testing.(31) In the reviewed studies, testing was conducted among participants at various locations. These included: emergency department/urgent care, HIV local testing sites, antenatal

and sexual health clinics, homes, HIV support organization, and outreach programs in both low and high-income countries. All reviewed studies reported psychosocial outcomes within a one-year period since initial diagnosis before entering treatment and care.

Six mutually exclusive mental (emotional, cognitive, spiritual) and social (relational, material and symbolic) domains emerged from the data with a total of one hundred and forty-eight (sub)-domains (5 after a negative- and 143 after a positive diagnosis). The proportion of harmful (sub)-domains (82% or 122/148) was larger than that of beneficial (sub)-domains (18% or 26/148). (Sub)-domains documented at the mental level (87/148) were overrepresented among all (sub)-domains compared to those found at the social level (61/148). Harmful (sub)-domains were also mostly found at the mental level (57% or 69/122) with the emotional (sub)-domains representing the largest proportion (74% or 51/69). By contrast, those at the social level represented a smaller proportion (43% or 53/122), where the highest proportion of harmful social (sub)-domains were documented at interpersonal levels (66% or 35/53). The total number of beneficial and harmful (sub)-domains were highest following provider-initiated routine testing (82) compared to targeted HIV testing (66). Beneficial (sub)-domains were more likely to be documented following target HIV testing (62% or 16/26) than after provider-initiated routine testing (38% or 10/26).

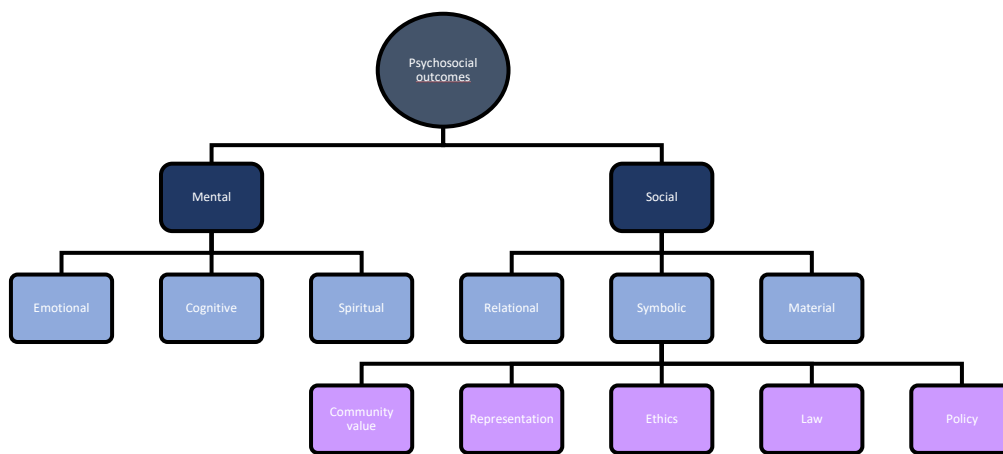
This study documented various instruments used to measure these (sub)-domains. Four studies used both quantitative and qualitative instruments, (70)(71)(81)(82) two studies used only quantitative instruments, (78)(80) while eight studies used only qualitative instruments (Table 2.8 above). (69)(76)(77)(79)(83)(84)(85)(86)

To identify (sub)-domains and their measurements, three steps were followed proposed by OMERACT,(62) and the COMET Initiative:(63) 1. Definition of the setting of the core set; 2. Determination of what to measure based on the review to arrive at a core domain set; and 3. Deciding how to measure the selected core domains based on the review. This scoping review defined the setting of the psychosocial outcomes (Table 2.1 Appendix 5) and determined the (sub)-domains and their measurements based on the reviewed articles. No core domain set was arrived at because of the breadth of the evidence suggesting the need for consensus on a standardized set of outcomes and their measurements. To identify measurement instruments, this scoping review relied on the definition provided by the COMET Initiative. They define an outcome measurement instrument as “a tool to measure an outcome, where the tool can be a single question, a questionnaire, a score obtained through physical examination, a laboratory measurement, a score obtained through observation of an image etc.”(63) ^(para.1)

This approach of defining (sub)-domains and specific measurement tools was adapted from the models of OMERACT(62) and the COMET Initiative,(63)because of their dedication to developing methods for standardizing outcome measures for randomized trials. These models use a systematic approach to define a “core set” of domains that should be measured; then identifying specific measurement tools for each domain. They define a (sub)-domain as a “component of Core Area: a concept to be measured, a further specification of an aspect of health, categorized within a Core Area”.(62)^(p.749)The core area in this study was psychosocial outcomes, which were associated with a range of (sub)-domains.

The (sub)-domains were analysed relying on the multi-level social-ecological approach at the intra-personal, inter-personal, organizational, community, and policy levels.(20) Based on this approach, a model of mental and social domains was developed to accommodate the study findings as shown in Figure 2.2 below. Figure 2.2 shows a model of post HIV diagnosis psychosocial outcomes.

Figure 2.2 A model of post HIV diagnosis psychosocial outcomes



Three levels of outcomes relate to mental domains: emotional, cognitive and spiritual. “Emotional” refers to feelings, “cognitive” to thoughts and “spiritual” to higher-level experiences. Three levels relate to social domains: relational, material and symbolic. “Relational” refers to interpersonal interactions with others and groups. The organizational level measures the “material” and “symbolic” levels because organizations include what is observable (material) and what is not (values). “Material” refers to available resources/conditions and “symbolic” to values. There are five related values: 1. Community values; 2. Ethical values or judgements of right and wrong; 3. Social representations or social values; 4. Legal or laws; and 5. Policy or organizational measures relating to HIV testing and treatment.

The majority of the reviewed literature measured (sub)-domains at mental and interpersonal levels consistent with existing literature relating to HIV testing that tend to limit its analysis on one or two of these levels.(39)(40)(68) This suggests that there is still little information on social domains. The novelty of this study is its focus specifically on outcomes after initial HIV testing in both the mental and social domains. A larger number of the reviewed studies (8) reported on participants diagnosed under provider-initiated routine testing,(30)(69)(76)(77)(78)(79)(80)(84) suggesting that recommendations by the WHO to make HIV testing routine are being implemented in many countries in efforts to normalise HIV.(48) Four studies conducted retrospectively were included in this scoping review since they focused on the initial HIV testing experience. A new negative diagnosis can strike at the inner depths of individuals leaving a profound mark in their lives, which is rarely forgotten.(85) All the studies had a qualitative part, which allowed participants to raise issues important to them.

In relation to Review Question 1, the findings in this study suggest a broad range of psychosocial outcomes that men and women undergo immediately following HIV testing, whether negative or positive. Nevertheless, although these studies are published in the peer reviewed literature, a lot of information is missing. This scoping review demonstrated that with the exception of one study about individuals with a new negative test, all the rest reported on individuals after a positive diagnosis. All studies mostly reported on psychological outcomes compared to social outcomes after testing irrespective of the testing strategy used. Understanding fully both psychological and social outcomes including after a new negative diagnosis is still needed to strengthen primary HIV prevention efforts. Differences in testing experiences may occur between individuals who test

positive under provider-initiated routine testing and those who test under targeted testing. Information about these differences are needed to inform clinical practice to improve access to treatment. For instance, patients who request testing may generally be able to control the timing and context of the testing experience in contrast to provider-initiated routine testing, where individuals may be unprepared especially for positive test result.(30) Individuals may still suffer harmful consequences, even after targeted testing even when using rapid testing or NAAT.(71)

By contrast, individuals may respond to a negative HIV test in various ways that can lead to increased HIV risk behaviours even after repeat negative HIV test results.(70) While many people who learn they are HIV status may reduce behavior that puts others at risk, the evidence from this study demonstrates that there are still some who may not. This has implications for prevention education interventions, calling for more primary studies among people with both new negative or positive test result.

Additionally, almost half of the sample (7) in this study has focused mainly on pregnant women without data on men. High quality reports about outcomes at all levels (mental, social) and across populations as well as testing approaches are still required to inform quality improvement. This is crucial to enable patients take advantage of the benefits of testing and accelerate achieving the UNAIDS target of 90 percent of people living with HIV receiving treatment by 2020.(64)

The evidence in this study demonstrates that HIV remains one of the most stigmatised diseases. Despite availability of HAART, which is a positive development in the fight against HIV/AIDS, traumatic experiences of people tested with HIV is not yet over. HIV is still perceived in some

contexts as a self-inflicted problem and thus undeserving of sympathy that continue to attract social reactions of discrimination and stigma.(81)85) As more people learn of their HIV diagnosis through routine screening processes and other emerging testing strategies, it will be important to examine the psychosocial impact of receiving an unexpected positive result on delays to accessing treatment. To do that higher-level studies are needed to understand this association. Policies and interventions to improve especially accessing treatment after a new positive diagnosis and prevention education after a new negative diagnosis, should be informed by experiences of patients. The beneficial outcomes documented after HIV testing strategies, also call for further study to understand how beneficial outcomes can be enhanced in order to link patients to treatment and prevention services.

Having said that, only three included studies were undertaken in low-income countries,(77)(78)(79) with the rest conducted in high-income countries. Given that most HIV infections occur in low-income countries where HIV is transmitted mainly through heterosexual contact, especially in sub-Saharan Africa, the dearth of studies from countries most affected by HIV is a major setback in the fight against HIV. Accessing early treatment in these countries is critical to ending HIV. Those tested positive provide an opportunity to intervene at the earliest convenience given the efficacy of early treatments. Delays to treatment may have substantial consequences for the future of the HIV epidemic especially in these countries.

A more complete picture about psychosocial outcomes is still needed to enable understanding especially the association between these outcomes and delaying reaching early treatment, support and care services in both high –and low-income countries. Developing pathways able to support

early referral to treatment and prevention services will require health practitioners above all to be well prepared and fully informed about all psychosocial outcomes. Health service providers are the “first responder interventionists”(87), who can reduce the level of distress during test results provision and guide patients through the diagnosis and linkage experience. These psychosocial outcomes may be experienced at, and between multiple levels, such as the intrapersonal, interpersonal, organizational, community, and policy levels.

In relation to Review Question 2, inconsistencies in the application of various instruments to measure (sub)-domains at these various levels complicated cross-comparison of the findings (Table 2.8 above). For instance, two studies used The Centre for Epidemiologic Studies Depression scale (CES-D) to measure the presence and extent of (postpartum) depression,(78)(80) while two other studies used open-ended questions to measure depression in mixed populations.(81)(83) Unevenness in instruments to measure similar (sub)-domains further complicated cross-examining the findings. For instance, two studies used two stigma scales,(78)(82) while one study used one HIV/AIDS Stigma Instrument–PLWA (HASI-P),(80) and still another study used open-ended questions to measure stigma.(81) Similarly, two studies used different scales to measure social support: an adapted version of Multidimensional Social Support Inventory,(78) and the Social Provisions Scale.(82) Some used mixed instruments, for instance, structured questions and open-ended questions,(70)(71) to measure psychological reactions to the receipt of a HIV test (negative or positive), while others used either structured questions (78)(80) or open-ended questions(69) to measure such reactions. Inconsistencies and unevenness in instruments point to the need for a core set of psychosocial outcome measurements to standardize outcomes essential to advance knowledge in this area. This study looked at only one point of testing-the initial diagnosis. It is a

powerful and life changing event that requires systematic study due to its fundamental effects on access to treatment and prevention of HIV transmission.

2.7 Limitations

A limitation of this study was that it did not evaluate the quality of the reviewed studies. A scoping review brings a wide body of literature but does not assess the quality of included studies. Other important sources may have been left out but its multidisciplinary team with primary care, legal and methods expertise added merit to this study by increasing the breadth of expertise. Similarly, there are potential benefits to the target population in this scoping review: to our knowledge, this is the first time a study that has systematically examined psychosocial outcomes immediately following a new negative or positive diagnosis, which can lead to further systematic studies for quality improvement.

2.8 Conclusion

Problems presented by inconsistent measurements of psychosocial outcome domains (concepts) immediately following HIV testing could be addressed by establishing a core set of psychosocial outcomes and measurements. Only then can there be complete documentation of these outcomes crucial to inform health care decisions in public health to achieve universal access to treatment.

Implications for research

Primary and systematic studies are required that fully examine all outcomes among individuals with a new negative and positive diagnosis to enable high quality reports. To do so, first a consensus among researchers is needed regarding a core set of psychosocial outcome measures.

Chapter 3: Paper 2. Access Barriers to Reaching HIV Testing Among Young Heterosexual African Migrants from HIV-Endemic Countries in Ottawa

Abstract

Barriers to accessing testing among heterosexual African migrant men from HIV-endemic countries are rarely the focus of research in Ottawa, Canada. Most of the literature on HIV testing focuses on men who have sex with men, people who inject drugs and women. Evidence about barriers before and after reaching testing across populations is required to inform policy and practice in planning more equitable HIV testing interventions to reach the 90 UNAIDS targets of undiagnosed people living with HIV knowing their HIV status and receive treatment by 2020 in Canada. This qualitative study examined HIV testing experiences among young heterosexual African migrants from HIV-endemic countries to identify barriers to reaching HIV testing services focusing on young men in Ottawa.

Methods

Relying on Grounded Theory informed by a social-ecological framework and a framework of access to care, face-to-face semi-structured interviews were conducted between May and October 2017 among twenty young heterosexual African migrants: fourteen men and six women aged 18-29 years. Participants were recruited from the University of Ottawa, and St Laurent/ Donald neighbourhood, Ottawa East.

Results

This study found interrelated access barriers and enablers at three stages of approachability, acceptability, availability and accommodation influenced by various determinants at the intrapersonal, interpersonal, organizational, community and policy levels that hindered participants to recognize the need for HIV testing, to choose seeking HIV testing and to reach HIV testing. Lack of outreach programs at the initial level of approachability interacting with the inability to obtain information about HIV testing options were major access barriers especially among young men in this study. This study found that young heterosexual African women experienced unique barriers, such as not being taken seriously by healthcare providers, even after reaching testing.

Conclusions

Researchers, policymakers, affected communities and patients should be aware of the dimensions of access to HIV testing services and their interrelatedness and how multi-level determinants can influence the ability of populations to test, or not, both before and after reaching services.

3.1 Introduction

What are the access barriers to reaching HIV testing among young heterosexual African migrants from HIV-endemic countries, especially young men, in Ottawa? Barriers to testing among heterosexual African migrant men from HIV-endemic countries are under researched. While young men aged 25-29 years are more likely to be diagnosed with HIV than other age groups, young heterosexual African migrant men are less likely to present themselves for testing, in Canada, including Ottawa, Ontario.(2)(88) Differences in HIV testing rates across populations call for explanations of barriers before and after reaching HIV testing from both health service

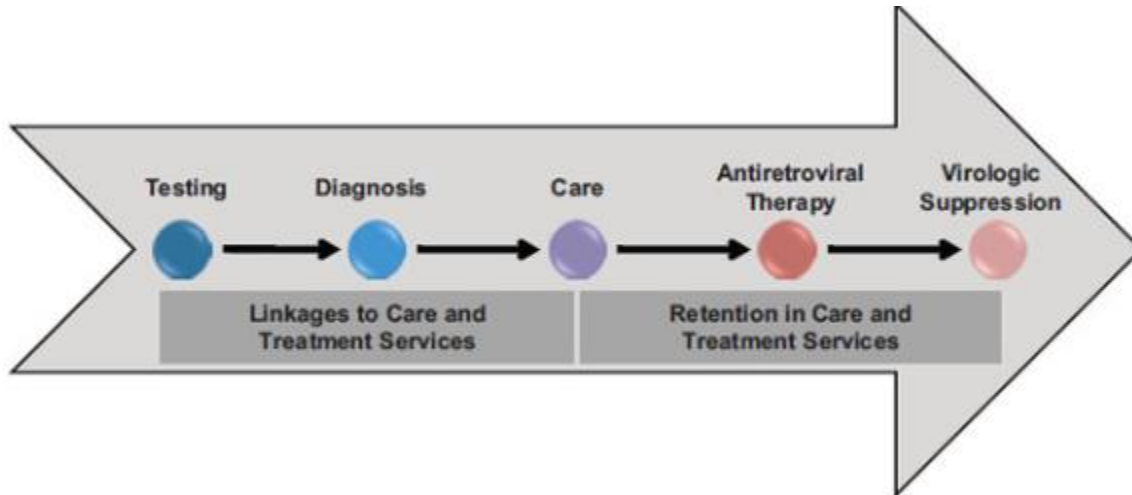
providers who make HIV testing services accessible and target populations. An assessment of barriers to testing among young heterosexual African migrant men is required to inform public health policy and practice. Patients can experience obstacles at various stages in accessing health care (19) and at multiple levels (20), which health planners, health practitioners, and affected communities need to recognize in programming more equitable HIV testing services that can attract this population to test. This paper reports findings about access barriers to reaching HIV testing services among young heterosexual African migrants from HIV-endemic countries, especially young men, in Ottawa. We begin with a review of the existing literature followed by the study framework and methods. We then present the results, discussion and implications for research, policy and practice.

3.1.1 Review of existing literature: Access barriers to HIV testing among heterosexual men

Addressing health inequities, including in HIV testing, remains a national priority of the Canadian provincial health systems that have a duty to ensure access to health services for all citizens following the principles of “universality” and “accessibility” enshrined in the Canada Health Act adopted in 1984.(27) Health inequities refer to individual and population health differences that are avoidable and unjust.(26) By contrast, HIV testing is the first stage along the implementation of the cascade of the continuum of treatment or the HIV care cascade (Figure 3.1).(89)

Figure 3.1 below illustrates the steps, which can be followed, especially by those with HIV, in accessing healthcare to suppress the viral load and achieve optimum health.(89)

Figure 3.1. Implementation Cascade for the Continuum of Care



Source: Institute of Medicine, et al. (89)^(p.244). Used with permission (Appendix 6).

HIV testing has individual benefits in terms of efficacy of treatment if started early,(13)(15) as well as reduction in risk-related behaviors on receipt of knowledge of positive HIV status.(12) At the same time, HIV testing has population benefits of knowledge of HIV status in terms of reductions in health care costs,(15) and prevention of onward HIV transmission.(12)(16) The province of Ontario offers a variety of HIV testing options. Targeted HIV testing, for example, is conducted with populations identified as at high risk for exposure to HIV, specifically men who have sex with men and people who inject drugs.(32)(47) Since some patients may not request an HIV test due to fear of stigma and discrimination, the province provides other testing options.

All pregnant women in Ontario, for instance, are offered HIV testing in antenatal clinics as a routine part of care where they are free to opt-out.(47) There are also currently thirty eight active anonymous testing site organizations in Ontario, all of which offer rapid or point-of-care tests.(33)^(p.5) A key consideration to the success of these efforts is whether undiagnosed people living with HIV can timely reach these services in Ontario. Not only is the inability to timely reach

HIV testing costly,(15) but it can also lead to poor health outcomes, especially among immigrant populations,(17) which may increase health inequities if not diagnosed early and left untreated.

While research specifically about experiences of immigrants and refugees in accessing health care exists in Canada,(90)(91)(92)(93)(94) relying mainly on national surveys(95), African migrants especially African men are rarely the focus of this research. Instead, researchers in this area have documented experiences of accessing primary health care services of non-African immigrant and refugee populations (90)(91)(92)(93) or only African women (94). Understanding how African migrant men construct experiences especially in accessing HIV testing is critical to planning services for these Canadian citizens who may face barriers to reaching available testing options in Ontario.

According to the 2016 Canadian census,(96)African, Caribbean and Black (ACB) people represented only 2.9 percent (1.2 million) of the Canadian population, yet these populations are overrepresented among the late presenters to care after contracting HIV.(72)(97)(98) While Africans who represent about half (637,485) of this population remain a minority population in Canada,(96) and the exact number of those undiagnosed is not known, a small proportion of undiagnosed people is still important. Some researchers have shown that undiagnosed people living with HIV can account for fifty percent of HIV transmissions.(99)

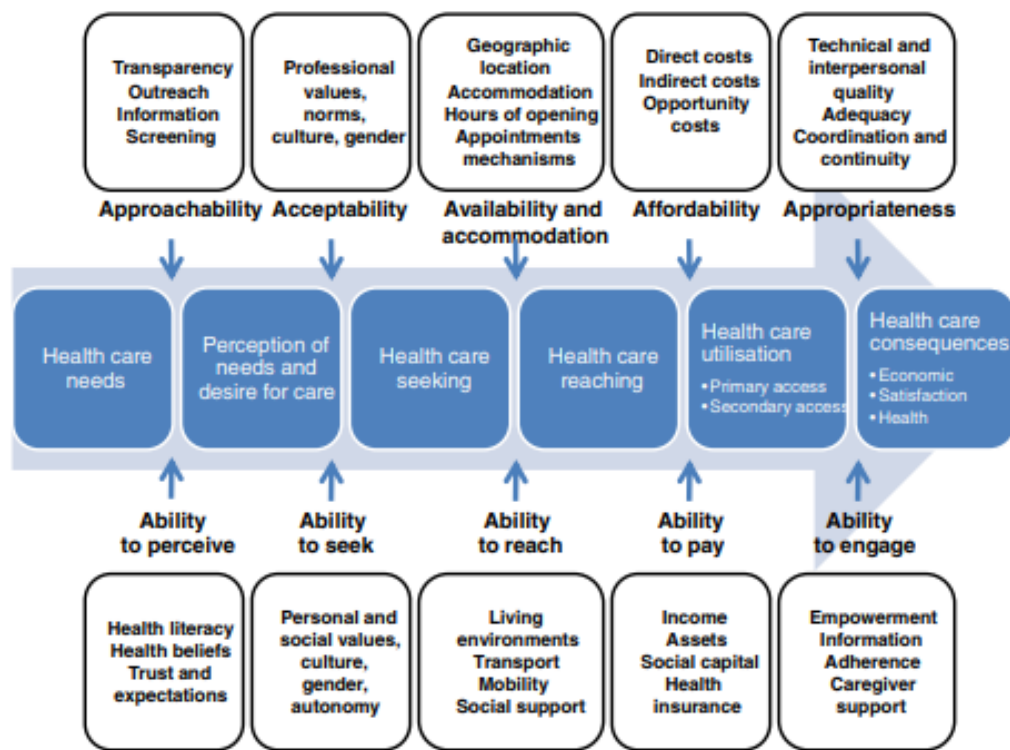
It is further reported that while more women than men had HIV tests in the past decade,(100) it is only in the last three years have more men than women been tested for HIV perhaps driven primarily by higher rates of testing among men who have sex with men.(33) All the same, the

increase in HIV testing uptake among women in Ontario (for instance, uptake was estimated at 98% in 2010) has been greatest among younger women, since the implementation of the policy to offer HIV testing to all pregnant women in 1999.(100) Many women in Ontario living with HIV are from sub-Saharan Africa and the Caribbean, some of whom are not able to access HIV testing (100) due to various barriers yet unknown in certain contexts, such as, Ottawa. One study reported that the HIV rate among women non-testers, including this population, was twice that among testers; where rates among young women non-testers (20–24 year-olds and 35–39 year-olds) were particularly high in Ottawa.(100) Preventing HIV transmission and controlling the epidemic are only possible if undiagnosed people living with HIV both men and women can timely reach testing and link with the HIV care cascade. According to Remis and colleagues (100) the undiagnosed for HIV in Ontario are members of key groups most affected by HIV including young heterosexual African migrants from HIV-endemic countries. Husbands, Makoroka and Tharao, studying patterns in HIV testing among HIV negative heterosexual Black men in Toronto, for instance, revealed that men aged 15-29 reported lower HIV testing rates (49.3%) than men aged 30-44 (82.4%).(97)^(p.111)

Despite barriers to accessing HIV testing being well-documented in the reviewed literature,(39)(40) a major issue is that many studies often do not disaggregate the aspects of access to HIV testing. Yet the concept of access to healthcare, including HIV testing, is multidimensional and complex shaped by multi-level determinants that impact accessibility.(19)(42) This complex set of factors and processes can be categorized into five dimensions of approachability; acceptability; availability and accommodation; affordability; and appropriateness.(42) According to Levesque et al., the five steps or transitions in accessing health care including HIV testing,

correspond to five abilities of populations: “ability to perceive; ability to seek; ability to reach; ability to pay and ability to engage”.(19)^(p.5) The framework of access to health care presented in Figure 3.2 below provides the basis for a stronger operational measurement of these stages than simply measuring accessibility without disaggregating the stages. This framework also measures the interaction between accessibility and the abilities of participants to access services. Figure 3.2 illustrates the various stages and the corresponding abilities of patients in accessing care.

Figure 3.2 A conceptual framework of access to care



Source: Levesque et al.(19)^(p.5). Used with permission (Appendix 6)

Approachability suggests, for example, that “people facing health needs can actually identify that some form of services exists, can be reached, and have an impact on the health of the individual”.(19)^(p.5) Various determinants such as transparency, information about available treatments and services and outreach activities may contribute to making services more or less approachable among certain population groups. Complementing the stage of approachability of

services is the ability of targeted populations to perceive the need for care, which may be determined, for instance, by health literacy and knowledge about health and beliefs related to health and sickness.(19)

Similarly, the stage of acceptability involves “cultural and social factors determining the possibility for people to accept the aspects of the service (e.g. the sex or social group of providers, the beliefs associated to systems of medicine) and the judged appropriateness for the persons to seek care.”(19)^(p.5)Some populations may fail to accept services, for instance, that they see are organized inequitably.(19) Complementing the stage of acceptability is the ability to seek health care, which can be influenced by “personal autonomy and capacity to choose to seek care, knowledge about health care options and individual rights that would determine expressing the intention to obtain health care.”(19)^(p.5)

Researchers elsewhere have demonstrated that barriers to accessing healthcare can occur at different steps, such as at the step of service availability interacting with the ability to reach the services both before and after physically reaching a provider.(101) Availability and accommodation refer to the fact that “health services (either the physical space or those working in health care roles) can be reached both physically and in a timely manner”.(19)⁽⁹⁾ Physical characteristics of facilities (such as, distribution of urban contexts) in terms of decentralisation relating to urban spread or transport systems) as well as provider characteristics (such as, their actual presence and qualification) can affect access. The modes of provision of services, such as contact procedure and possibility of virtual consultations can affect access.(19)

Even the availability of various HIV testing options and how they help to serve (or accommodate) the needs of patients can interact with the ability of patients to enable or prevent them accessing these services. The ability of populations to reach healthcare can be influenced by “personal mobility and availability of transportation, occupational flexibility, and knowledge about health services”.(19)^(p.9) Considering both the availability of HIV testing services and the ability of target populations to reach services is important to ensure that service availability and accommodation responds to the population characteristics and priorities in real world conditions.

Thus, each transition in accessing care is crucial to examine since barriers may arise that will affect the timely access to HIV testing services at multiple stages. Disaggregating the different dimensions of accessibility as indicated in Figure 3.2 above can provide a more complete description of the access barriers at each stage in interaction with the abilities of populations at various ecological levels before and after reaching testing services. These barriers may represent important markers of health inequities,(19) which policymakers, practitioners and affected communities need to know if healthcare needs of the disadvantaged are to be met. Although the different transitions in accessing healthcare are not independent constructs but interrelated, empirical evidence is needed to help policymakers, health practitioners and the affected community to understand how interrelated dimensions of access to HIV testing services can influence reaching these services to enable them plan more effective interventions.

While Levesque and colleagues (19) highlight the determinants influencing accessibility, they fail to provide precise measurements of these determinants. Barriers at each transition in accessing care may still be experienced at multiple levels. Richard, Gauvin, & Raine,(20) provide precise

environmental levels of influence at the intrapersonal, interpersonal and broader organizational, community, and policy levels to measure these determinants. Meanwhile, the main tendency of the reviewed literature has been to focus on one or two levels, that is, either individual and interpersonal or structural level barriers to utilisation of HIV testing.(39)(40) Yet, availability of HIV testing services alone may not be sufficient to determine if young heterosexual African migrants, especially young men, can reach services in time.

Social programs, such as HIV testing, involve “interactions between mechanisms and contexts”.(102)^(p.371) Contexts are what is externally observed,(102) such as HIV testing program inputs, activities, and outcomes within specific communities. Mechanisms, on the other hand, are “underlying entities, processes, or structures through which outcomes of interest are generated”.(102)^(p.368) Barriers to reaching HIV testing can begin from the initiation of the process of seeking HIV testing or approachability to the actual benefit of reaching these services. Interactions between individual determinants and characteristics of providers, for instance, can deter or enable timely reaching HIV testing in Ontario.

Ontario has the largest proportion of people originating from countries where HIV is endemic, representing 4.5 percent of the provincial population, according to the Public Health Agency of Canada.(103)^(p.7) Ottawa is among the five cities with the largest number of people originating from HIV-endemic countries (Toronto, Montreal, Vancouver and Calgary are the other cities).(103)^(p.7) Understanding mechanisms through which problems in accessing testing are experienced calls for grounded perspectives from affected populations themselves to help better understand these experiences.

Using a grounded theory approach can be particularly appropriate since relatively less is known (23)(24) to explain testing experiences of heterosexual African people from HIV-endemic countries. Grounded findings about experiences of HIV testing will be useful to stakeholders than simply applying a theory that is not developed for this group. What is lacking are in-depth studies to identify experiences to reaching HIV testing among young heterosexual African migrants from HIV-endemic countries, especially men important to reduce the pool of those still undiagnosed living with HIV in Canada. This study used a qualitative methodology with the aim of investigating experiences of HIV testing among this population, especially young men in Ottawa, relying on the Grounded Theory (23)(24) informed by a multi-level socio-ecological approach(20) and a framework of access to care(19).

3.2 Study theoretical framework

This research reflected socio-ecological analytical concerns. Socio-ecological constructionist assumptions were applied to Grounded Theory method to build a theory about HIV testing experiences. Socio-ecological constructionists assume that participants, including observers and those being observed, construct meanings in their own contexts based on “the interrelationships between persons and settings”.(20)^(p.308) By contrast, Grounded Theory is an approach that uses constant comparative method of data analysis with specific assumptions and procedures to generate theory about a certain practical issue.(23) It has roots in symbolic interactionism, which assumes that individuals give meanings to their interactions through interpretations. Grounded Theory also differs from other qualitative approaches most of which stress collecting data before analysis. The specific procedures of Grounded Theory are simultaneous collection and analysis of

data, a two step data coding process, constant comparison, memo writing, sampling to refine the researchers emerging theoretical ideas or theoretical sampling and integration of theoretical framework.(23)(24)

Applying socio-ecological constructionist assumptions to Grounded Theory in this study meant the following. We assumed that social reality is constructed during interactions based on interpretations, including those of the observer, in specific contexts. Thus, data collected in this study were assumed to be the creation of study participants based on their HIV testing experiences in their own contexts. Similarly, researchers in this study were assumed to be active participants who constructed concepts to generate a theory about HIV testing experiences based on interpreting data from participants beginning from research and interview questions to reporting of results.

The development of this study further drew from socio-ecological assumptions of “collaborative style, and social processes” in developing new knowledge.(20)^(p.308) For this study, this meant developing the design, research questions, analysis and reporting of data collaborating with a team of researchers including the community.

The methods used in this study are outlined in the section below.

3.3 Methods

To achieve the research objective, this study used constant comparative analysis (23)(24) by creating and refining the research and data collection questions; constructing analytic concepts

from codes; writing memos to create categories; and writing and re-writing to gain more analytic clarity while integrating other theories within the discussion and analysis.

3.3.1 Participants

This study was conducted among twenty young heterosexual migrants from African HIV-endemic countries aged 18-29 years. As we wanted to include a wide variety of lived experiences, views and interpretations those asked to participate had various characteristics. This was important to reach maximum theoretical variation.(104) (see Table 3.1). Table 3.1 shows interview participant characteristics.

Table 3.1: Interview participant characteristics

Characteristics	Men (n=14)	Women (n=6)	Total (n=20)
African Region of Birth			
Central Africa	6	1	7
East Africa	5	2	7
Horn of Africa	3	1	4
West Africa	0	2	2
Highest level of education completed			
Higher education			8
Secondary education			11
Primary education			1
Employed			
Yes			8
No			2
Marital status			
Never married			18
Cohabiting			2
Duration of stay in Canada			
Born in Canada			8
15+ years			2
11-14 years			0
6-10 years			5
Newcomers (5 years or less)			5
Diagnosis of HIV			
Negative			13
Never tested			7

Religion			
Muslim			6
Christian			13
No formal religion			1

All participants lived in Ottawa, except for one who lived in Gatineau but was a student at the University of Ottawa. All were aged 18-27 years. Of the twenty young heterosexual African migrants, fourteen were men and six women as indicated in Table 3.1 above. Participants included first immigrants mostly from Central Africa and East Africa, while the rest were from the Horn of Africa and West Africa as indicated in Table 3.1. Eight participants were children of first immigrants born in Canada of African origin of birth. Among the 14 men, nine were between 19-21 years, three were 22-27 years, and two were 18 years. The six women were between 20-22 years. Of the twenty participants, nine reported being students, eight were employed and the rest were unemployed (n=3). The most reported level of education was secondary school. Higher education was defined as college or university (including higher professional qualifications). Languages spoken were French (n=8) or English (n=12). Other characteristics included duration of stay in Canada and language spoken. Newcomers were those who lived in Canada five years or less, while the rest lived in Canada for more than five years (+ born in Canada). Most participants had lived in Canada for more than 15 years (n=10), of whom eight were born in Canada (four men and four women). Five reported living in Canada 6-10 years. Five were newcomers (one woman and four men) who reported living in Canada for five years or less. Participants included English and French speakers.

Still other characteristic were diagnosis of HIV and employment. Of the participants from nine HIV-endemic African countries, only half of the men (n=7) reported having tested for HIV, five

of whom requested anonymous HIV testing and two tested at a request of a healthcare provider in Ottawa. By contrast, all women (n=6) reported testing at a request of a healthcare provider in Ottawa. As indicated in Table 3.1, eight reported employment at various odd jobs: general construction (n=1), service jobs (n=4), and self-employment (n=3). All participants reported heterosexual as their sexual orientation. Most of the participants were Christian (n=13), with six Muslims and one who reported no formal religion. Men and women outside African HIV-endemic countries, those below 18 years and above 29 years, and those who do not identify as heterosexual were excluded.

3.3.2 Setting

The study took place at the main campus of the University of Ottawa and at a community park during summer.

3.3.3 Procedure

The University of Ottawa Health Research Ethics Board gave ethics approval for the study. (Appendix 7). Thereafter fliers about the study were distributed by emails to African student organizations, the Ottawa immigration centre and University campuses without volunteers coming forward. The common answer was no time or a simple shake of the head indicating unwillingness to volunteer. It took several attempts to connect with participants due to the sensitivity of the topic. After a written and verbal information about the study was sent to all those eligible for the study, the first author (JN) contacted the participants personally to explain more thoroughly the study. In consultation with the participants a date and convenient time was set for an interview. The right to decline to participate or withdraw from the study was explained. It was also explained that data would only be solely used for this doctoral thesis. Written informed consent was obtained prior to

the interview. To ensure confidentiality, all names and identifying information has been changed. The participants received \$20 for their participation.

3.3.4 Data collection

Data were collected through face-to-face, open-ended, in-depth semi-structured interviews by the first author (JN) between May and October, 2017. All interviews were conducted with a mean duration of 30 minutes at a secluded place in a community park or in a closed room at the University of Ottawa. A community park was the convenient place chosen by some participants. The interviews were audio recorded, put on an encrypted flash drive and transcribed verbatim. One participant preferred not to be audio-recorded. Notes were taken during the interview of the participant who requested not to be audio-recorded and were revised after the interview to make any corrections/additions while still fresh in the memory the following day. Comparative analysis was then started after collecting socio-demographic information from the participants (see Appendix 7).

A general prompt was: “What do you think about HIV testing?” This allowed the participants to express the meaning they attributed to HIV testing. Since the aim of the study was to find out more about HIV testing experiences, participants were asked other specific interview questions relating to these experiences based on their responses (see some examples Appendix 8). Member checking was done through highlighting important aspects during the interview so that participants could confirm or disconfirm their views. This was important to allow checking and ensuring accurate interpretation of data throughout interviews with participants.

Following each interview, field notes were taken about participants and what we observed, which documented reactions, emotions and related actions. This led to exploring, challenging and intensifying sensitivity to the concepts and theoretical categories, which enabled to identify the direction for further data gathering.(24)Changes in the direction of the research and the rationale for decisions made were documented. When new data analysis provided no additional material to existing theoretical categories, and the categories were sufficiently explained or were comprehensive, data collection stopped as no new information could be gained from the interviews.

3.3.5 Data Analysis

Data from the interviews were analysed and categorized according to the constant comparative method of data analysis, which allowed exploring emergent categories and their properties/dimensions.(23)(24) NVivo 11Pro was used to help organize and manage the interview data and memos. Properties referred to the characteristics that were common to all the concepts in the category. Dimensions were the variations of a property.(24) The data analysis started directly after the first interview and consisted of open coding followed by and focused coding. Open coding or the initial coding was done through an in-depth line-by-line analysis of the data that included repeated readings of the interviews.

The codes were compared with data, codes with codes. After interviewing a few participants, we compared their views, situations and experiences of HIV testing. We compared data from same individuals in different situations, for instance, testing experience of participants in schools and testing elsewhere in Ottawa. We compared incident with incident. After initial analysis theoretical

sampling was employed based on our field notes, which directed collection of additional data that informed the developing theory about experiences to HIV testing. For instance, while our original focus was on utilisation of testing, initial responses from participants about their experiences, such as, “*Easy. Why because to me it is easy. Because I didn’t pay. It was free,*” alerted us to look for additional data about what makes testing so easy and under what conditions is testing facilitated.

Once categories began to develop initial coding advanced into focused coding. Focus coding transformed basic data into more abstract concepts allowing the theory to emerge from the data.(24) To construct abstract concepts or categories, we went from field to the literature, back and forth, which at the same time enabled sharpening our research question from the general experiences about testing to focus specifically on access barriers, since this was the emerging category. The statements of most participants expressed obstacles to testing they experienced. For instance, initial interviews made us ware of the many hard and often confusing decisions participants made about whether and where to test from statements, such as: “*....before the door I was transfixed with fear. I returned, and I have never had a test.*” This led us to find out more from the field about these obstacles, but also from the literature. It was becoming clear that our understanding of access, as utilisation of HIV testing services, was being challenged by the evidence from the field. As a result, we constructed the concept of “access to care” drawing from the literature, which meant not simply utilisation of services but a process with stages. Thus, from particular experiences reported by participants, we were able through the process of constant comparison, to generate general concepts that referred to categories. The same was repeated for other concepts such as “barrier” and “enabler”. While we did not intend to focus on enablers as

such, statements like those mentioned above about facilitators led us back to the field to learn more from participants and back to the literature.

In focused coding, categories were linked together. We compared data with category and each category with other categories. The properties or dimension of the developed categories were refined, all of which resulted in a core category. This was combined with routine cross-checking on research and interview questions, data, explanations, methods, informants, theories and the researcher.(105)

3.4 Results:

A core category emerging from the process of data analysis showed how young heterosexual African migrants, especially men from HIV-endemic countries accessed HIV testing in Ottawa. Three main categories were identified as being important to explain these experiences: barriers, abilities and enablers. “Barriers” referred to obstacles or deterrent factors experienced at various stages in accessing HIV testing services at multiple levels. “Abilities” referred to capacities of participants to access testing at various stages and multiple levels. “Enablers” were opportunities facilitating accessing HIV testing services at various stages and multiple levels. The first author provided English translations from interviews given in French. Back translation was used to confirm these translations, which was done by professional translators not part of the study.

3.4.1 Core category: Accessing HIV testing

Accessing HIV testing may be understood as a process rather than simply utilization of services. It includes stages of approachability and acceptability that involve participants making numerous decisions even before the stage of reaching the available HIV testing services. These stages defined

the properties of the experience of accessing testing and had mental and social dimensions. Mental or intrapersonal included emotional, cognitive and spiritual dimensions, while the social included relational, material and symbolic dimensions. Symbolic dimension had five values: community, ethical, social representations, legal and policy. The above-mentioned categories of “barriers” and “enablers” are necessary to understand the experiences relating to accessing HIV testing and should interact with the category “abilities” for these experiences to happen. The ability of participants was influenced by diverse determinants, which interacted with the three stages to enable participants perceive the need for testing, seek testing, and reach testing. In some cases, participants who experienced opportunities provided by available options to testing said that they were enabled to test. All participants reported obstacles and problems to do so and, in most cases, said that they experienced barriers.

3.4.2. Barriers

The category “barriers” included two mental dimensions: lack of information on HIV, relating to first property approachability; and fear relating to another property availability of HIV testing services. Participants expressed fear due to the characteristics of these services and the modes (mechanisms) of service provision. They also expressed distress over the failure of services to help serve (or accommodate) their needs, which turned out to be an obstacle to approaching testing. It emerged that a major barrier for participants to begin even thinking about whether and where to test was lack of information on HIV.

“I think that many people don’t know about what it is and what the disease is actually like. We all hear AIDS AIDS AIDS HIV HIV HIV but people don’t know like what it is really hey.”

(Participant N06, a 20-year-old woman (born in Canada))

“I was afraid I was scared. Like I said finding out is the difficult part.” (Participant N019, a 19-year-old man (born in Canada))

“The fear of results.” (Participant N02, a 22-year-old woman (four years in Canada), (French-speaking participant)) *“It can be shocking. Not prepared to believe that you are in that category.”* (Participant N03, a 27-year-old man (25 years in Canada))

The category “barriers” had one social dimension of limited outreach of HIV testing programs, relating to the property availability of testing services. Participants strongly expressed feelings of frustration at the lack of outreach HIV testing services especially in schools. *“For example, like schools you know what I mean...they have vaccines and stuff like that ...but vaccines they are injected... this is HIV testing and sexuality. And we say that oh people should have sex above 18 years of age. But nowadays f... people are having... excuse my language ...people are having sexual activity at a very young age.”*(Participant N017, a 19-year-old man (born in Canada))

The category “barriers” included legal and values dimensions, relating to property acceptability. Participants railed against the criminal law of HIV non-disclosure, which they described as a major barrier to accepting testing due to fear of prosecution. *“One has to control sexual behaviour. The law builds a barrier. People are already in denial you add another barrier. People want to have sex without knowing they did not commit a crime. It is psychological.”* (Participant N03, a 27-year-old man (25 years in Canada) *“Certainly, I find this law terrible and unhelpful because it says as an HIV-positive person, you are a criminal.”* (Participant N08, a 20-year-old woman (born in Canada) (French-speaking participant). While the law acts as a barrier, one participant did not see it as a discouragement to accept a test and described the law as a possible enabler to testing.

“If ever you are having sexual relationships with somebody else they also need to be aware of what they are getting themselves into.” (Participant N04, a 21-year-old woman (born in Canada))

The category “barriers” further included cultural dimensions of representing HIV as death, testing as a disciplinary tool, and youth as invincible, relating to property acceptability. Participants took to task the way society represents HIV as death, which made it so difficult to accept testing. Some thought they were invincible denying them to accept testing, especially for participants who reported never testing in Ottawa, including those who had previously tested for immigration reasons before coming to Ottawa. Participants also felt grossed out by testing, which they described as a tool used to identify sexually deviant behavior and remarked that this represented a major constraint to judging HIV testing as appropriate. Because of that they did not want to be seen in that light by others. As a result, participants interpreted a negative test as vindication.

“Yes, I have done nothing to blame myself of.” (Participant N09, a 21-year-old man (ten months in Canada), (French-speaking participant))

“At this age our blood is still strong.” (Participant N021, an 18-year-old man (six years in Canada).)

“I am in good health.” Participant N07, a 21-year-old man (one year in Canada) (French-speaking participant) *“You know HIV is a horrible disease, so people are afraid. It is death. From the moment one contracts HIV there are no other ways to survive. It is death, which is not really correct.”* (Participant N023, a 24-year-old man (four years in Canada) (French-speaking participant)) Barriers at the stage of approachability interacted with abilities of participants to perceive the need for testing, chose testing and reach testing.

3.4.3. Abilities

The category “abilities” included two mental dimensions of low health literacy and inability to obtain information about HIV, relating to property approachability. It emerged from the interviews that ability of participants to recognize the need for HIV testing, which is crucial in seeking and obtaining testing was greatly reduced by low health literacy. For some, the inability to perceive the need for testing contrasted sharply with their experience from their countries of origin where knowledge about HIV is widespread. Participants expressed great disappointment at the inability of some of their friends to obtain adequate information they needed about condom use, which can break during sex and may lead to contracting HIV. All participants expressed a sense of hopelessness and gloom at the low health literacy and inability to obtain information.

“It is not like hepatitis disease. It is not like everyone has it. A lot of people just don’t think about it. So, I think may be that is why people don’t just go... like too many reasons.” (Participant N06, a 20-year-old woman (born in Canada)). *“They like just say don’t worry man I have got this you know they just try to play tough. Me I always tell them no it is not like that... that’s how it works. One day it is going to break up. You are going to wake up and you are not going to understand this happened.”* (Participant N015, a 27-year-old man (15 years in Canada)) *“I never knew HIV is a big deal. No warning about it.”* (Participant N01, a 20-year-old man (seven years in Canada): *“I don’t see many people living with HIV. It is of little importance. I think there is no HIV here.”* (20-year-old man (one year in Canada), (French-speaking participant))

The category “abilities” also included two mental dimensions of inadequate knowledge about HIV testing options and fear of certain healthcare places, relating to property availability of HIV testing. Participants who had never tested described an acute sense of fear to reach testing in certain

healthcare places, especially where targeted risk-based HIV testing was offered. *“One time I was afraid when I went to visit a clinic where HIV testing was offered for free. I wanted to go in but unfortunately, before the door I was transfixed with fear. I returned, and I have never had a test.”*

(Participant N013, a 19-year-old man (born in Canada) (French-speaking participant))

The category “abilities” further included two social dimensions of beliefs about HIV as a disease that happens to others and of lack of policy, relating to property approachability. Participants who did not have a test done clearly expressed a reduced sense of perceiving the need for testing and were dismayed at the little publicity on HIV testing opportunities, which left little opportunity for them to obtain the needed information about available options. Participants expressed that something needs to be done to disseminate the required information at the policy level to enable individuals recognize need for testing.

“It is necessary that people in public health communicate at all community levels, be it family television. It is necessary that they listen... that they are in danger....if somebody does not know their HIV status.” (Participant N023, a 24-year-old man (four years in Canada), (French-speaking participant) *“I do not want to be thought of as having one.”* (Participant N01, a 20-year-old man (seven years in Canada))

The category “abilities” also included two ethical dimensions of not wanting to lose reputation and racialization, relating to property acceptability. Participants described the embarrassment and pain to choose testing due to racialization of HIV. Participants including those who had been tested prior to coming to Canada but had never tested in Ottawa further expressed in agitation their view of losing reputation if tested HIV positive. This in turn reduced their ability to exercise personal

autonomy to choose seeking testing. *“My reputation. It is very important for my reputation...like people ...maybe people may run away from me I don't know.”* (Participant N025, an 18-year-old man (three years in Canada). *“Why not it is a good thing. But I can feel ill at ease if I am targeted to test because I am African. It is the way of presenting it. It can be misunderstood. I am African, black.”* (Participant N02, a 22-year-old woman (four years in Canada), (French-speaking participant).

The category “abilities” included more social dimensions of lack of family and community support and still others at material and symbolic levels, relating to property availability of HIV testing services. It emerged from the interviews that lack of social support from peers, parents, and society and healthcare providers was a major deterrent that affected ability to utilise HIV testing at the interpersonal level. Participants felt disturbed that parents did not inform their offspring about the dangers of HIV infection, which limited their ability to utilise HIV testing services. For participants, even more alarming were the social reactions about HIV that were rejecting rather than supportive. All these acted as constraining factors to reaching testing. The lack of community support emerged as a major barrier as participants expressed that reaching these services can be bothersome given the stigma associated with HIV.

“I think scientifically we have made enormous progress on the subject of HIV or AIDS but socially there is not much progress because there is still discrimination and stigmatization around HIV.”

(Participant N08, a 20-year-old woman (born in Canada): (French-speaking participant))

“Maybe sometimes their friends may know that they are affected by HIV.” (Participant N011, a 20-year-old man (eight years in Canada)) *“A major reason preventing people to test is fear, will someone see me?”* (Participant N08, a 20-year-old woman (born in Canada), (French-speaking

participant)) *“And if you have it that sucks for you.”* (Participant N21, a 19-year-old man (six years in Canada)) *“The parents don’t discuss these affairs directly with their children. The parents need to be open with their children about the effects of HIV and how they can acquire it”* (Participant N023, a 24-year-old man (four years in Canada) (French-speaking participant)). *“Our society is rejecting today, right, that is why people are afraid of getting tested.”*(Participant N04, a 21-year-old woman (born in Canada)) Or *“The people will point fingers at you that you have HIV.”* (Participant N02, a 22-year-old woman (four years in Canada), (French-speaking participant))

One participant was troubled after reaching a healthcare provider of not being taken seriously, which could reduce using testing services in future. *“Ohhh well I think my experience with the Doctor wasn’t ve...ry good. I found he was very dismissive...how can I say that...very impersonal. For someone who does that for the first time and is very fearful, to go through something like that without support of a person like the Doctor or the nurses, it is not correct.”* (Participant N08, a 20-year-old woman (born in Canada), (French-speaking participant))

Participants expressed apprehension about the material poor living conditions and less occupational flexibility that reduced their ability to reach HIV testing. This was true even for participants who never tested.

“Not familiar with the context, studies, stress, personally I cannot go to hospital to test.” (Participant N07, a 20-year-old man (one year in Canada) (French-speaking participant)) *“Other than fear, other barriers are – I work, family, all that. I don’t have time for testing.”* (Participant N05, a 21-year-old man (born in Canada), (French-speaking participant)) *“It is not only HIV that*

is... that is being detrimental to their life. Sometimes it is just life. People have things blocking them getting there. So, no point of having 21 clinics, if people can't actually get access to them."

(Participant N012, a 20-year-old woman (ten years in Canada))

Moreover, participants were concerned that cultural taboos about sex, foreclosed discussions about using HIV testing services. They also put the blame on some faith leaders for discouraging discussing condoms, which in turn limits knowing more about HIV testing services, which would enable them individually to physically reach these services.

"You do not go to Church telling people to use condoms... I think in Church they will tell them to not having sex with anybody whom you don't know or you are not married to." (Participant N027, an 18-year-old man (six years in Canada)) *"People don't talk about sexuality in African contexts."*(Participant N02, a 22-year-old woman (four years in Canada), (French-speaking participant))

3.4.4 Enablers

The category "enablers" included the mental dimensions of knowledge, peace of mind, and being responsible, relating to property acceptability. Participants highlighted that the best thing was to know, which enabled them to judge and accept HIV testing services as appropriate. Participants recognized the spiritual aspects that encouraged them to choose testing. They appreciated that HIV testing can save lives of others, such as, of a partner, children and others, which influenced them to accept testing for HIV as appropriate.

"Children, morality, for the marriage. Avoid transmission. You will be having children. Avoid opportunistic infections ...consequences for your children and your partner." (Participant N02, a 22-year-old woman (four years in Canada) (French-speaking participant)) *"I figure like if I would*

be in that situation, I feel like it is better for me the best thing... to know it is better right and I can talk to my doctor and think about like the steps to follow.” (Participant N04, a 21-year-old woman (born in Canada) *“But then sometime if you don’t use protection you going to have that doubt in your head. So by having that test it gives the peace of mind to live in comfort.”* (Participant N017, a 19-year-old man (born in Canada))

The category “enablers” further included social dimensions of availability of HIV testing technology, medication and HIV testing policy, relating to property approachability. Participants expressed that availability of HIV testing technology, medication and HIV testing policy made them perceive the need for testing. Despite the initial barriers, participants freely talked, for instance, about availability of medication, which increases survival and hope enabling to see how important testing is.

“I have heard that there is people out there that have had HIV and they live 20 years and even more because of the tools they have been given...the medicines that they have been given... there is hope this is not the end of the world.” (Participant N017, a 19-year-old man born in Canada).

“Back in the days we did not know whether if you have HIV or not people were like kind of afraid they didn’t really understand what was going on. But now we are living in a world where we got the technology to do it and I think it is pretty a good thing so yah why not.” (Participant N015, a 27-year-old man (15 years in Canada))

One participant born to an HIV-positive mother articulated the positive aspects of maternal HIV testing. *“I can tell you that personally I have no problem because I understand very well what HIV is. This is about my health. I want to know how...that does not affect me.”* (Participant N08, a twenty-year-old woman born in Canada (French-speaking participant))

The category “enabler” further included two social dimensions: availability of opt-out testing and support of a healthcare provider after reaching HIV testing. Participants acknowledged the availability of anonymous HIV testing as free, convenient, and easy.

“Easy. Why because to me it is easy. Because I didn’t pay. It was free. It didn’t take all that long to give me the results. Here in Ottawa.” (Participant N025, an 18-year-old newcomer (three years in Canada)) *“It is not difficult. Why? Because like it is available it doesn’t take long. Took me maybe 10 minutes in Ottawa.”* (Participant N023, a 24-year-old man (four years in Canada)) *“There wasn’t really much. You sign a form. They tell you that what is going to happen if you do have something they will call you to come in. They will talk to you... it is all private they told me it was all confidential. So, it was pretty an easy experience. It wasn’t frightening at all.”* (Participant N010, a 21-year-old woman born in Canada)

One participant said that strengthening their bonding was a major enabler to seeking testing: *“We don’t have family here. So, I want to be safe with my partner. Right. Personally, I cannot have kids I have problems with my eh ...uterus or something like that.. So, I am always ...have an appointment with my doctor. From there I feel like check up my physical body. I like to keep everything safe. I test for HIV and the other part women stuff.”* (Participant N04, a 21-year-old woman (born in Canada))

The category “enablers” also included an ethical dimension of being responsible. Participants expressed unequivocally that testing was the responsible thing to do in a relationship. This was a major enabler to judge and accept HIV testing as appropriate. *“Well, for me, honestly it is when I became sexually active that I was motivated to test because that is part of being responsible.”* (Participant N08, a twenty-year-old woman (born in Canada) (French-speaking participant))

3.5 Discussion

Principal Findings

This study aimed to fill a gap in the literature about HIV testing experiences among undiagnosed young heterosexual African migrants from HIV-endemic countries, especially young men, in Ottawa. The results show cumulative interrelated barriers and enablers experienced by participants in accessing HIV testing services at various stages and levels. That is, at three stages of approachability, acceptability, and availability of services influenced by determinants at the intrapersonal, interpersonal, organizational, community and policy levels that shaped abilities of participants in perceiving the need for HIV testing, seeking HIV testing and reaching HIV testing.

Barriers, abilities, and enablers

The three categories discussed under the results section above are important to explain the experiences in accessing testing among the participants. A review of the literature shows that barriers and facilitators to accessing HIV testing are often examined on either personal and interpersonal or structural level.⁽³⁹⁾⁽⁴⁰⁾ Individual-level barriers discussed in the reviewed literature include, fear, lack of awareness and perception of risk,⁽³⁹⁾⁽⁴⁰⁾ while interpersonal-level barriers often identified have been partner considerations and provider characteristics.⁽⁴⁰⁾ Other previous studies have found that testing is not always accompanied by adequate pre- and post-test counseling in Canada, if at all.⁽¹⁰⁶⁾ At the structural-level, location of testing services, strategies to test, discretion, barriers of transportation and lack of comfort among men in antenatal clinics are some of the other barriers to testing reported.⁽⁴⁰⁾ Still others are national and local guidelines, which can act as barriers and facilitators to HIV screening.⁽⁴⁰⁾ A clear example is the law that

criminalizes HIV, which is a major barrier to HIV testing for many Canadians due to fear of non-disclosure prosecutions.(107)(108) Most studies have often studied men who have sex with men (107)(108), people who inject drugs (109) or pregnant women (106)(110) to investigate barriers to testing in Canada. For instance, even as HIV non-disclosure charges have been brought against heterosexual men, with African men disproportionately represented,(111)(112) still little is known about experiences to testing including legal barriers among this group,(7) which is overrepresented among the late presenters to care after contracting HIV.(72)(97)(98)

A recent review among heterosexuals that included Canada (and the UK) also found personal related barriers (including socio-demographics), provider-related and system-related barriers that affected the uptake of testing in Canada.(8) For instance, the young (younger than 25 or 30) and older populations as well as recent immigrants were less likely to have been tested for HIV.(8) Respondents in the reported studies who had lived in Canada for less than ten years were more likely to report testing compared to those who had lived in Canada for more years.(8) Other barriers included lower risk perception, level of knowledge on testing, cultural beliefs, and the role of doctors in recommending the HIV test to clients.(8)

On the other hand, several studies have found a gender difference in HIV testing uptake, with migrant men being not only less exposed to HIV testing but also less willing to be tested.(113) Various barriers to sexual health care seeking among men that have been documented include conflict of traditional masculinity with a feminized health care culture, concerns over wait times and cost, and perceived lack of community support for sexual health care seeking.(114)(115)(116) Examples of expected masculine behaviour are invulnerability and sexual prowess,(114) implying

that gender role conformity can impact healthcare seeking behaviour. For instance, the understanding among young men of care seeking and health care spaces as “feminine” acts as a barrier to utilization of sexual healthcare services,(115) including testing for HIV.

Research on improving care for patients with other stigmatized diseases,(117) such as leprosy,(118) and mental health (119) has further demonstrated the existence of barriers and challenges behind accessing care for these patients. According to a recent systematic review, most multi-level stigma intervention research focus at one or two levels, mainly the individual/interpersonal levels or structural levels.(120) Yet, the impacts on stigma reduction efforts can be improved if multi-level barriers are addressed than single-level interventions.(120) This may bring about farther reaching, more synergistic, and more holistic outcomes, including for HIV testing interventions.

The above reviewed studies endorse the findings of the present study. This study, for instance, found fear, lack of awareness and perception of risk as major barriers to accessing testing at the personal level. The duration of stay in Canada presented a major barrier. Four men in this study who had stayed in Canada for more than ten years reported never testing, while three men reported testing outside the country for immigration reasons but not in Ottawa, two of whom were newcomers. Low health literacy was also identified as a major barrier to testing, especially among young men. This study found little information on adequate pre-test counseling. Structural-level barriers found in this study included the location of testing services and the strategies to test. Young men reported feeling uncomfortable approaching clinics that target men who have sex with men or people who inject drugs. Strategies to test especially, opt-out testing and anonymous testing

were preferred in this study. National and local guidelines reported in this study as barriers and facilitators to HIV screening, included Canadian law that criminalizes HIV. Another major barrier was lack of outreach programs.

There were gender differences also observed relating to barriers to accessing testing. Only two young men, one of whom was a newcomer, reported testing at the request of a health care provider, but five men reported anonymous HIV testing at a facility in Ottawa at their own initiative, of whom only two were newcomers. All the women (n=6) reported testing for HIV in Ottawa at the request of a health care provider, of whom only one participant was a newcomer suggesting a higher perception of risk among women than men in this study. Although a test is generally accepted if offered in the prenatal period, when testing is often presented as "good for the baby", (65) men and women reported different barriers before and after reaching testing. Despite the success of provider-initiated HIV testing programs among young women in Ontario,(100) young women reported experiencing unique problems even after reaching testing services in this study such as not being taken seriously by a provider.

While HIV testing decisions in this study were influenced by a variety of competing factors including sex and gender, certain strategies to testing can be important in improving access. Provider-initiated routine testing if implemented in Ontario may enable minorities, including the study population to access testing, since they reported acceptance of this strategy as long as it is for all and not targeting only Africans. Scaling anonymous testing in Ontario will enable especially young men access testing. This strategy was preferred by many in this study.

Although our findings are in agreement with prior studies, it is important to point to differences between these studies and our findings. A major difference and contribution of this study is its focus on African heterosexual migrants from HIV-endemic countries, especially men. The conceptualization and operationalization of access to care in this study is an additional contribution. Access to care was understood as a process interacting with the abilities of participants rather than simply utilization of available testing services. Access to healthcare has been defined as “the opportunity to identify healthcare needs, to seek healthcare services, to reach, to obtain or use healthcare services and to actually have the need for services fulfilled”.(19)^(p.8)

This has implications for policy and practice in programming interventions that address gaps in the abilities of patients at various stages, not only relating to HIV testing, but for also other stigmatized diseases. Similarly, the socio-ecological assumptions espoused in this study enabled to highlight complex causal pathways of the experiences to accessing testing, which we could have missed if only one or two levels were examined. These causal pathways should be reflected in planning more equitable HIV testing services. Prioritizing a collaborative style working with an interdisciplinary team together with the community health service providers from the beginning of research to reporting further contributed to the development of new theory about accessing HIV testing in this study.

Cumulative interrelated barriers to testing

Participants reported barriers beginning from the initial stage of approachability until reaching the available testing options. Lack of outreach opportunities at the organizational level especially the absence of HIV testing in schools that participants mostly frequented, presented a major barrier to

initiate the process of approaching an HIV testing facility. Yet, all participants reported some educational background and almost half of them (n=9; 45%) reported attending an educational institution at the time of the interview. The deterring factors to approachability of services interacted with determinants that affected the ability to recognize the need for testing. This study identified major mental barriers relating to the inability to obtain adequate information about available HIV testing options, which prevented recognition of the need for testing. Social barriers included social representations about HIV as a disease that happens to others and HIV policies that fail to provide adequate information. These barriers made it difficult to see the need for testing. Barriers to testing increased at the stage of acceptability with participants reporting social and cultural determinants. At the legal level, fear of prosecution was further influenced by judgemental reactions from society that made participants not to choose seeking testing. Other factors were racialization of HIV and the way society represents HIV.

Thus, many obstacles already accumulate before physically reaching available HIV testing services and the service provider. At the stage of availability, this study identified emotional barriers relating to fear and stress arising from the mechanisms of HIV testing. It is possible that the mechanisms of HIV testing, for instance, standard testing where blood is drawn and sent to a public health laboratory, take longer.⁽³³⁾ This can lead to fear of results and increased stress in comparison to rapid testing. Barriers at this stage of availability interacted with the lack of knowledge about HIV testing options, especially in the case of young men, who expressed feeling unwelcome in health spaces that offered target testing to men who have sex with men and people who inject drugs. Social level barriers included lack of social support, which prevented reaching the available services due to anticipated negative reactions arising from interactions with peers,

parents, society and healthcare providers. At the material level, participants reported poor living conditions and having less occupational flexibility, while at the symbolic level, cultural values relating to sex taboos were identified. All these interrelated mental and social factors obscured the ability to know more about testing, which would enable reaching the available testing.

To complicate matters further, the above access barriers at each stage were sequential at the intrapersonal, interpersonal, organizational, community and policy levels. But these sets of processes cannot be considered linear. The deterrent factors at each stage can be different, while the abilities of individuals may depend on several factors. Moreover, feedback loops – within and across levels – demonstrated that the context at times reinforced, and at other times corrected, barriers within and across multiple levels. Feedback loops in this study referred to interactions across multiple levels that reinforced (perpetuated) or corrected existing barriers (enabled or provided opportunities to reaching testing). As a result, despite the cumulative and sequential barriers, this study also found access enablers at the mental and social levels before reaching testing, especially, the ability to judge HIV testing as appropriate at the mental level and the availability of opt-out testing and anonymous testing at the social level. These grounded perspectives about access barriers as well as enablers to reaching HIV testing interacting with abilities of populations have implications for various stakeholders.

3.6 Limitations

A major limitation of the study was that it focused on only two sites in Ottawa and the results must be interpreted in this light. Applying Grounded Theory enabled generating theory grounded in the

data (23)(24) that is a fit for this group rather than a theory developed elsewhere for other groups. The techniques that were applied, and the multidisciplinary team with primary care, legal and methods expertise as well as the consistency between findings in this study and previous studies point to the merit of this study. The comprehensiveness of the findings allowed making recommendations that may resonate in other Ontario contexts. This being one of very few qualitative studies among young African heterosexual migrants from HIV-endemic countries that involved both men and women added to the merit of these recommendations.

3.7 Practical implications

This study recommends benchmarking enablers that can attract young heterosexual African migrants to test. A needs assessment study in neighborhoods is, thus, recommended to know more about these enablers as well as barriers to achieve more effective results. Interventions based on knowledge from the ground are more likely to work.

Some barriers to testing were obvious and closely connected to HIV testing and related to stakeholder capacities or input, such as “fear of results”, “fear to be judged” or “fear of discrimination”, lack of awareness of available HIV testing options, and feeling unwelcome in health care spaces targeting other key groups. This study recommends strengthening HIV awareness campaigns to reach young heterosexual African migrants, especially men in areas where they can be found, such as, social networks and sports to create awareness. In addition, we recommend mobile outreach programs to reach those who are difficult to reach. The present study suggests interventions to focus on newcomers and those born in Canada or stayed in Canada more than 10 years paying special attention to the sex and gender characteristics of target populations to address gaps in their

abilities. This study recommends healthcare providers to strengthen provision of pre-test counselling for informed consent. Communities should provide support (emotional and moral) to young people to overcome all barriers to test and advocate for their reduction. Communities have the power to do so given the strong ties young people have to communities. This study recommends that faith leaders should be more open about sexuality to address obstacles to approaching testing relating to taboo surrounding sex and the masculine value judgments that arise. Faith leaders have the capacity to reach these groups and should play a major role in making a difference in overcoming stigma surrounding HIV.

Other barriers were less obvious or implicitly linked to HIV testing often due to poor policies, laws and programming. These may be more challenging to resolve but may contribute more to addressing these barriers in terms of outcomes or performance. Federal Government of Canada should decriminalize HIV to address the fear of non-disclosure prosecutions, which remains an obstacle to accessing HIV testing among African migrants both men and women in this study. Ontario Government should implement provider-initiated routine testing and HIV self-testing policies, while increasing the reach of anonymous testing that should include rapid testing, to address efficiently the issue of minorities who are not approaching testing. This study recommends the design, implementation and evaluation of HIV testing policy and programs that should include health service providers, communities, and representatives from target populations in Ontario.

Still other barriers in this study have root causes requiring long term interventions. These interventions can have an impact on the barriers, and if changed meaningfully may address a number of issues. First, policy interventions on various levels of government should alleviate

adverse determinants hindering accessing HIV testing. Ontario Government should implement policies that improve employment and working conditions as well as education opportunities to address precarious socio-economic conditions of young people that left little time to test. This study recommends further that Government of Ontario conduct health reforms to improve the present system of delivery of care services by considering social determinants of health that affect health of populations in utilizing these services as revealed in this study. Health reforms will also address issues relating to accessing healthcare in general for patients with other conditions.

Chapter 4: Paper 3. Access Barriers to Reaching HIV Testing among Young Heterosexual African Migrant Men from HIV-Endemic Countries: Challenges Experienced by Community Health Service Providers in Ottawa

Abstract

Objectives: Health service providers rarely understand the challenges behind HIV testing for young heterosexual African migrant men from HIV-endemic countries in Ottawa, Canada. These challenges may be contributing key barriers to HIV testing but remain under analyzed. Most of the literature on HIV testing in high-income countries, including Canada, focuses on men who have sex with men, people who inject with drugs and women. Evidence about challenges and barriers before and after reaching testing is required to inform policy and practice in planning more equitable HIV testing interventions across populations that involve African migrant men. This qualitative study explored the experiences of health service providers to identify challenges that may be contributing to barriers before and after reaching HIV testing among undiagnosed young heterosexual African migrants from HIV-endemic countries living with HIV, focusing on young men, in Ottawa.

Methods: Using Grounded Theory informed by a socioecological approach and access to care framework, face-to-face semi-structured interviews were conducted among eight health service

providers recruited from community health centres, AIDS service organizations and community-based organizations between May and October 2017, in Ottawa.

Results: Health service providers reported challenges, which contributed barriers to test approachability, acceptability, and availability of services influenced by various determinants. Multiple problems were encountered by health service providers at intrapersonal, interpersonal, organizational, community and policy levels. This corroborated findings from the prior study showing that young heterosexual African migrants often were unable to recognize the need for testing, choose to seek testing and obtain testing due to multi-level determinants. Differences in accessing HIV testing between young heterosexual African women and young men also presented further challenges that increased barriers to testing among this population. Participants reported especially the lack of outreach programs as a major barrier among young men at the initial stage of test approachability and the inability of this population to obtain information on HIV testing options they needed.

Conclusions: Translating knowledge into HIV testing programs that can be timely reached among young heterosexual African migrants from HIV-endemic countries, especially men in Ottawa will require health service providers and planners to be fully aware of the challenges involved; if these challenges are to be addressed in order to deliver culturally safe and competent HIV testing services. Several other recommendations have been provided to improve access to HIV testing that may reduce access inequities in Ottawa.

4.1 Introduction

What are the challenges experienced by health service providers in making HIV testing services accessible to undiagnosed young heterosexual African migrants from HIV-endemic countries, especially young men, in Ottawa? Health service providers rarely understand challenges behind HIV testing for young heterosexual African migrant men from HIV-endemic countries in Canada. These challenges may be contributing to barriers to accessing testing but remain under researched.(7)(8) Research shows that heterosexual African migrant men in high income countries, including Canada, are not only less exposed to HIV testing but also less willing to be tested.(2)(97)(113) Patients may experience obstacles at the various stages of accessing health care,(19) before and after reaching HIV testing services and health service providers. These obstacles may increase health inequalities among populations. Challenges experienced by providers that may be contributing barriers to testing can be more complex and may be experienced at multiple environmental levels of influence, such as at the intrapersonal, interpersonal and broader organizational, community, and policy levels.(20) Evidence about challenges and barriers to accessing testing across populations and at multiple levels of analysis is urgently needed to inform planning more equitable services critical in achieving UNAIDS target of 90 percent of people living with HIV knowing their HIV status and receiving treatment to achieve viral suppression by 2020.(64) This paper reports findings about challenges experienced by community health service providers contributing barriers to reaching HIV testing services among young heterosexual African migrants, especially young men, in Ottawa. We begin by providing a review of the existing literature followed by the study framework and methods. We then present the results, discussion and the implications for research, policy and practice.

4.1.1 Review of existing literature

Provider-related challenges in offering testing to young heterosexual African migrant men

Realizing equitable access to HIV testing services will require prioritizing sustainable healthcare.

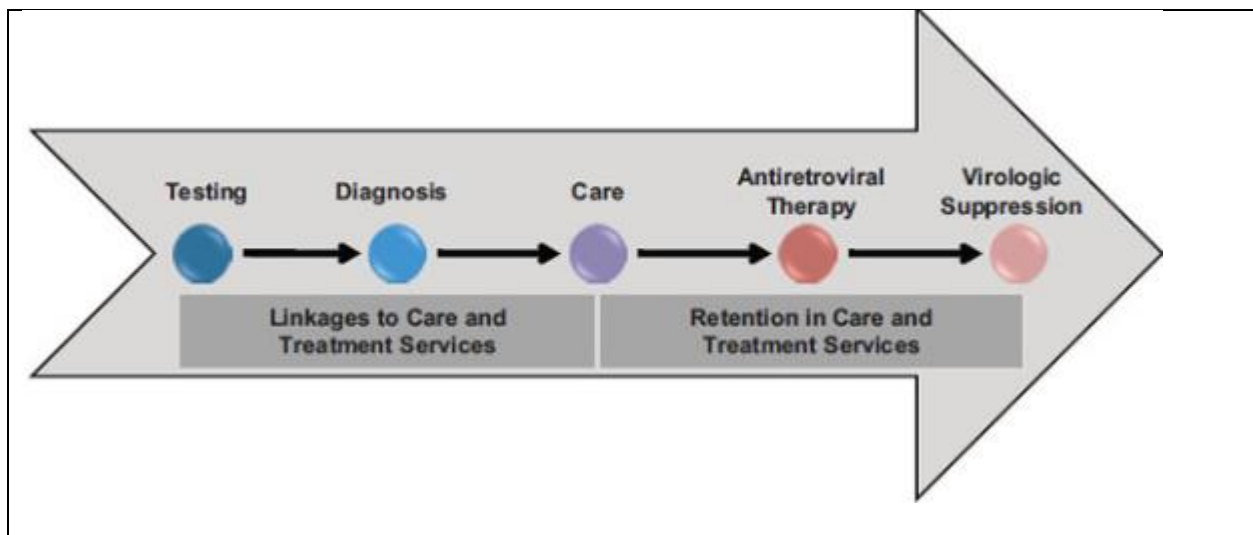
Fair and timely access to care is one of the guiding principles in achieving sustainable healthcare

in Canada.(114) Figure 4.1 illustrates the steps that especially those living with HIV undergo to

access health care required to suppress the viral load and achieve optimum health.(89) HIV testing

is the first but most crucial step in the HIV treatment cascade.

Figure 4.1. HIV cascade care/ care continuum



Source: Institute of Medicine et al. (89)^{p.244} Used with permission (Appendix 6)

At the individual level, HIV testing enables linkage to treatment for those diagnosed with HIV

(13)(122)(123) as well as reduction in risk-related behaviors on receipt of knowledge of positive

HIV status.(123) Research shows that early initiation of HAART restricts establishment of the

HIV reservoirs considered a major barrier to cure HIV infection.(122)(123) It means that without

timely initiation of HAART, most patients will experience the gradual failure of the immune

system from infection by opportunistic diseases and even death.(123) At the population level, there

are benefits of knowledge of HIV status in terms of reductions in health care costs and HIV

transmission.(124)(125)(126)Research shows that late presenters incur a significantly higher cost for medical services, in addition to their poorer health.(124)(125)Some reports further indicate that HIV transmission by undiagnosed individuals living with HIV unaware of their status is greater (126) than among those aware of their HIV status. It becomes critical to timely access HIV testing given the many negative individual and population health consequences among people living with HIV who present late to care. HIV diagnosed individuals who enter early effective treatment and care improve their health; and greatly reduce the probability of transmission of the virus due to reduced viral loads.(71)

The province of Ontario offers a variety of HIV testing options. Targeted HIV testing, for example, is conducted with populations identified as at high risk for exposure to HIV, specifically men who have sex with men and people who inject drugs.(32)(47) Some patients may not seek or ask for an HIV test due to fear of stigma and discrimination. As a result, the province has made available other testing options. HIV testing is offered in antenatal clinics to all pregnant women in Ontario as a routine part of care where they are free to opt-out.(47) Currently thirty eight active anonymous testing site organizations in Ontario also provide rapid or point-of-care tests.(33)^(p.5)A key question to the success of these efforts is whether healthcare providers and frontline providers can timely reach undiagnosed people living with HIV in Ontario. Healthcare providers offer testing to those in need, and frontline providers link those diagnosed with HIV to treatment and care. Nowhere is the need to timely reach HIV testing greater than among undiagnosed populations living with HIV, which can increase health inequities if not diagnosed early and left untreated. According to the World Health Organization, health inequities refer to individual and population health differences that are avoidable and unjust.(26)

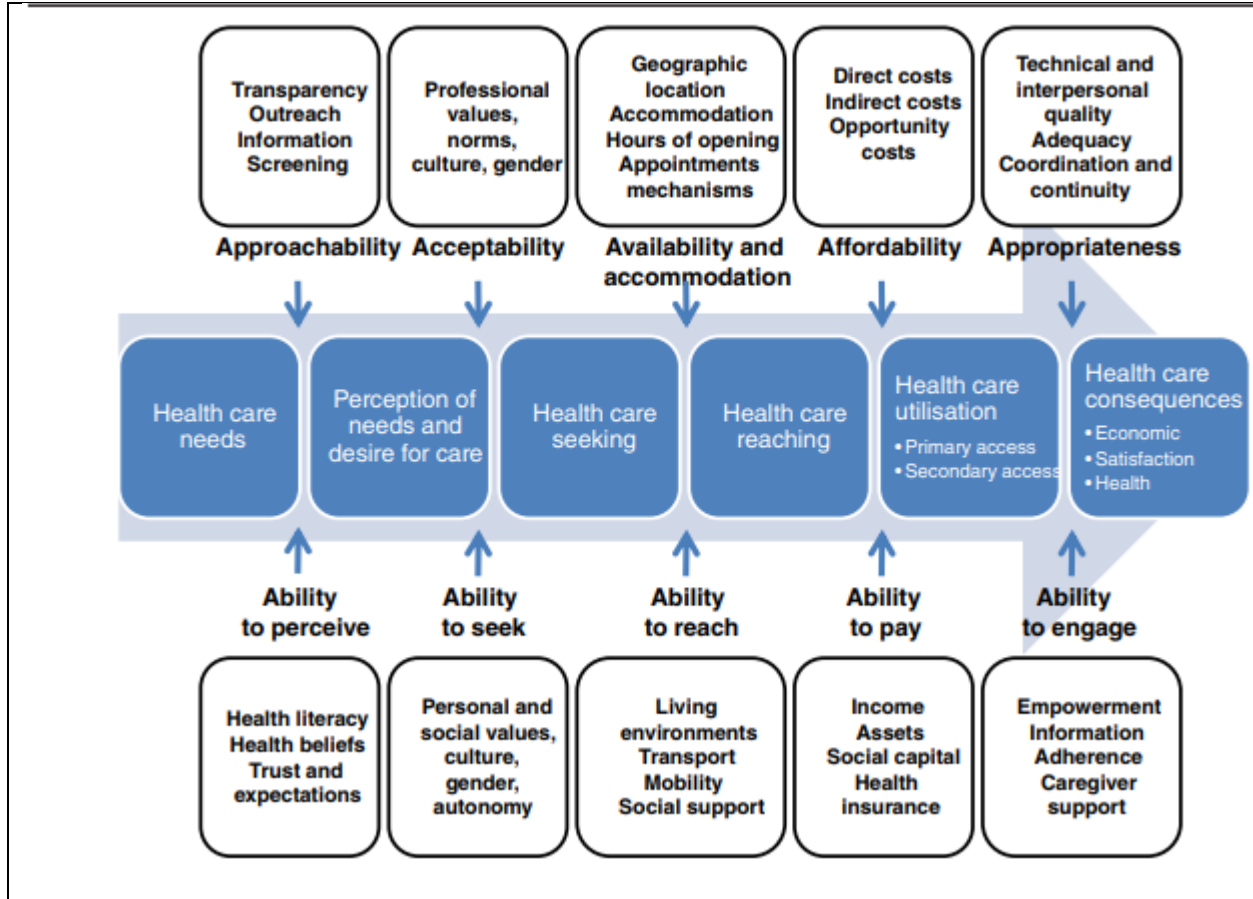
Research shows that eliminating service-level barriers may enhance the uptake of HIV testing in key populations.(127)(128) Knowledge about challenges encountered by health service providers is, thus, required to inform programming interventions in order to eliminate HIV testing service-level barriers and reduce health inequities in Ontario. Young heterosexual African men appear to be unable to reach available testing options in the province. Research shows that African Canadians from HIV-endemic countries remain under-diagnosed and overrepresented among the late presenters to care after contracting HIV,(72)(97)(98) due to reasons that remain less known in Ontario. African, Caribbean and Black (ACB) people only represented a small proportion (2.9 percent or 1.2 million) of the Canadian population, of whom about half (637,485) were Africans, according to the 2016 Canadian census.(96) Even if a minority of individuals are deterred from HIV testing, the ability to meet the UNAIDS target of 90 percent of those with HIV knowing their HIV status by 2020 will be compromised in Canada.(64)

Preventing HIV transmission and controlling the epidemic are only possible if available HIV testing services can be made accessible to undiagnosed people living with HIV and at the same time both undiagnosed men and women living with HIV can timely reach testing and link with the HIV care cascade. Although attempts have been made to describe the complex set of challenges encountered by health service providers in making HIV testing accessible among key groups, two recent systematic reviews have found scant literature in this area.(39)(40) Other reports have provided encouraging evidence about health service providers in overcoming certain challenges, such as the lack of HIV related knowledge and negative attitudes towards homosexuality.(10)

Improvements in the attitude towards HIV-positive patients and a committed, professional staff of care and support service providers have also been reported in Ontario.(129)

Despite these achievements, challenges experienced by healthcare providers and frontline service providers in meeting the complex needs of HIV patients continue to be reported in Ontario and elsewhere.(10)(129)(130) It is reported that even where specialist training has been provided, for instance, nurses may still encounter challenges to incorporate HIV testing effectively into routine care.(10) Studies about challenges facing nurses are still rare, yet the implementation of HIV testing relies heavily on nursing and midwifery staff.(41) Also there are is a dearth of knowledge about challenges faced by frontline providers who encourage accessing HIV testing and linkage to treatment, care and support. Enhancing timely access to HIV testing services, in addition to the health system and service delivery factors, will require encouraging widespread uptake of HIV testing.(131) To achieve that calls first for awareness of the real challenges faced by all health service providers from different disciplines who play a critical role in encouraging uptake of HIV testing services so that more effective HIV testing interventions can be planned.

Although attempts have been made to study provider-related challenges in this area,(9)(10)(11) the stages of access to health care are often not disaggregated in the reviewed literature. Disaggregating the stages is important since obstacles experienced in accessing HIV testing at various stages can be markers of inequities crucial to inform health planners to improve the quality of testing. The concept of access to healthcare, including HIV testing services, is multidimensional involving multi-level determinants that can impact access to care.(19) Figure 4.2 illustrates the various stages and corresponding abilities of patients in accessing care.

Figure 4.2 A conceptual framework of access to care

Source : Levesque and colleagues (19)^(p.5) Used with permission (Appendix 6)

This framework provides the basis for a stronger operational measurement of the stages in accessing healthcare than simply measuring accessibility without disaggregating the stages. It also measures the interaction between accessibility and the abilities of participants to access services important to identify gaps in the ability of participants. Approachability is the initial stage. It is where various determinants including transparency, information on available treatments and services and outreach activities may contribute to making services more or less approachable among certain population groups. The ability of targeted populations to perceive the need for care, also may be compromised by various determinants, for instance, low health literacy and knowledge about health and beliefs related to health and sickness. (19)

Similarly, the stage of acceptability involves patients judging the appropriateness of seeking care.(19) Cultural and social factors can influence the possibility for people to accept aspects of the service (e.g. the sex or social group of providers, the beliefs associated to systems of medicine).(19) At this stage of acceptability, the ability of patients to seek health care may be undermined by lack of personal autonomy or knowledge about health care options and individual rights that would enable them choose seeking to obtain health care.(19)

By contrast, availability and accommodation refer to the fact that “health services (either the physical space or those working in health care roles) can be reached both physically and in a timely manner”.(19)⁽⁹⁾ It implies that both physical characteristics and provider characteristics as well as the modes of provision of services (or accommodation) influence accessibility of services. (19) The ability of populations to reach healthcare can be influenced by many factors such as “personal mobility and availability of transportation, occupational flexibility, and knowledge about health services”.(19)^(p.9) Thus, each transition in accessing care is crucial where multi-level challenges may be experienced by providers that call for explanation.

Health service providers may further encounter challenges relating to the above stages at multiple environmental levels of influence. Levesque and colleagues (19) fail to provide precise measurements for these challenges, despite highlighting the various determinants influencing accessibility. By contrast, Richard and colleagues(20) provide precise environmental levels of influence at the intrapersonal, interpersonal and broader organizational, community, and policy levels to measure these determinants. It means that availability of HIV testing services themselves

may not be enough to determine if providers will timely make accessible testing services to young heterosexual African migrants, especially young men. Interactions between the various stages and abilities of patients beginning from approachability of testing services to the actual benefit of reaching these services can create challenges for providers that may contribute access barriers at multiple levels in Ontario.

Ontario has the largest proportion of people originating from countries where HIV is endemic, representing 4.5 percent of the provincial population, according to the Public Health Agency of Canada.^{(103)(p.7)} Ottawa is among the five cities with the largest number of people originating from HIV-endemic countries (Toronto, Montreal, Vancouver and Calgary are the other cities).^{(103)(p.7)} Translating knowledge into culturally competent HIV testing services essential to reduce the pool of undiagnosed people including young heterosexual African migrants living with HIV and link them to care, in Ontario, will call for evidence that provide meaningful insights needed to inform planning these services.

Using a Grounded Theory approach is particularly appropriate to provide such evidence since relatively less is known about testing experiences in this population.⁽²³⁾⁽²⁴⁾ Such grounded theory analyses will inform health service providers about challenges behind HIV testing for this population not readily available in clinical settings as well as enable policy makers and the communities to scale up more equitable HIV testing services. What is lacking are in-depth studies about challenges behind HIV testing for young heterosexual African migrants in Ottawa. This study used a qualitative methodology to explore experiences among health service providers with

the aim of identifying challenges they face that may be contributing to access barriers in reaching HIV testing services among this population, especially young men.

4.2 Study theoretical framework

This study followed socio-ecological assumptions.(20)Socio-ecological constructionist assumptions were applied to Grounded Theory method. Socio-ecological constructionists assume that participants, including observers and those being observed, construct meanings based on their own contexts.(20) By contrast, Grounded Theory is an approach that uses constant comparative method of data analysis with specific assumptions and procedures to generate theory.(23) It has roots in symbolic interactionism, which assumes that individuals give meanings to their interactions through interpretations. Grounded Theory also differs from other qualitative approaches most of which stress collecting data before analysis. The specific procedures of Grounded Theory are simultaneous collection and analysis of data, a two step data coding process, constant comparison, memo writing, sampling to refine the researchers emerging theoretical ideas or theoretical sampling and integration of theoretical framework.(23)(24)

Drawing on socio-ecological constructionist assumptions, this study assumed that social reality is constructed from interpretations, including those of the observer, during interactions in specific contexts. First, data collected in this study were assumed to be the creation of study participants based on their experiences of providing HIV testing in their contexts. Similarly, this study assumed that researchers were active participants who constructed concepts to generate a theory based on data from experiences of health service provider participants who provide HIV testing services. At the same time, drawing on socio-ecological assumptions, this study developed the design,

collection, analysis and reporting of data in collaboration with a team of researchers including the community. The methods used in this study are outlined below.

4.3 Methods

Grounded Theory

This study used constant comparative analysis,(23)(24) by creating and refining the research and data collection questions, constructing analytic concepts from codes, writing memos to create categories; and writing and re-writing to gain more analytic clarity, while integrating other theories within the discussion and analysis.

4.3.1 Participants

This study was conducted among participants from community health centres, AIDS service organizations and community-based organizations. Because we wanted to include a wide variety of lived experiences, views and interpretations to reach maximum theoretical variation,(104) health service providers who were asked to participate had various characteristics (see Table 4.1).

Table 4.1 shows interview participant characteristics.

Table 4.1. Interview participant characteristics

Characteristics	Number of participants (8)
<i>Country of origin</i>	
Canadian	3
African	5
<i>Gender</i>	
Male	3
Female	5
<i>Highest level of education completed</i>	
Post-secondary ¹	6
PhD	2
<i>Employment</i>	
Health care provider ²	3
Frontline health service provider ³	5

1. Post-secondary education was defined as university education (including higher professional qualifications)
2. Healthcare provider was defined as either nurse, nurse practitioner, physician or outreach HIV testers
3. Frontline health service provider was defined as care and support service provider working in AIDS service organizations and community-based organizations, including faith-based organizations

Four (one physician, two nurses, one outreach worker) were involved in HIV testing in three community health centres; and four frontline health service providers, of whom three worked in two community-based AIDS organizations and one in a faith-based organization. Most of the participants were of African descent (n=5) and the rest were of Caucasian descent (n=3). Five were women and three were men. Most (n=6) had post-secondary education and two with PhD. People who are not community health service providers in Ottawa were excluded.

4.3.2 Setting

The study took place in Community Based Organizations.

4.3.3 Procedures

The University of Ottawa Health Research Ethics Board gave ethics approval for the study (Appendix 1). Thereafter the first author (JN) contacted the participants through e-mail. After a written information about the study sent to all those eligible for the study, personal contacts by first author followed to explain more thoroughly the study to the participants. In consultation with the participants, a date and convenient time was set for an interview. The right to decline to participate or withdraw from the study was explained and that data would only be for this doctoral thesis. Written informed consent was obtained prior to the interview. To ensure confidentiality, all names and identifying information changed. The participants received \$25 for their participation.

4.3.4 Data collection

Data were collected through face-to-face, open-ended, in-depth semi-structured interviews conducted by the first author between May and October, 2017. The interviews were conducted in a closed room with a mean duration of 45 minutes. The interviews were audio recorded and put on an encrypted flash drive and transcribed verbatim. The comparative analysis started after collecting socio-demographic information (see Appendix 9) with a general prompt: “What do you think about HIV testing?” This allowed the participants to express their views about testing in general. Since we wanted to find out more about their experiences of making available HIV testing to young heterosexual African migrants, especially men, participants were asked specific questions relating to these experiences based on their responses (see examples Appendix 10). Member checking was accomplished by highlighting important aspects during each interview so that participants could confirm or disconfirm their experiences. This enabled checking and ensuring accurate interpretation of data throughout the interviews with participants.

Following each interview field notes were taken that documented reactions, emotions and related actions about participants, which enabled to explore, challenge and intensify sensitivity to the concepts and theoretical categories that resulted into identifying the direction for further data gathering.(23)(24) Changes in the direction of the research and the rationale for decisions made were also documented. When new data analysis provided no additional material to existing theoretical categories, and the categories were sufficiently explained or were comprehensible, data collection stopped as no new information could be gained from the interviews.

4.3.5 Data analysis

Data from the interviews were analysed and categorized according to the constant comparative method of data analysis that enabled exploring emergent categories and their properties/dimensions.(23)(24) NVivo 11Pro was used to help organize and manage the interview data and memos. Properties referred to the characteristics that were common to all the concepts in the category. Dimensions were the variations of a property.(24) The data analysis started directly after the first interview and consisted of open and focused coding. Open coding or the initial coding was done through an in-depth line-by-line analysis of the data that included repeated readings of the interviews. Based on our field notes theoretical sampling was employed after initial analysis to direct collection of additional data that informed the developing theory about experiences to offering HIV testing services among participants. For instance, we originally had chosen to focus only on experiences of healthcare providers who offer testing. But initial statements from the first interviews among healthcare providers, such as, *“If vulnerable people are coming in and they are a little hesitant and they are not used to health care -to have another person say I am going to come with you or I know a person to help you navigate health care,”* alerted us to look for additional data about community support. Following such statements, we noted in our memo the following questions “who provides community support to people with HIV in Ottawa? “what do they exactly do?” “Do they face any challenges in doing so?” The only individuals well positioned to provide us answers were those working in community-based organizations and AIDS organizations in Ottawa. These organizations are associated with people affected by HIV. These developments raised other issues about the meaning of “access to care” that required more data from the field but also from the literature. Our initial understanding of care had focused on

utilization of available services. The evidence from the field such as the above statements showed that this was far from the case.

Once categories began to develop initial coding advanced into focused coding that transformed basic data into more abstract concepts allowing the theory to emerge from the data.(24) To construct abstract concepts or categories, we went from the field to the literature, back and forth, which at the same time enabled sharpening our research question from the general question about experiences about providing testing services to focus on challenges, in particular, which was the main emerging category from the statements of the provider participants.

In the focused coding, categories were linked together, with sub-categories describing the specific category.(24) We compared data with category and each category with other categories. This was combined with routine cross-checking on data, explanations, methods, informants, theories and the researcher.(105) The properties or dimension of the developed categories were refined, all of which resulted in a core category.

4.4 Results

The data analysis gave rise to a process leading to a core category showing how health service providers experience making HIV testing accessible to young heterosexual African migrants, especially men in Ottawa. Three main categories that emerged were: challenges, abilities and enablers. “Challenges” were defined as problems/difficulties encountered at various stages in making HIV testing services accessible to young heterosexual African migrants at the

intrapersonal, interpersonal, organizational, community, and policy levels. “Abilities” referred to capacities of participants in offering testing shaped by various determinants in their contexts at various stages and levels. “Enablers” were opportunities that facilitated offering testing at various stages and multiple levels. The first author provided English translations from interviews given in French. Back translation was used to confirm these translations. Professional translators who were not involved in the project did the back translation.

4.4.1 Core category: Making accessible HIV testing

“Making HIV testing accessible” may be understood as a process involving various stages that patients go through including approachability and acceptability, even before the stage of reaching available HIV testing services. These stages defined the properties of making testing accessible with multiple dimensions: intrapersonal (emotional, cognitive and spiritual) and social (relational, material and symbolic). Symbolic level had five values: community, ethical, social representations, legal and policy. The above-mentioned categories “challenges”, and “enablers” are necessary to understand the experiences of health service providers in making accessible HIV testing and should interact with category “abilities” for this to happen. For instance, making HIV testing accessible depended on the abilities of young heterosexual African migrants to perceive the need for testing, seek testing, and reach testing. Diverse determinants shaped the processes of offering testing services. Where participants experienced opportunities to make accessible HIV testing to this population, participants said that they were enabled to do so. Most participants expressed problems that contributed barriers to making these services accessible, in most cases, said they faced challenges.

4.4.2 Challenges

The category “challenges” included three mental dimensions of: accommodating the complex needs of the target population; making decisions about whom to test; and communicating with patients about testing and the mechanisms of testing. Participants expressed being apprehensive to talk about HIV because of its complexity in relationship to the needs of the patients. Making emerging HIV testing technologies available also required to educate and support the target populations and making sure that these technologies serve their needs. This was expressed by participants as a major challenge, which could deter reaching testing if not well presented to patients. Participants further expressed uneasiness presently about individual HIV risk assessments because it was easier then at the beginning of the epidemic as the symptoms were obvious, which is not the case now presenting a major challenge relating to making decisions about whom to test. *“I find really when I first worked in HIV we would diagnose people because they came in so sick. Like, you would see someone and you would just throw in, they are HIV because of their pneumonia fungal infection.”* (Healthcare provider participant N04)

“Talking about HIV includes talking about other activities it means talking about sex and drugs and relationships amm and orientation and gender and all these things. So those are all amm complex topics on their own intertwined and intersected amm it can make talking about HIV amm very tricky to navigate.” (Frontline participant N03)

“But there is time to educate the patients about using this test because they must know how to do it, to have the time to explain to them and supposing I have positive result, it is not the end of the road. They must do a confirmation test.” (Healthcare provider N05 (French-speaking participant))

One participant expressed problems in bonding with the person tested during test-result provision from lessons learnt in the past, which may create barriers to reaching services in the future.

“I have learned from my mistakes a little bit. What I want to learn to do when I do HIV testing is make a bond with someone that they would come back and see me whenever they are ready to come back and see me.” (Healthcare provider participant N04)

The category “challenges” included three social dimensions of: lack of transparency, limited outreach of HIV testing programs and inadequate information regarding available types of HIV testing at the organizational level, relating to property approachability. It emerged that the most important challenge for participants was at the initial stage, when participants make choices about whether and where to seek testing. Participants expressed defeatism in making HIV testing approachable due to the absence of transparency, outreach programs, and information about available HIV testing services, which made these services inapproachable. While participants expressed strong motivation in their work, they voiced frustration at the service provision system they felt was opaque and complex, which acted as an obstacle to making services approachable and yet nothing was being done about it and was further impeded by little inter-agency coordination:

“You call they tell you go and see public health or Somerset. Go see this. There is no direct response. Ok you call it is available. Come we are going to do it. Or you call such a place always the information is: go here go there. It is complicated there is no direct access. There is no direct access unless you know someone who knows the system. There is no direct access.” (Frontline provider N07 (French-speaking participant))

“Before I worked here I moved...I worked at the Immigration centre ... at the immigration centre our problem is that we deal a lot of time with education and employment but we don't tackle people's health. So our mandate a lot of the time is not health care it is more Are they

employed? Are they housed? Is there a citizenship immigration problem? Everything....the legal aspects.. but never health care. So I used to see people it was hard for us to connect them to agencies like this.” (Frontline provider participant N08)

“Sometimes it is not just about knowing. Sometimes it is not just stigma and all other things. Sometimes the root of it is just let’s have testing available to begin with.” “So, I think, and I feel like a lot of the testing sometimes caters to more demographics that are high at risk let say the gay community. But I feel sometimes also when you cater to certain risk communities you are also leaving out other communities.” (Frontline provider participant N08)

“The access can be increased like that by publicizing information in all pharmacies and clinics to make patients aware.” (Healthcare provider N05 (French-speaking participant))

The category “challenges” further included social dimensions of : racialization of HIV, gender related beliefs and the criminalization of HIV, relating to property acceptability. Participants were perturbed that despite existing science showing those with HIV on treatment can have viral loads suppressed, the law that criminalizes HIV is still enforced in Canada. One participant expressed concern about socially representing young men as “immune” to diseases including HIV and said it was a significant barrier to supporting this population accept testing. Participants also expressed an ethical concern that HIV testing could be used to target Africans which would work against encouraging this population to test. Non-Caucasian participants expressed fear about the experience of racism they themselves go through, which may turn out to be a major obstacle to making HIV testing acceptable among the target population.

“I think that racism rooted in the system is the part we see that is really the problem. It is always there but if we can say that racism does not exist in Canada we are totally mistaken. ...It is like

that. Even the fact that I have an accent that is not so-called Canadian, when the person answers you on the phone it is not easy to negotiate these services. You know they are available, yes, they are there but accessing them is the problem. Not easy. This is something of every day. It is an everyday battle unfortunately.” (Frontline provider N07 (French-speaking participant))

“De-criminalise HIV, work on stigmatisation around HIV and certainly make other services accessible” (Frontline provider N07 (French-speaking participant))

“For me so long as the question is being asked of anyone who shows up there irrespective of your color of the skin I have no problem of that....I would be offended if I go in there with my Caucasian friend and then I am asked to do HIV testing and he is not asked to do it. So if everybody is being asked that is fine.” (Frontline provider N02)

“I have noticed that it is easier for girls to request an HIV test than boys. I have noticed that mostly girls do not refuse to test if they are sexually active. They refuse if they are not sexually active...The boys are somewhat reluctant and we see them less.” (Healthcare provider N05 (French-speaking participant))

“There is a perception that they are immune, they are ok, they protect themselves, they know what they are doing. That is the perception.... So andso and that alone is sort of problematic. That is why we don't see really more of the young men testing.” (Frontline provider N02)

The category “challenges” also included social dimensions of: hours of opening, characteristics of patients and location of services at the material level, relating to property availability of services. Participants expressed regret that services did not often respond to the needs of the community, including the limited availability of anonymous testing and absence of services to youths in

schools. These and the way testing services relating to sexually transmitted infections are organized left participants exasperated. Some participants offered examples of what they were doing about these problems, while others expressed the need to do something about problems in making available services physically to the target populations.

“I believe one thing we have to do is go where they are. We have to go to them instead of asking them to come to us. Sometimes it is a struggle for them to come to us.” (Frontline provider N02)

“We need mobile testing clinics which meet the needs of the community. We need to look for people. All people do not have the time to come and look for us. We need to go to people where they meet for sports or other activities. We need to provide an easy access. Join them where they gather.” (Frontline provider N07 (French-speaking participant))

“People will have a big buy in to have their results earlier. And now the anonymous testing ... point of care testing is only offered to high-risk individuals, which is too bad because that idea of easy testing ...results right away... that appeals to the young people like nobody’s business...Like they are used to like instant results. And so I feel.... Even if you are doing HIV testing you have to come back for your results.” (Healthcare provider N04)

“We know that the earlier we detect infection the sooner we can stop it. Why not provide HIV testing in schools, especially in colleges and universities? Young people go to schools. It is there that we can find them.” (Frontline provider N07 (French-speaking participant))

“Recently, there have been an increase in sexually transmitted diseases. Especially Chlamydia has increased, but also syphilis has increased in risk groups. We know that sexually transmitted diseases have certain risk factors for HIV infection. They create doors for HIV infection. Youths

are exposed to these diseases. They risk contracting HIV. So campaigns against STDs must include HIV.” (Healthcare provider N05 (French-speaking participant).

“So I think it is time for us to consider HIV testing as part of a panel. But I know that has implications for all service organizations who have been set up to run HIV and round it. I am kind of tired of giving it so much attention which I think is negatively reinforced what it is. Anyway. That is the wrong answer.” (Healthcare Provider Participant N04)

One participant lamented the opening hours of the HIV testing services that further complicated making HIV testing physically available to the target population due to conflicting schedules that often arise.

“Public health testing is early in the morning...Or it can be from say 9 to 12 ...it is somewhere in the morning anyway. And so I am not quite sure how many places where testing is offered on the weekend... in the ACB communities where they are taking care of their children during the day and cannot bring their children with them and get tested.” (Frontline Provider N08)

“We speak”: it is a research project about heterosexual men including young men and that is an opportunity for heterosexual men because we realized there wasn't any intervention towards heterosexual men.” (Frontline provider N02)

Participants expressed deep apprehension about how sometimes characteristics of individuals especially being migrant or having heterosexual orientation presented problems to making testing accessible.

“Sometimes people in different situations whether they are asylum seekers or refugees or sponsored they are not always forthcoming with health. ...aam problems like health complexities.

Because it can sometimes make their status more difficult for them...you know... applying or getting whatever kind of citizen status they need a lot bit more difficult.” (Frontline provider N08)

4.4.3 Abilities

The category “abilities” included two social dimensions of: low health literacy among young heterosexual African migrants and incompetent HIV testing services that do not meet expectations of these populations, relating to property approachability. While healthcare provider participants recognized the need for HIV testing, they were disheartened that making HIV testing accessible in this population was hindered by the ability of this population to recognize the need for testing. Participants even recommended the kind of services that would respond to the needs of this population.

“You go to a place and somebody is asking a question.. ehh... she or he may be coming from a place of ignorance, but the way people perceive it people realize that something is wrong somewhere and that is why it is important that we have health service providers who are culturally competent.” (Frontline provider N02)

“It is not just we as a black community, this is happening to us because we are black. But it is a general message to anybody. And now it becomes easy for me to say did you guys see that billboard at the corner of Baseline and Merivale? What does it say? It says we should test. We know that everybody is going to test. We also need to be responsible enough and go to test.” (Frontline provider N01)

The category “abilities” further included social dimensions of: language issues, lack of knowledge about HIV testing options, and mistrust of the care system, relating to property acceptability. Participants acknowledged the mistrust of the care system that hinder accepting testing among

patients, but also were positive about the possibility of building trusting relationships between provider and patient. Participants expressed realization that other factors come into play even before reaching services that include knowledge of testing options that may require assistance from others to get this knowledge, such as , someone to vouch for those in need of testing. According to participants, these and language difficulties prevented target populations to exercise personal autonomy to choose seeking testing.

“So sometimes it is something as simple as language because people are navigating a health care system that that they are not used to and sometimes it is difficult for me and I was born here, I speak English as my first language.” (Frontline participant N08)

“If vulnerable people are coming in and they are a little hesitant and they are not used to health care -to have another person say I am going to come with you or I know a person to help you navigate health care.” (Frontline participant N04)

“Because sometimes there is that mistrust of the health care system, so we can tackle it in different ways and make it more accessible.” (Frontline participant N03)

The category “abilities” also included two social dimensions of: difficult living environments and lack of social support, relating to property availability of testing services. It emerged from the interviews that availability of HIV testing services alone did not mean that young African migrants can reach these services. Participants expressed disappointment that this population was not reaching services even though HIV was just like any other disease. Participants vividly expressed how difficult living conditions and lack of community support affected abilities of African migrants to reach testing. Participants repeated often and many times the adverse social health determinants experienced by young African migrants, such as, food insecurity, shelter, education,

lack of employment and immigration issues that added further obstacles to providers in encouraging these populations.

“It is more socio-determinants of health. If we can kind of figure out all kind of different things that are intersecting in a person’s life and help them get access to resources they need that affect them as a whole instead of focusing just on the HIV status.” (Frontline provider participant N08)

“It is not just education we are talking about. Poverty ehh we are talking about ehh struggle with immigration just general..... People are figuring out where to sleep tonight, what to eat. They are not as educated and even if they were their education is of no value to them here... For you to tell them to do HIV testing... Look I have enough problems then you tell me something that may be an additional problem to me.” (Frontline provider participant N01)

“Oh my god! You know the services are available but it is the access that is difficult. To say the truth the access depends on where you come from, your origin, your social class, who you know and how you have adapted or integrated into society. So it is not easy.” (Frontline provider N07 (French-speaking participant))

“There is a notion that if you have HIV you must have done something wrong. Right and it becomes a taboo ...certain in our community. So it is something that we need to break. And let people know that it is just like somebody having cancer, diabetes. Somebody having... HIV doesn’t kill. Other diseases kill. Right. But HIV doesn’t kill. So we have to let them know that just like having... getting a flu or any other disease that is prevalent. That hasn’t that stigma associated with them.” (Frontline provider participant N02)

One participant expressed the need for faith leaders to do more to support this population to fight the stigma associated with HIV.

“I think their faith hasn’t to be used like a barrier and I don’t think it as a barrier. We have to come up with tactics and strategies where we can kind of reach like congregations, you know. Whether you are a Muslim woman or Catholic man, prevention can still be translated in a way within the boundaries of their faith where they feel it is respected and it is not so taboo.” (Frontline provider participant N08)

One participant also wondered if the absence of role models living with HIV undermined efforts of service providers to encourage the target population to reach testing.

“Identifying people that young black not only young but the black community identifies with as HEROES who are HIV positive and who have undergone therapy and are living a very decent life very healthy life. That could be very very helpful.” (Frontline provider participant N01)

4.4.4 Enablers

The category “enablers” included two personal dimensions of: perseverance and professionalism. Participants expressed personal perseverance and professionalism in their job.

“The only problem most clients never come with those documents and most of them never know the results of that test. So when I meet clients here at this clinic I usually offer them an HIV test because I tell them that it was done before they came. If they were shared the results I offer them again. I tell them: is this something you would like to be done?” (Frontline provider participant N06)

“First if the person comes to see us we make a needs assessment. Oh I don’t have medicines for HIV. We assess what we can do for that person. It means applying to [Ottawa Disability Support Program] or [Ontario Works] for those looking for work. or look for pharmaceutical companies who offer free medicines for HIV.” (Frontline Provider N07 (French-speaking participant))

“Sometimes there are some who come to see us. We respect that many come. They are many young people sometimes who are aware. That makes me happy that someone comes willingly to request the test. Often, it is we who request an HIV test.” (Healthcare provider N05 (French-speaking participant))

The category “enablers” further included four social dimensions of: credible technology, social support, free HIV testing, and strong care and support services at the organizational level. Participants expressed with great appreciation that offering free HIV testing was a major enabler in making the target population approach, accept and physically reach HIV testing. Participants further highlighted that testing positive carries serious effects but with social support, individuals could stay healthy and live longer. Participants also described with passion the available care and support services they provide. Moreover, participants articulated a clear grasp of guidelines about standard testing, and anonymous point-of-care testing.

“There are guidelines for the ELISA [enzyme-linked immunosorbent assay] test, and then there is the laboratory. If the ELISA test is positive, this is where we do the confirmation test called Western Blot. And after the Western Blot test, if it is negative or if it is positive they return the results to us. Often if it is a negative so it is negative. It means that it is neither positive nor negative. If it is not clear. It’s in a grey area... Here one can repeat the serological test. But at the same time, you can do a viral load test to check if this is someone who is changing his status, if there is a sero-conversion. On the contrary, there are possibilities to do the rapid test now in certain sexual clinics. ...So we do a prognostic test as a prevention measure, not to spread the disease. There is a possibility to treat the person early and also use treatment as prevention from continuing

transmitting. So there is a public health aspect as well.” (Healthcare provider N05, (French-speaking participant))

“I think the anonymous point of care testing has improved testing. One it is offered in many parts of the city the other piece of that it is anonymous. I think that it improves access to people. And the other thing is the rapid test....people know the results right away. Those components of that particular program improve access.” (Healthcare provider participant N06)

“People can book either on line in advance by appointment or they can walk in again no name, no health card.” (Frontline provider participant N03)

“HIV testing is free, it is free of charge. So often it is the access to information that is difficult.” (Frontline Provider N07 (French-speaking participant)) had this to say: *“So that other clinic that we do anonymous testing it is funded it has a specific funding but here people would do their testing from their [University Health Insurance Plan] card so their UHIP would pay their testing. There wouldn't be any cost to the patient. I don't think there are any funding issues around being tested.”* (Healthcare participant N06)

“If someone tests positive, it will be a bad day for that person. We cannot avoid that. We need to design HIV testing together with emotional support you know.” (Frontline provider N07, (French-speaking participant))

“Having to know your status would be useful to accessing like the food bank that is associated with the AIDS community of Ottawa. But ...so not only having [Ontario Disability Support Program] with the food bank, but you can have workers that can assist you with housing you can even apply for specific housing. So knowing your status isn't just ... I feel like it opens doors for you.” (Frontline provider participant N04)

“At times they come to see us for affordable housing. So we help them to register on waiting lists at the city of Ottawa or we send them to Bruce House [a community-based organization] to access services for people living with HIV. Sometimes they come for language classes. If it is French or English, we assess their level because language schools are not on the same level.” (Frontline provider N07, (French-speaking participant))

“If they need an immigration lawyer, we refer them to a lawyer we work with. If it is a family physician or HIV specialist, we refer them to the physicians we work with. So generally speaking we have practical assistance such as the food bank, laundry services and others including Fax, email, surfing and lunch programs.” (Frontline provider N07, (French-speaking participant))

4.5 Discussion

Principal Findings

This study aimed to fill the gap in the literature about experiences of community health providers in making accessible HIV testing to young heterosexual African migrants, especially men in Ottawa. The results demonstrate multiple cumulative and interrelated challenges behind HIV testing for this population experienced by provider participants at various stages and levels. At three stages of approachability, acceptability, and availability interacting with abilities of the participants at intrapersonal, interpersonal, organizational, community and policy levels. These challenges contributed to barriers in perceiving the need for HIV testing, seeking HIV testing and reaching HIV testing among target population. The term “community health providers” included both healthcare providers and frontline service providers. Focusing on only community health

service providers was important in providing viewpoints outside the clinical setting, which we would have missed in sexual health clinics that focus mainly on delivery of services.

Community health provider participants in this study were from diverse disciplines including two nurses, a physician, one frontline provider involved in outreach testing, three frontline providers working in education and prevention of HIV in AIDS organizations and one faith leader. Providers from AIDS organizations, who often do not offer testing, were included in this study. First, because of their insider view about communities, which provided an opportunity to learn more about different viewpoints relating to challenges behind HIV testing at the frontlines, especially social determinants of health outside the clinical environment that impacted abilities of young African migrants to reaching the available testing options. The views of providers from AIDS organizations in this area enriched this study. This was also made possible because of the grounded approach used. Initial statements at the beginning of the interviews from healthcare participants such as *“If vulnerable people are coming in and they are a little hesitant ...to have another person say .. I know a person to help you navigate health care,”* led us to go back to the field to find additional data about challenges community organizations such as AIDS organizations face in encouraging this population to access testing services. Providers in AIDS organizations were the only people able to provide this information. Similarly, since HIV testing services include linking to care and support services, experiences of providers in AIDS organizations demonstrated similarities between challenges they faced in encouraging communities to test and the difficulties they experienced in linking those tested to care and support. That is, making available testing services is important but not sufficient for young African migrants especially men to reach them. There are gaps in abilities of patients before and after reaching these services, which should be

reflected in planning more effective testing interventions that can be timely reached. Late presenters to HIV testing can incur higher costs for all medical services during their first year following diagnosis in addition to poorer health.(124)(125) All barriers, including those outside the clinical environment should be addressed to enable timely reaching services to avert avoidable costs.

Community health providers further work with specific communities, such as, neighbourhoods or people with certain characteristics. Linking with community health service providers was important in collecting grounded perspectives that helped better understand challenges behind HIV testing for this group. This has greatly contributed to developing a practical theory that can be applied in this context. Theories developed in other contexts or based on experiences of other key groups, who are often more likely to test, may not work for this population who are less likely to test.

Experiences providing HIV testing: Challenges, ability and enablers

The three categories discussed under the results section above are important to explain the experiences in providing testing reported by the participants. Many studies that have looked at challenges experienced by health service providers in making accessible testing in key populations, including in Canada, have found some interesting results at the personal, interpersonal and structural levels.(11)(106)(110)(132). A recent systematic review reported system-related barriers to opt-out HIV testing including lack of time, resources, and adequate training among healthcare providers.(11)System factors enabling opt-out HIV testing reported are integration into standard practice, support of the medical setting, and electronic reminders.(11) By contrast, health care

system barriers to accessing HIV testing in Canada are racism, colonization, and homophobia.(132) Other system barriers are lack of time to go through the counselling process in pre-natal care, immigration contexts, or by family physicians.(106)(110) In Canada, a committed and professional staff, free testing and adequate funding arrangements have also been reported as enabling factors.(129)(130)

At the provider-level, challenges reported in the reviewed literature that create barriers to HIV testing for communities at risk in Canada include intersectional discrimination in the provision of healthcare to all patients, or healthcare providers who are uncomfortable, reluctant and/or undertrained about the lives, experiences, and needs of people at risk for HIV.(132) Other challenges in Canada are linguistic, cultural and experiential specificities of the person being tested, and a judgmental attitude of the healthcare provider of testing.(132) Elsewhere, strong beliefs about who should be tested for HIV underpinned by moral or values based judgments of the healthcare provider have also been reported.(11)

Gender differences have further been reported relating to challenges behind HIV testing in Canada. For instance, women may not want to ask for information, ask to be tested, or return for results if they feel judged.(106)(110) Reports also have shown that perceptions of risk of healthcare providers have denied HIV testing to women whom they assumed were not at great risk for HIV.(106)(110) On the other hand, men including migrant men may not only be less exposed to HIV testing, but also less willing to present themselves for testing.(113) Other challenges making accessible healthcare to men include conflict of traditional masculinity with a feminized health

care culture, concerns over wait times and cost, and perceived lack of community support.(114)(115)(116)

These findings in previous studies are consistent with our findings about individual-level barriers, provider-level barriers and system-level barriers to testing in Ottawa. This study found system-level barriers such as racism and lack of outreach programs. Individual-level barriers included judgmental attitude of the provider of testing and little information that testing was always accompanied by adequate pre-testing counselling. By contrast major enablers in making accessible HIV testing included a committed and professional staff, free testing and adequate funding arrangements. Challenges behind HIV testing in this study were, thus, influenced by a variety of competing factors including sex and gender. Participants observed that it was less challenging to reach young women than young men for HIV diagnosis. On the other hand, young women generally accepted a test if offered one in contrast to young men who were less likely to seek an HIV test.

Also, research about improving care for patients with other stigmatized diseases, (117) such as leprosy,(118) and mental health (119) have demonstrated barriers and challenges behind accessing care for these patients. A recent systematic review revealed, in addition, that most multi-level stigma intervention research often focuses at one or two levels.(120) Yet, stigma reduction efforts can be improved if multi-level barriers are addressed than single-level interventions,(120) which may result in more holistic outcomes, including in the area of HIV testing.

Although our findings are in agreement with prior reviewed studies, including those about other stigmatized diseases, it is important to point to differences between these studies and our findings. A major difference was that making accessible HIV testing services to target populations was understood as a process rather than simply making available these services. Access to healthcare has been defined as “the opportunity to identify healthcare needs, to seek healthcare services, to reach, to obtain or use healthcare services and to actually have the need for services fulfilled”.(19)^(p.8) These processes include determinants that shape abilities of patients and health service providers at various stages and multiple levels, where challenges occur that may contribute to barriers and increase inequities. The grounded perspectives from this study led to a theory about these challenges and barriers useful in understanding the pathways of these inequities crucial to planning more equitable HIV testing interventions.

Cumulative interrelated provider related challenges

The results in this study show cumulative interrelated provider related challenges that contributed access barriers at various stages and multiple levels. At the stage of approachability, for instance, health service provider participants reported challenges at the social level often due to a lack of transparency about services, limited outreach of HIV testing programs and inadequate information regarding available types of HIV testing that contributed deterring factors to approach these services. Corresponding to these challenges were various determinants hindering young heterosexual African migrants themselves to perceive the need for testing. Among them were failure in obtaining information about HIV testing and lack of competent HIV testing services to meet their expectations. Additional challenges reported at the second stage of acceptability related

to cultural and social factors such as, legal, ethical, gender and other value-related considerations contributing access barriers at the organizational level. According to the study participants, criminalization of HIV, racialization of HIV, racism, and social representations about immunity of young men often prevented the possibility of young heterosexual African migrants to seek and judge HIV testing as appropriate. Corresponding to these challenges and barriers were determinants inhibiting this population to exercise their autonomy to choose seeking testing. These included language problems, lack of knowledge about HIV testing options and mistrust of the care system acting as barriers mainly at the interpersonal levels.

Challenges continued to accumulate at the third stage of availability relating to the physical presence of the services and characteristics of providers. HIV testing service characteristics, such as location, accommodation, hours of opening, and mechanisms of HIV testing added barriers to accessibility at the material level of organization. Examples included centralization of services, lack of services that respond to the characteristics and needs of migrant heterosexual men and women, lack of mobile clinics, lack of testing in schools, especially anonymous HIV testing and the existing organization of testing provision relating to sexually transmitted diseases that exclude HIV testing in Ottawa. An inclusive or universal testing policy of “Anonymous Sexually Transmitted Disease Testing” was suggested in this study. Also, one participant reported a challenge relating to test provision. Corresponding to these challenges and barriers were determinants that deterred young heterosexual migrants to reach testing such as low health literacy, difficult living environments, lack of social support, and lack of role social models.

To complicate matters, the empirical evidence shows how these challenges at three stages of approachability, acceptability, and availability interacting with abilities of patients to perceive the need for testing, choose to seek testing and reach the available testing services arise from a series of sequential challenges. That is, at the intrapersonal, interpersonal, organizational, community and policy levels. If intrapersonal problems such as test provision were overcome among health service providers, then other challenges arising from the policy organization of health care could be encountered, such as lack of outreach programs. These processes cannot be considered linear. The deterrent factors at each stage may be different, while the abilities of individuals may depend on several determinants. Moreover, feedback loops – within and across levels – demonstrated that the context at times reinforced, and at other times corrected, barriers within and across multiple levels. Feedback loops in this study referred to interactions across multiple levels that reinforced (perpetuated) or corrected existing barriers (enabled reaching testing). As a result, despite the cumulative and sequential barriers, this study also found access enablers to reaching testing. This study builds on previous reports about other key groups but also provides original insights relating to the operationalization of accessing care with implications for research, policy and practice.

4.6 Limitations

A major limitation of the study was its focus on only two community health centres and two AIDS community organizations. The number of participants is very small and may not be representative of all community healthcare providers. The results must be interpreted accordingly. Applying Grounded Theory enabled generating theory grounded in the data (23)(24) that is a fit for this group rather than a theory developed elsewhere for other groups. The comprehensiveness of the findings allowed making recommendations that may resonate in other contexts in Ontario given

the multidisciplinary team of researchers with primary care, legal and methods expertise as well as the consistency of findings in this study with previous research.

4.7 Practical implications

This study recommends benchmarking enablers to provide HIV testing to young heterosexual African migrants. Challenges contributing barriers to accessing testing can be avoided. Some of these challenges are obvious, while others are less obvious or have root causes. A needs assessment study in neighborhoods is, thus, recommended to know more about these enablers as well as challenges providers face. Interventions based on knowledge from the ground are more likely to work.

Obvious challenges in this study were closely connected to HIV testing and related to stake holder capacities or input. For example, lack of HIV awareness, language problems, lack of knowledge about HIV testing options, and individual risk assessment. Policy and practice should design and implement HIV awareness campaigns that include information about available testing options. Mobile clinics that are sensitive to the linguistic, cultural, social and spiritual needs of the community as suggested by participants in this study should be provided.

Less obvious challenges in this study were implicitly linked to HIV testing often due to poor policies, laws and programming and may be more challenging to deal with but may contribute more to improving outcomes or performance of HIV testing. This study recommends policy and practice to implement provider-initiated routine testing in all health facilities to address individual biases in risk assessment of HIV. In addition, we recommend scaling-up of anonymous testing,

rapid testing, and HIV self-testing important to address issues of fear, time and other gender related barriers. Policy and practice should provide testing in schools and mobile HIV testing clinics to address issues of location that also consider sex and gender. Decision-making, communication, stakeholder engagement and preferences in accessing interventions, including HIV testing, are shaped by sex and gender.(133) Ontario Government should design and implement universal sexually transmitted infections screening that include HIV testing to reduce stigma attached to HIV, while recognizing that sexually transmitted disease may also act as ports of entry for HIV.

Still other challenges in this study may have root causes requiring long term interventions that will have an impact on HIV testing interventions, and if changed will meaningfully address a number of issues. Government of Ontario should carry out healthcare reforms whereby the delivery of care must consider social determinants of health to address the mistrust of the care system and improve access to care. Ontario Government should endorse an interdisciplinary approach that includes community health service providers and affected communities and individuals in designing, implementing and evaluating HIV testing interventions. Community health workers should help healthcare systems reach out to patients, instead of always relying on the patient to come to the system for testing. Government of Ontario should make policies towards a diverse workforce and use of interpreter services when needed. Affected communities and individuals themselves who may suffer from particular vulnerabilities due to their life circumstances should be part of the healthcare reforms in order to contribute their views about what prevents them accessibility so that culturally competent HIV testing services can be designed and implemented. Health service providers should be trained with skills and provided tools to ensure provision of competent and safe services. This suggests that providers depend on others, such as administrators, health care

institutions who must ensure that community health service providers have easy access to available resources. These include information, supplies and equipment necessary for providers successfully do their job. The testing experience can be improved by health service providers who feel competent and confident and are sensitive to the emotional state of the person receiving the diagnosis or being linked to services.(83)

This study suggests research about culturally competent HIV-related services among heterosexuals to address this lack in the literature. Translating knowledge into culturally competent HIV testing services should address challenges, in addition to, benchmarking enablers in order “to balance quality, to improve equity and reduce disparities”(59)⁽¹²⁸²⁾ in improving services.

Chapter 5 Conclusion

This is the first qualitative study to explore experiences of HIV testing services among young heterosexual African migrants and multidisciplinary community health service providers in Ottawa. Various stakeholders should be aware of the dimensions of access to HIV testing services and their interrelatedness and how this can through multi-level determinants influence the ability of populations to test, or not, both before and after reaching services. The great opportunities (enablers) identified in this study should be strengthened and used as benchmarks for further improvement of HIV testing services in the fight against HIV transmission.

UNAIDS 90 90 90 targets provide an important roadmap to end HIV, but these targets appear to be executed within a context where many healthcare systems worldwide are primarily centered around the delivery of care. This may be a set back to achieving these targets in certain contexts. Findings from this study show that simply delivering HIV testing services is not enough for target populations to reach and obtain these services. Addressing barriers at critical steps of the HIV care cascade essential to achieve UNAIDS targets will only be possible if Governments and policy makers make deliberate efforts to deliver care that is sensitive and responsive to the needs and priorities of patients to promote sustained engagement. Since the needs and priorities of patients are often shaped by social determinants in the contexts they live as demonstrated by findings in this study, Governments must conduct healthcare systems reforms where unfavorable circumstances in which care is delivered to patients are also considered. UNAIDS should do more to advocate for practical healthcare system reforms to improve testing services worldwide, especially among groups and regions that bear the brunt of the disease.

First, problems presented by inconsistent measurements of psychosocial outcome domains (concepts) immediately following HIV testing could be addressed by establishing a core set of psychosocial outcomes and measurements. Only then can there be complete documentation of these outcomes crucial to inform health care decisions in public health to achieve universal access to treatment that benefits those just diagnosed HIV positive. And timely reaching preventive services to benefit those just diagnosed HIV negative. UNAIDS needs to do more to encourage both medical and psychosocial interventions. While availability of treatment has changed how the trauma of HIV is experienced, this does not mean that the experience of trauma immediately after a new positive test result is over.

Canada has removed structural constraints to accessing HIV testing services by making it free. Therefore, HIV testing is feasible. It is also possible to reduce the large pool of undiagnosed fourteen percent of those living with HIV that includes young heterosexual African migrants, especially the young men. Thus, it is unjust if these populations cannot reach HIV testing services in Ottawa. The findings from this study have practical implications. We have provided a summary of recommendation below to improve access to HIV testing in Ottawa.

Summary of practical implications

Stakeholders	Proximate Goals	Long- term Goals
UNAIDS	Do more to encourage and advocate for psychosocial interventions together with medical interventions	Advocate more for practical healthcare reforms
Federal Government	Decriminalization of HIV	
Ontario Government	Political will to address all barriers to testing among all youth	Reforms in healthcare systems; Improve social determinants of health; train health service providers in provision of competent and safe services; a diverse workforce and use of interpreter services when needed
Health professionals	All health professionals to contribute to a health needs assessment study	All health professionals to contribute to designing and implementing health reforms
Researchers	To do research in collaboration with various stakeholders	
Health service providers	Providing more competent and safe services Provision of adequate pre-test counselling	
Policy makers Testing approach	Designing/implementing/evaluating HIV testing policy and programs in collaboration with all stakeholders; design policies towards provision of mobile HIV testing clinics; design HIV awareness campaigns; Provision of testing in schools; universal sexually transmitted infections screening; HIV testing interventions focusing on newcomers and native-born Canadians of African origin (+ those in Canada over 10 years); more facilitation to Community Based Organizations, such as Faith leaders. Policy and practice should implement PITC and HIV self- testing, while scaling up anonymous testing/ rapid testing	
Civil society organizations	Take part in awareness campaigns Advocacy for HIV testing among the youth	
Communities and affected populations	Communities should support and advocate for reducing all barriers: fear, lack of community support, racism, lack of employment; young people should mobilize themselves through social networks, sports to create awareness of health problems and barriers they face or about enablers in seeking and reaching services	To work towards owning programs implemented in their milieu; young people should contribute to policy and programs addressing health inequities and advocating for equity

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Appendix 1: Ethics Approval

File Number: H08-16-35

Date (mm/dd/yyyy): 10/19/2016



Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Certificate of Ethics Approval

Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Peter	Tugwell	Medicine / Medicine	Supervisor
Vivian	Welch	Health Sciences / Others	Co-Supervisor
John Baptist	Ngobi	Health Sciences / Population Health	Student Researcher

File Number: H08-16-35

Type of Project: PhD Thesis

Title: HIV testing in young straight African migrant men in Ontario: Gendered barriers

Approval Date (mm/dd/yyyy)

10/19/2016

Expiry Date (mm/dd/yyyy)

10/18/2017

Special Conditions / Comments:

N/A

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Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada
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File Number: H08-16-35

Date (mm/dd/yyyy): 10/19/2016



Université d'Ottawa **University of Ottawa**
Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement and other applicable laws and regulations in Ontario, has examined and approved the application for ethical approval for the above named research project as of the Ethics Approval Date indicated for the period above and subject to the conditions listed the section above entitled "Special Conditions / Comments".

During the course of the study the protocol may not be modified without prior written approval from the REB except when necessary to remove participants from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the study (e.g. change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, information/consent documentation, and/or recruitment documentation, should be submitted to this office for approval using the "Modification to research project" form available at: <http://research.uottawa.ca/ethics/submissions-and-reviews>.

Please submit an annual status report to the Protocol Officer 4 weeks before the above-referenced expiry date to either close the file or request a renewal of ethics approval. This document can be found at: <http://research.uottawa.ca/ethics/submissions-and-reviews>.

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: ethics@uOttawa.ca.

Appendix 2: African HIV-endemic countries

The Public Health Agency of Canada (4)^(p.101) provides the following list of 43 African countries considered to be HIV-endemic.

Angola, Benin, Botswana, Burkina Faso, Burundi, Cameroon, Cape Verde, Central African Republic, Chad, Democratic Republic of Congo (formerly Zaire), Djibouti, Equatorial Guinea, Eritrea, Ethiopia, Gabon, Gambia, Ghana, Guinea, Guinea-Bissau, Ivory Coast, Kenya, Lesotho, Liberia, Malawi, Mali, Mozambique, Namibia, Niger, Nigeria, Republic of the Congo, Rwanda, Senegal, Sierra Leone, Somalia, South Africa, Sudan, Swaziland, Tanzania, Togo, Uganda, Zambia, Zimbabwe.

These countries are indicated in the map below, produced at <https://mapchart.net/africa.html>.



Appendix 3: Detailed search strategy for three major databases

Results: 257

Database: Embase Classic+Embase <1947 to 2019 March 01>, Ovid MEDLINE(R) ALL <1946 to March 01, 2019>, PsycINFO <1806 to February Week 4 2019>

Search Strategy:

-
- 1 exp HIV/ (316649)
 - 2 HIV.mp.(759784)
 - 3 exp diagnosis/ (14916736)
 - 4 exp anonymous testing/ (539)
 - 5 diagnos*.tw.(5918503)
 - 6 test*.tw.(7828298)
 - 7 screen*.ti,ab.(1703395)
 - 8 psychosocial.mp.(332727)
 - 9 psycho social.mp.(14192)
 - 10 (psychological* adj6 social*).ti,ab.(87095)
 - 11 (psychological* adj6 outcome*).ti,ab.(21417)
 - 12 (social* adj6 outcome*).ti,ab.(34747)
 - 13 (psychosocial* adj6 outcome*).ti,ab.(16295)
 - 14 benefit.ti,ab.(924510)
 - 15 harm.ti,ab.(120675)
 - 16 1 or 2 (790395)
 - 17 3 or 4 or 5 or 6 or 7 (23175487)
 - 18 8 or 9 or 10 (417915)
 - 19 11 or 12 or 13 or 14 or 15 (1097914)
 - 20 16 and 17 and 18 and 19 (533)
 - 21 limit 20 to english language (518)
 - 22 limit 21 to yr="2007 - 2019" (421)
 - 23 remove duplicates from 22 (257)

Appendix 4: Excluded studies (n=23)

Participants linked to care (n=13)

- Braunstein S L., Umulisa M J., Veldhuijzen N M., Kestelyn E. H., Ingabire C., Nyinawabega Van De Wijgert J. et al. Linkage to HIV Care, and HIV Risk Behaviors Among Newly Diagnosed HIV-Positive Female Sex Workers in Kigali, Rwanda. *J Acquir Immune Defic Syndr* 2011;57 (4): E70-76.
- Conserve DFJ. Mwen di li m'fe maladi sida: An exploration of the HIV serostatus disclosure experience of Haitians living with HIV in Haiti and the United States. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2016; 76(10-B(E)).
- Dass-Brailsford P, Eckman A, Kwasnik D. The Complexity of Women's Lives: Decision-making about Maternal HIV Disclosure. *Curr Psychol* 2014;33(4):557-577.
- Genoway S, Caine V, Singh A E, Estefan, A. Point-of-care testing in bathhouses: A Narrative inquiry into the experience of receiving a positive preliminary HIV test result. *Journal of the Association of Nurses in AIDS Care*, 2016; 27(4), 430-443.
- Grodensky CA, Golin CE, Jones C, Mamo M, Dennis AC, Abernethy M G, Patterson KB. "I should know better": The roles of relationships, spirituality, disclosure, stigma, and shame for older women living with HIV seeking support in the south. *Journal of the Association of Nurses in AIDS Care*, 2015; 26(1), 12-23.
- Kaplan L, Kremer H, Inowlocki L. Coping with HIV and the decision to disclose HIV Status: An examination of sexual behavioral responses to HIV diagnosis in biographical perspective. *Journal of the German Society of Dermatology*. Conference: Jubiläumskongress der DSTIG und zum Leopoldina-Symposium 2012. Conference Publication: 10 (pp 40), 201.
- Kay ES, Rice WS, Crockett KB, Atkins GC, Batey DS, Turan B. Experienced HIV-Related Stigma in Health Care and Community Settings: Mediated Associations With Psychosocial and Health Outcomes. *J Acquir Immune Defic Syndr*, 2018; 77(3): 257–263.
- Kemp C, Gerth-Guyette E, Dube L., Andrasik M, Rao D. Mixed-Methods evaluation of a novel, structured, community-based support and education intervention for individuals with HIV/AIDS in KwaZulu-Natal, South Africa. *AIDS and behavior*. 2016; 20 (9): 1937-1950.(59 91% out of 66 participants on ART).
- Kremer H, Ironson, G. Everything Changed: Spiritual transformation in people with HIV. *Int J Psychiatry Med*. 2009; 39 (3): 243 – 262.
- Musheke M, Bond V, Merten S. Couple experiences of provider-initiated couple HIV testing in an antenatal clinic in Lusaka, Zambia: lessons for policy and practice. *BMC Health Services Research*. 2013;13:97.
- Noh MS, Rueda S, Bekele T, Fenta H, Gardner S, Hamilton H, et al. Depressive symptoms, stress and resources among adult immigrants living with HIV. *Journal of immigrant and minority health / Center for Minority Public Health*. 2012;14 (3):405-412.
- Trevino KM, Pargament KI, Cotton S, Leonard AC, Hahn J, Caprini-Faigin CA, Tsevat J. Religious coping and physiological, psychological, social, and spiritual outcomes in patients with HIV/AIDS: cross-sectional and longitudinal findings. *AIDS and Behavior*. 2010; 14(2):379-89.

HIV diagnosis was not examined in the study below

Bravo P, Edwards A, Rollnick S, Elwyn G. Tough decisions faced by people living with HIV: A literature review of psychosocial problems. *AIDS Reviews*. 2010; 12 (2):76-88).

Outside of concept (n=3)

Not about actual experiences after a new positive or negative test

Bulman D, Mathews M, Parsons K, O'Byrne N. HIV testing in pregnancy: using women's voices to inform policy. *Women Birth* 2013; 26(1):e3740

Potential concerns of HIV self-testing

Brown AN, Djimeu EW, Cameron D.B. A review of the evidence of harm from self-tests. *AIDS and behavior*. 2014; 18(Suppl 4): S445-449.

Preventive counselling

Duffus WA, Ogbuanu IU. Prevention counseling for HIV-infected persons: What every clinician needs to know. *Current Infectious Disease Reports*. 2009;11(4): 319-326.

Irrelevant type of study (n=7)

Intervention

Brashers, Dale E, Basinger, Erin D, Rintamaki, Lance S; Caughlin, John P; Para, Michael. Taking control: The efficacy and durability of a peer-led uncertainty management intervention for people recently diagnosed with HIV. *Health Communication*. 2017; 32(1): 11-21.

Hosek SG, Lemos D, Harper GW, Telander K. Evaluating the acceptability and feasibility of project accept: An intervention for youth newly diagnosed with HIV. *AIDS Education and Prevention*. 2011; 23 (2): 128-144.

Minson, J. The influence of HIV stigma and disclosure on psychosocial behavior. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2015;76(2-B(E)).

Characteristics not outcomes and does not mention who is on ART and who is not

Palummieri A, Balzano R, Orchi N, Grisetti S, Sampaolesi A, Corpolongo A, et al. Depression in patients with a newly-diagnosed HIV infection. Conference: Italian Conference on AIDS and Retroviruses, ICAR 2010. Brescia Italy. Conference Publication: 2010;38: 68.

Prenatally HIV infected youth-not clear when they learnt of their HIV status

Santamaria EK, Dolezal C, Marhefka SL, Hoffman S, Ahmed Y, Elkington K, Mellins CA. Psychosocial implications of HIV serostatus disclosure to youth with perinatally acquired HIV. *AIDS Patient Care and STDs*. 2011;25 (4):257-264.

Workshop

Tilley PJM, Brown G, Martinez C. An evaluation of the genesis workshop for newly diagnosed HIV positive people. *Journal of Sexual Medicine*. Conference: 20th World Congress of Sexual Health. Glasgow United Kingdom. Conference Publication: 2011; 8:187.

Prenatally or behaviorally HIV infected adolescents

Ross A.C., Camacho-Gonzalez A., Henderson S., Abanyie F., Chakraborty R. The HIV-infected adolescent. *Current Infectious Disease Reports*. 2010; 12 (1): 63-70.

Appendix 5: Table 2.1 Extraction of data

Author	Country	Aims	Pop. sample size	Methods	Study period	Outcome domains	Instruments	Key findings
148 Anderson et al.(85)	England	To explore the initial responses of Caribbean people to their HIV diagnosis	25 patients, 10 gay men or bisexual men, 5 heterosexual men, 10 heterosexual women. Age not specified	Semi-structured interviews	9 months-13 years after diagnosis	Relief, acceptance, profound shock and distress, associated HIV with death and stigma; loss known self, present life, envisioned future denial, confusion, suicidality, withdrawal, end of intimate relationships, domestic violence, intensified distress; biographical disruption; ambiguity, uncertainty, fear	Open-ended questions	Experiences of multifaceted loss: of their known self, their present life, their envisioned future and partner, a minority of accounts suggest healthcare practitioners in delivering the diagnosis intensified the participants' distress.

Christopoulos et al.(84)	United States of America (USA)	To understand patient perceptions of the emergency department/urgent care (ED/UC) HIV diagnosis experience and factors that may promote or discourage linkage to HIV care	14 in the ED and 10 in the UC. 24 median age 45 (range 25,61).	In-depth interviews; Retrospective study	2011-2012 6months after diagnosis	Kindness, compassion, and “active” linkage to care by health care providers, shock, betrayal, guilt, immediate confidentiality concerns, stigma, anxiety, isolation(due to medical reasons) moral judgement, sadness, shame, no desired emotional supports, difficulty accepting HIV-positive status, logistical hurdles, traumatic, delayed emotional processing of diagnosis	Open-ended questions	Experiences of physical discomfort and limited functionality, presence of comorbid diagnoses, a wide spectrum of HIV risk perception, and feelings of isolation and anxiety.
Galletly et al.(30)	USA	To review potential reactions of		Review		Devastation, rage, overwhelming guilt, harm to	Commentary	Factors likely to moderate reactions to unanticipated diagnosis include gender,

		people who receive unanticipated HIV-positive diagnoses				oneself / suicidality, harm to others increased by pre-existing mental conditions, drugs and alcohol use, impulsive disclosures to sexual partner, friends, workplace; losses of social, instrumental, and financial support, violence, HIV is untreatable or death sentence		relationship status, mode of infection, extent to which an individual is isolated, education level, and social status.
Grace et al.(71)	Canada	To appreciate the lived experiences of gay men	24 gay (96%) White (72%) Asian (12%) Hispanic 8%)	Surveys and qualitative interviews	2009 – 2012 after a median of	Relief test explained symptoms, compassion of	Structured questions and open-	Experiences of uncertainty due to emerging technological innovations that have changed learning of

		newly diagnosed with a recent infection	Aboriginal, First Nations, Metis, or Inuit (4%); African/Black (4%) Mean age 39		35 days postdiagnosis (range 8 to 128 days)	provider, identified medical benefits/treatment, refraining from sexual activity, terrified of having sex at all, troubled/sought cause for their seroconversion confused, suicide ideation, increased anxiety due to provider/patient uncertainty about interpretation of HIV test results Unclear about information, not able to fully “absorb” the	ended questions	one’s HIV positive status and have created new diagnostic categories that require successful interpretation and translation to alleviate uncertainty, and to support public health objectives.
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						information, seeking information about acute HIV infection online		
Hult et al.(82)	USA	To understand the process of adjustment to HIV diagnosis in newly HIV diagnosed individuals	50 Men (92%), gay 78%, 63% white, 19% African American, 12% Latino	Surveys and qualitative interviews	2004-2008, interviewed 1, 3, and 9 months after HIV diagnosis	Relief of telling someone, social support, moral/ethical commitment to disclose, stigma concerns made it not right to disclose, lying about their serostatus, feeling shame, guilt, confidential concerns, stressful, difficult to get social support,	Open-ended question and standardized instrument s: Stigma scales	Disclosure both a stressor and a way to cope with stress, non-disclosure and even lying as sources of stress or methods of coping with implications for effective disclosure, counseling to take into consideration an individual's context and appraisal of HIV, plus stigma concerns and needs for social support.

						selectivity in disclosing, wrong not to disclose		
Hult et al.(83)	USA	To describe the experience of testing positive for HIV	50 Men 92%, people of color 36 % Mean Age 40.5 years	Face-to-face baseline interviews	2004-2006. Mean Time since HIV diagnosis 6.7 weeks	Relief to know, not stressful/determination, ready to deal with the situation, calmed, comforted by provider, shock, surprise, disbelief, sadness, depression, suicidality, crying, distressed by judgmental, overly emotional, or impersonal-provider	open-ended questions	For 7 (14%) of the participants, the provider giving the results was so upset or agitated, increasing participant's distress over the diagnosis. Great variation in responses to the news from being too shocked to immediately accepting the news and feeling ready for action, patient/provider interaction plays a pivotal role in both follow-up care and prevention decisions.

Kelly et al.(69)	Northern Ireland	To understand the uniqueness of the experience of testing HIV positive from the perspective of pregnant women	3 women age 25 -45 years	In-depth interviews	2008–2009 through antenatal screening during the study’s recruitment period	Better to know, baby was a metaphor for hope, trauma, chaos, lack of justice for their infection, experience being different, fear of partner notification, emotional, stressful, worrisome for the child, chaos, stigma, disruption of biographies, felt separation from family and culture, like going to hell and back	Unstructured and conversational style	HIV diagnosis disrupted women’s biographies in terms of their health, relationships and social identity, the threat of HIV experienced in relation to their unborn child, while traumatic in the context of pregnancy, HIV diagnosis provided a focus for regaining continuity in their lives, as the baby became a metaphor for hope and orientation toward the future.
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Kotze et al.(78)	South Africa	To identify psychosocial variables related to the use of coping strategies	224 HIV-positive women	Surveys	4 weeks after diagnosis during pregnancy and 3 subsequent postpartum interviews at 6, 12- and 21-months after the baseline interview (three, nine and 18 months after the	Active coping self-esteem and positive social support, avoidant coping, internalized stigma and depression, lower levels of self-esteem	Structured questions, standardized instruments : Brief COPE, the Multidimensional Social Support Inventory: stigma scales, Rosenberg Self-Esteem scale, Centre for Epidemiologic	Increases in active coping were associated with decreasing levels of internalized stigma and depression, increasing self-esteem and positive social support, knowing someone who is living with HIV, being physically healthy and living above the poverty line, increases in avoidant coping were associated with increasing internalized stigma and depression, lower levels of self-esteem, HIV-knowledge and lower levels of education.
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					infant's birth		Studies, Depression scale (CES-D): a seven-item scale to measure women's empowerment	
Larsson et al.(79)	Uganda	To explore pregnant women's experiences of provider-initiated HIV testing in antenatal care (ANC) health facilities	18 women unknown (n = 10) vs confirmed HIV infection (n = 8) age not specified	Semi-structured interviews and sit-in observations	2008 interviewed while waiting for their HIV test results or other ANC services	Felt forced by ANC staff to unwillingly disclose HIV status, fear of abandonment by partner, fear to disclosure status,	Open-ended questions	Pregnant women who received HIV testing in ANC on-site thought HIV testing was compulsory, without fully realizing the benefits of HIV testing and prevention of mother-to-child transmission of HIV. No referral for HIV testing or information about testing was given at ANC facilities that lacked HIV

						fear of negative reactions and severe consequences, fear of HIV sero-discordance within the couple, if the woman is positive and the man not, unfair testing that allows men to opt-out, couple-testing experienced as precarious		testing on-site. Pregnant women were made responsible for recruiting their spouses for testing, even without having the power to do so.
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Lingen-Stallard et al.(77)	England	To explore women's experiences of receiving a positive HIV test result following antenatal screening	13 black African women	In-depth semi-structured interviews, Retrospective design (2-12 years)	2011-2012	Acceptance, resilience, shock, disbelief, anger, turmoil, loss of old self, confidentiality issues, stigma, consider abortion, suicidal thoughts, felt isolated from others, relationship breakdowns; dislocation from the pregnancy, positive diagnosis as death, sought retesting or further assurance, believed baby would be positive,	Open-ended questions	Extreme reactions to positive HIV diagnosis, compounded by the cultural belief that they would die, the unexpected result led to initial disbelief, which developed into sadness at the loss of their old self, turmoil as women considered termination of pregnancy, self-harm and suicide, women felt isolated from others, relationship breakdowns often occurred, stigma was pervasive, coping strategies included keeping HIV 'secret' and making their child(ren) the prime focus of life, resilience apparent with time.
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						erosion of self-worth		
Moskowitz et al.(81)	USA	To describe illness appraisals in 100 people who had been diagnosed with HIV within the past two months and determine associations of initial appraisal with depressive mood over the course of the first year after diagnosis	100 people Mean age 39.4 (range 19 - 57).	Structured interviews, Qualitative-baseline interviews	2003 - 2008 qualitative data on illness appraisal s and quantitative data on depressive mood from interview s at baseline, and 2, 3, 6, 9, and 12 18 months	Upset but not overwhelmed, internalized stigma, social stigma, suicide ideation, reluctance to disclose to sex partners, loss of social support, would die from HIV, less stressful than other things in their lives, threat to their group identity	Structured questions; Open-ended questions	5 groups that differed in their initial illness appraisals: 1) HIV as Chronic Illness 2) Concern about Dying 3) Stigmatization 4) Threat to Identity 5) Other Threats Overshadow HIV.

					after diagnosis			
Mustanski et al.(70)	USA	To develop and evaluate the psychometric properties of a scale to measure psychological reactions to the receipt of a negative HIV test and explore the scale's associations with unprotected anal intercourse	Two focus (n=9) groups 725 gay men surveyed	Surveys, focus groups	Surveys in May in 2013 More than half (53.7%) of the sample had received an HIV test in the prior 3 months	Reinforced safety, immunity/invulnerability, luck, reducing perceptions of personal HIV risk	Structured questions and open-ended questions	Factor analyses confirmed the presence of three subscales—reinforced safety, invulnerability, and luck, regression analyses demonstrated that the subscales interacted with HIV testing behavior to influence unprotected anal intercourse.

Turan et al.(80)	Kenya	To study associations between linkage to HIV care, postpartum depression, and internalized stigma in newly diagnosed HIV-positive pregnant women	135 HIV-positive women, mean age 24.26 years average 5 months pregnant	Surveys	November 2007 and April 2009	Depression and internalized stigma, risk of intimate partner violence	Structured interview questionnaires, standardized instrument: HIV/AIDS Stigma Instrument (HASI-P); Edinburgh Postpartum Depression Scale (EPDS): survey questions to measure	At 6 weeks postpartum, women who had not linked to HIV care after testing positive at their first antenatal visit had higher levels of depression and internalized stigma, compared to women who had linked to care, internalized stigma mediated the effect of linkage to care on depression, furthermore, participants who had both linked to HIV care and initiated antiretroviral therapy reported the lowest levels of depressive symptoms.
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							Pre/Postpartum intimate partner violence (IPV)	
Valle, Levy.(86)	USA	To examine the cognitive interpretations African American injection drug users make of an HIV-positive test result and the attitudinal and behavioural patterns that accompany those interpretations	80 IDUs men 64% women 36% female age 24-67, 50%>40-49 years	Semi-structured interviews	73 interviews conducted within 3-6 months postdiagnosis, 7 between 6-18 months	Wake-up call, being blessed, living clean, advocacy, death knell, self-destruction, pleasure-seeking, blame, vengeance, just another problem, resignation, minimization	Open-ended questions	Individuals who interpreted testing HIV-positive as a 'wake up call' displayed the attitudinal and behavioural patterns of 'being blessed,' 'living clean' and 'advocacy,' those that interpreted the test result as a 'death knell' displayed 'self-destructive,' 'pleasure-seeking' and 'vengeance,' those that interpreted the positive test result as 'just one more problem' displayed 'resignation' and 'minimization.'

Willcocks et al.(76)	England	To explore the impact of being diagnosed with HIV during pregnancy on mother–infant bonding	10 participants: eight from sub-Saharan Africa, one UK, one Jamaica, age 25-41 years	Semi-structured interviews, retrospective study	Age of their first post HIV-diagnosis children varied from 18 months to four years	Anxiety about fetal death, fearful for the future of a positive baby, fears about HIV transmission to baby, stressed about starting medication, feelings of guilt, shame, distancing from their babies, maternal uncertainty, avoiding disclosure of their own HIV status	Open-ended questions	A model of mother–infant bonding composed of four theoretical codes: (a) facing barriers to bonding (b) feeling disconnected from the baby (c) developing a special bond (d) strengthening and moving on, challenges with bonding emerged primarily during early stages after diagnosis and birth, with maternal resilience and positivity about the future developing as the infant HIV testing process progressed.
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Appendix 6: Permissions granted for figures

1. A conceptual framework of access to care Levesque et al.(4)^(P.5)

Dear John,

Thank you very much for your email. My team forwarded your request to use Figure 2A from my 2013 conceptual framework published in the International Journal for Equity in Health. It is a pleasure for me to grant you authorisation to reproduce the figure with appropriate citation of the source.

Thank you.

Jean-Frederic Levesque

Jean-Frederic Levesque, MD PhD FRCPC

Chief Executive



AGENCY FOR
CLINICAL
INNOVATION

"I acknowledge the traditional owners of the land I work on as the first people of this country."

2. Implementation Cascade for the Continuum of Care Institute of Medicine, et al.(86)^(p.244)

This is not an invoice

Order Details

Evaluation of PEPFAR

Billing Status:
N/A

Order detail ID: 71838192	Permission Status:  Granted
ISBN: 9780309267809	Permission type: Republish or display content
Publication Type: Book	Type of use: Thesis/Dissertation
Publisher: National Academies Press	Order License Id: 4542120999671
Author/Editor: Institute of Medicine (U.S.), Committee on the Outcome and Impact Evaluation of Global HIV/AIDS Programs Implemented under the Lantos-Hyde Act of 2008	Order ref number: 00716117

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Appendix 7: Socio-demographic questions for interviews among young heterosexual African migrants

How old are you?

...

I am...:

Male

Female

I identify as...

My ethnicity/country of origin is...

My religion is...

My residence is...

Declined to answer

Education. What was the last level of school that you completed?

No formal education

Primary

incomplete

Primary complete

Secondary/vocational incomplete

Secondary/vocational complete

Post-secondary

Other (please specify)...

Declined to answer

Are you...?

Never married

Married/cohabiting

Divorced/separated

Widowed

Declined to answer

Now I have some questions about the work you do and your access to food.

What kind of work do you do? By that I mean, what kind of activities keep you busy during an average day, whether you earn money from them or not....

During the past month, how often have you had problems getting the food you need?

Never

Sometimes

Often

Always

Declined to
answer

Now I would like to ask you some question about your home and living conditions.

Do you live alone?

Yes

No

Declined to
answer

With whom do you live? Mark all that
apply

Family

Friends

How long have you lived in Canada?.....

My sex orientation is:

Homosexual/lesbian

Heterosexual

Other

Appendix 8: Questions and probes for interviews among young heterosexual African migrants

1. What do you think about HIV testing?

Probes:

- Tell meis it important to know one's HIV status?
- What do you think of offering an HIV test at a health centre when patients come for something else?
- What could be done to help somebody with HIV stay healthy and live longer?

2. Was it your own initiative or the test was offered at the request of a health worker?

Probes:

- Have you ever been tested?
- How many times?
- Was it hard to be tested?
- Why?

3. How were your pre-test services and experiences?

Probes:

- How important is it that health workers keep their results confidential?
- Are you willing to tell me your HIV status?
- *HIV positive*: What did the health worker do after that?

Only those who said they had never tested for HIV were asked the following questions before questions 4 and 5 mentioned above:

Have you ever thought of having an HIV test?

Probes:

- Do you know of any one personally who had a test and if they think it was helpful?
- Any facilities offering HIV you know of?
- How easy or difficult it is to go there?

3. Why did you not have one?

Probes:

- Have you ever been offered an HIV test and refused? Why?
- Do you think health workers keep results confidential?
- Tell me about other factors that could influence your decision not to go for HIV testing.
- Why do your friends not want to go for HIV testing?

4. Do you know about the criminal law that obligates one who is HIV positive to disclose his/her status?

Probe:

- *(if yes)* Could that be the reason for not testing?

5. “What could be done to improve access to HIV testing for those who want it or in your age group?”

Probe:

- Do you have any suggestions on how HIV testing can be improved for people in your own age-group and sex?

Appendix 9: Socio-demographic questions for interviews among health service providers

How old are you?

...

I am...:

Male

Female

I identify as...

My ethnicity/country of origin is...

My religion is...

My residence is...

Declined to answer

Education. What was the last level of school that you completed?

No formal education

Primary

incomplete

Primary complete

Secondary/vocational incomplete

Secondary/vocational complete

Post-secondary

Other (please specify)...

Declined to answer

Are you...?

Never married

Married/cohabiting

Divorced/separated

Widowed

Declined to answer

Now I have some questions about the work you do and your access to food.

What kind of work do you do? By that I mean, what kind of activities keep you busy during an average day, whether you earn money from them or not....

During the past month, how often have you had problems getting the food you need?

Never

Sometimes

Often

Always

Declined to

answer

Now I would like to ask you some question about your home and living conditions.

Do you live alone?

Yes

No

Declined to
answer

With whom do you live? Mark all that
apply

Family

Friends

Other (please specify)...

Appendix 10: Questions and probes for interviews among health service providers

1. What do you think about HIV testing?

Probes:

- Tell meis it important to know one's HIV status?
- What do you think of offering an HIV test at a health centre when patients come for something else?
- What could be done to help somebody with HIV stay healthy and live longer?

2. What do you want to achieve?

Probes:

- Tell me....**for HIV test providers**: is offering an HIV test part of your job?
- Do you ever go out into the community to encourage people to test for HIV?
- Do clients usually accept?
- Do they ever get upset?
- What is the typical way (and circumstances) that you offer the test?
- Do you follow certain guidelines?

For Frontline service providers only:

- Do you personally provide HIV prevention information to HIV-positive patients on a regular basis as a part of your work?
- What type of prevention information do you discuss with them?
- What social support do you offer them?

3. How is easy or difficult is it to achieve that?

Probes:

- **(for both)** Do you think young African heterosexual migrant men in this community think that HIV or AIDS is less dangerous than in the countries they originally come from?

4. What hinders young straight African migrant men in this community from testing for HIV?

Probes:

- Do you know if there are funding arrangements legally enforced for HIV testing in Ontario?

5. What could be done to improve access to HIV testing for those who want it in this case study?

Probes:

- Do you have any suggestions on how HIV testing can be improved for young heterosexual African migrant men?