Assessing the reproductive healthcare needs and priorities of women living with HIV in Canada

Lashanda Stéphanie Skerritt

Department of Family Medicine

McGill University

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List of Abbreviations

ACB African, Caribbean, and Black
AIDS Acquired Immune Deficiency Syndrome
aOR adjusted odds ratio
ART antiretroviral therapy
AZT azidothymidine
CHIWOS Canadian HIV Women’s Sexual and Reproductive Health Cohort Study
CI confidence interval
ERR excess risk ratio
FCM Fuzzy Cognitive Map
GIPA/MIPA Greater/Meaningful Involvement of People Living with HIV/AIDS
HCP healthcare provider
HIV Human Immunodeficiency Virus
IUD intrauterine device
LGBTTQ Lesbian, Gay, Bisexual, Transgender, Two-Spirit and Queer
MIWA Meaningful Involvement of Women living with HIV/AIDS
PRA Peer Research Associate
REB Research Ethics Board
U=U undetectable = untransmittable
WHO World Health Organization

Abstract

Background

Women living with HIV describe a lack of health services that respond to their comprehensive health needs. Among measured indicators of comprehensive healthcare, reproductive health represents one of the largest gaps in care for this population. Advancements in treatment and medical care have transformed HIV into a chronic manageable condition, eliminated the risk of sexual HIV transmission and significantly reduced the risk of perinatal transmission. Reproductive health considerations for women living with HIV have evolved, but care delivery has lagged. The marginalization of women in HIV research and the design of HIV services has led to a poor understanding of their contemporary care needs and priorities.

Objectives

The goal of this dissertation was to assess the contemporary reproductive healthcare needs and priorities of women living with HIV in Canada. Specifically, this dissertation had three main research objectives: (1) to examine how the pregnancy intentions of women living with HIV change over time, (2) to identify factors that lead to reproductive discussions with healthcare providers and examine the mediating role of women's comfort, and (3) to assess the importance of reproductive health in women's definition of satisfying HIV care.

Methods

Guided by Reproductive Justice and Social Determinants of Health frameworks, I conducted three studies using multiple methodological and participatory research approaches: two quantitative studies analyzed data from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), a community-based longitudinal cohort study conducted between 2013 and

2018. The first study (n=284) described changes in pregnancy intentions over 36 months. The second study (n=536) used causal mediation analysis to estimate direct and indirect effects of healthcare provider gender on reproductive discussion, examining the role of women's comfort as a mediator. The third study applied Fuzzy Cognitive Mapping, a qualitative and semi-quantitative approach, to integrate existing literature on satisfaction with HIV care and the experiential expertise of 23 women living with HIV in British Columbia and Quebec, Canada.

Results

The findings from the three studies reveal missed opportunities to support the diverse and dynamic reproductive health needs of women living with HIV. Over 18 months, 29.6% of participants changed their pregnancy intentions, while 42% had some change in their pregnancy intentions over 36 months. Over 18 months, 34.1% of participants discussed their reproductive goals with a healthcare provider. Reproductive discussions were more likely to occur if participants were receiving care from a woman care provider. Women's comfort discussing their reproductive goals mediated 66% (95%CI: 32%, 99%) of the observed association between provider gender and whether reproductive discussions occurred. Fuzzy Cognitive Mapping participants identified feeling safe and supported by healthcare providers and clinics as the most important and central consideration in their satisfaction with HIV care.

Conclusions

Women living with HIV face multiple, intersecting social and structural barriers to reproductive health and rights. Findings from this dissertation point to the importance of interpersonal aspects of care in HIV and primary care delivery. Creating environments where women living with HIV feel

safe, supported, and comfortable discussing their evolving reproductive goals can help understand and support their reproductive health needs and priorities.

Résumé

Contexte

Les femmes vivant avec le VIH décrivent un manque de services de santé qui répondent à leurs besoins globaux en matière de santé. Parmi les indicateurs mesurés de soins de santé complets, la santé reproductive représente l'une des plus grandes disparités en matière de soins pour cette population. Les progrès réalisés en matière de traitement et de soins médicaux ont transformé le VIH en une maladie chronique gérable, éliminé le risque de transmission sexuelle du VIH et réduit de manière significative le risque de transmission périnatale. Les considérations relatives à la santé reproductive des femmes vivant avec le VIH ont évolué, mais la prestation des soins a évolué plus lentement. La marginalisation des femmes dans la recherche sur le VIH et dans la conception des services liés au VIH a conduit à une mauvaise compréhension de leurs besoins et priorités actuels en matière de soins.

Objectifs de la thèse

L'objectif de cette thèse était d'évaluer les besoins et les priorités des femmes vivant avec le VIH au Canada en matière de soins de santé reproductive. Plus précisément, cette thèse avait trois objectifs de recherche principaux : (1) examiner comment les intentions de grossesse des femmes vivant avec le VIH évoluent dans le temps, (2) identifier les facteurs qui conduisent à des discussions sur la reproduction avec les prestataires de soins de santé et examiner le rôle médiateur du confort des femmes, et (3) évaluer l'importance de la santé reproductive dans la définition par les femmes d'une prise en charge satisfaisante en matière de VIH.

Méthodes

Guidée par les cadres de la justice reproductive et des déterminants sociaux de la santé, j'ai mené trois études en utilisant de multiples approches méthodologiques et de recherche participative : deux études quantitatives ont analysé les données de l'étude sur la santé sexuelle et reproductive des femmes vivant avec le HIV au Canada (CHIWOS), une étude de cohorte longitudinale communautaire menée entre 2013 et 2018. La première étude (n=284) a décrit l'évolution des intentions de grossesse sur 36 mois. La deuxième étude (n=536) a utilisé une analyse de médiation causale pour estimer les effets directs et indirects du sexe du prestataire de soins de santé sur les discussions concernant la reproduction, en examinant le rôle du confort des femmes en tant que médiateur. La troisième étude a appliqué la cartographie cognitive floue (Fuzzy Cognitive Mapping), une approche qualitative et semi-quantitative, pour intégrer la littérature existante sur la satisfaction à l'égard des soins liés au VIH et l'expertise expérientielle de 23 femmes vivant avec le VIH en Colombie-Britannique et au Québec, au Canada.

Résultats

Les résultats des trois études révèlent des occasions manquées de répondre aux besoins divers et dynamiques des femmes vivant avec le VIH en matière de santé reproductive. Sur une période de 18 mois, 29,6 % des participantes ont modifié leurs intentions de grossesse, et 42 % d'entre elles ont modifié leurs intentions de grossesse sur une période de 36 mois. Sur une période de 18 mois, 34,1 % des participantes ont discuté de leurs objectifs en matière de reproduction avec un prestataire de soins de santé. Les discussions sur la reproduction étaient plus susceptibles d'avoir lieu si les participantes recevaient des soins d'un prestataire de soins qu'elles identifiaient comme une femme. Le fait que les femmes se sentent à l'aise pour discuter de leurs objectifs en matière de reproduction a joué un rôle de médiateur dans 66 % (IC 95 % : 32 %, 99 %) de l'association observée entre le sexe du prestataire et l'existence ou non de discussions sur la reproduction. Les participants au Fuzzy Cognitive Mapping ont indiqué que le fait de se sentir en sécurité et soutenus par les prestataires de soins et les cliniques était la considération la plus importante et la plus centrale dans leur satisfaction à l'égard des soins liés au VIH.

Conclusions

Les femmes vivant avec le VIH sont confrontées à des obstacles sociaux et structurels multiples et croisés en matière de santé et de droits reproductives. Les résultats de cette thèse soulignent l'importance des aspects interpersonnels des soins dans la prestation de soins primaires et de soins liés au VIH. La création d'environnements dans lesquels les femmes vivant avec le VIH se sentent en sécurité, soutenues et à l'aise pour discuter de l'évolution de leurs objectifs en matière de reproduction peut aider à comprendre et à soutenir leurs besoins et leurs priorités en matière de santé reproductive.

To my dad, who always encouraged me to ask questions.

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Statement of originality and author contributions

Contribution to original knowledge

The body of work described in this dissertation presents original research and an original contribution to the field of reproductive and HIV health research. In Manuscript 1, I examined contemporary pregnancy intentions longitudinally, whereas previous research was conducted prior to u=u messaging and focused on pregnancy intentions at one point in time. The findings demonstrate that not only are pregnancy intentions among women living with HIV diverse, but intentions are also dynamic. This was the first study describing the contemporary patterns in changing pregnancy intentions longitudinally among a cohort of women living with HIV in the global north in the u=u era.

In Manuscript 2, I applied a causal mediation model and statistical approach to untangle the association between features of care and reproductive health discussions between women living with HIV and their care providers. The use of causal medication analysis allowed for an estimation of the direct, indirect and interaction effects of healthcare provider gender and patient comfort on the occurrence of reproductive discussions in the healthcare setting. Findings identified comfort as a significant mediator in the causal pathway between healthcare provider gender and reproductive discussions, suggesting addressing comfort may be an important intervention to support ongoing reproductive discussions in the healthcare setting.

In Manuscript 3, I used Fuzzy Cognitive Mapping and a Reproductive Justice lens to update existing literature on satisfaction with HIV care by integrating the perspectives of women living with HIV.

In this study, a conceptual map derived from a previously published systematic review of the literature on important aspects of healthcare delivery among people living with HIV in the global north was updated through the systematic integration of the perspectives of 23 women living with HIV in Canada. The study expands on existing literature by identifying categories that influence satisfaction with HIV care for women, which were not previously described in the literature. These categories include gendered health and social considerations. The study contributes a deeper understanding of how gender shapes the care needs and priorities of women living with HIV.

Contribution of authors

Under the supervision and guidance of my research supervisors, Dr. Alexandra de Pokomandy and Dr. Angela Kaida, and my thesis advisory committee composed of Drs. Gillian Bartlett, Ann Burchell, and Nadia O'Brien, I conceptualized the research questions, carried out an extensive literature review, planned and conducted the data analyses for the studies described in Manuscript 1, 2 and 3. I secured funding to conduct the study described in Manuscript 3 through a seed grant from the SPOR Evidence Alliance. I lead the data collection as well as the data analysis for the Fuzzy Cognitive Mapping study described in Manuscript 3. I drafted the 3 manuscripts that comprise this dissertation. As my dissertation applied participatory research approaches and was partly embedded within the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), a community-based study by, for and with women living with HIV, my research was also highly collaborative and conducted in partnership with Peer Research Associates, women living with HIV who contributed lived experience and who I trained in the Fuzzy Cognitive Mapping approaches described in Manuscript 3. For Manuscripts 1 and 2, I analyzed existing data from the CHIWOS.

Prior to beginning my dissertation research, my thesis supervisors conceptualized the CHIWOS research program with the aim of addressing knowledge gaps in the use of women-centred HIV/AIDS services and the impact of these services on the sexual, reproductive, mental and women's health of women living with HIV in Canada. Along with my thesis committee member, Dr. Nadia O'Brien, they hired and trained CHIWOS Peer Research Associates. They also led the development and validation of the survey instrument and the recruitment of study participants.

Manuscript 1: Lashanda Skerritt, Angela Kaida, Nadia O'Brien, Ann N. Burchell, Gillian Bartlett, Édénia Savoie, Isabelle Boucoiran, Rebecca Gormley, Mary Kestler, Deborah Money, Mona Loutfy, and Alexandra de Pokomandy. Patterns of changing pregnancy intentions among women living with HIV in Canada. BMC Women's Health 2021; 21(1):350

LS, AK, ML, and ADP conceptualized the study. NO, ES, and RG collected the survey data. LS conducted the statistical analyses. LS led the interpretation of findings with input from AK, ES and ADP. LS drafted the manuscript. All authors revised the manuscript for intellectual content and approved the final version for publication.

Manuscript 2: Lashanda Skerritt, Alexandra de Pokomandy, Nadia O'Brien, Nadia Sourial, Ann N Burchell, Gillian Bartlett, Tibor Schuster, Danielle Rouleau, Karène Proulx-Boucher, Neora Pick, Deborah Money, Rebecca Gormley, Allison Carter, Mark H Yudin, Mona Loutfy, Angela Kaida &

CHIWOS Research Team. Discussing reproductive goals with healthcare providers among women living with HIV in Canada: the role of provider gender and patient comfort. Sexual and Reproductive Health Matters 2021; 29(1): 1932702

LS, ADP, ML, and AK conceptualized the study. NO, KPB, RG, and AC collected the survey data. LS conducted the statistical analyses. LS led the interpretation of findings with input from ADP, AK, NS, TS. LS drafted the manuscript. All authors revised the manuscript for intellectual content and approved the final version for publication.

Manuscript 3: Lashanda Skerritt, Angela Kaida, Édénia Savoie, Margarite Sánchez, Iván Sarmiento, Nadia O'Brien, Ann N Burchell, Gillian Bartlett, Isabelle Boucoiran, Mary Kestler, Danielle Rouleau, Mona Loutfy, Alexandra de Pokomandy. Understanding the relative importance of reproductive health in comprehensive HIV care for women living with HIV in Canada: a participatory Fuzzy Cognitive Mapping study. To be submitted

LS conceptualized this study with input from AK, ADP and ES. LS wrote and submitted the grant for operational funding and ethics approval from the McGill University Health Centre (MUHC) Research Ethics Board and the University of British Columbia and Simon Fraser University Research Ethics Boards. LS hired, trained, and supported the Peer Research Associates. LS, ES, MS, and ADP recruited study participants. LS, ES, and MS facilitated the interviews and focus group discussions. LS, ES, and MS conducted the content analysis. LS analyzed the quantitative Fuzzy Cognitive

Mapping data with guidance from IS. LS, ES, and MS led the interpretation of findings with input from AK, NO and ADP. LS drafted the manuscript.

1. Introduction

1.1 Background

Advances in HIV treatment and healthcare have changed the reproductive landscape for women living with HIV. HIV is now a chronic condition managed through life-long use of antiretroviral therapy (ART) and engagement in HIV care (1), the goal of which is maintaining a suppressed viral load. With a suppressed viral load, people living with HIV are not only living longer, healthier lives compared to the early years of the HIV epidemic but also pursuing fulfilling sexual and reproductive lives (2) with no sexual HIV transmission risk and minimal perinatal transmission risk during pregnancy (3, 4). However, gaps in reproductive healthcare delivery exist despite these improvements in HIV treatment and healthcare, particularly for women (5).

The intersection of social, economic and political determinants of health explains gendered disparities in health outcomes among people living with HIV. The socially constructed roles, identities, behaviours, expectations and expressions that define gender play an important role in how women experience and navigate HIV healthcare. Women's experiences are uniquely shaped by historical, social and cultural ideals around HIV. In the early years of the epidemic, HIV was largely considered a disease affecting men who have sex with men, but in 2019 women made up 30.2% of new HIV diagnoses in Canada (6) and more than half of people living with HIV globally (7). The intersection of gender and other determinants of social positioning contribute to worse HIV-related health outcomes for women compared to men across the HIV care cascade, including the exclusion and underrepresentation of women living with HIV in research and health service design (8). Hence, gender is an important consideration in HIV care. In addition, researchers are examining a potential biological basis for disparities across sexes (9). In Canada, women are more likely to be diagnosed late, less likely to be engaged and retained in care, and less likely to maintain viral suppression compared to men (10, 11). Healthcare services that fail to acknowledge gender inequities and respond to the needs, priorities, and contexts of women living with HIV further exacerbate these gender disparities (12, 13, 14, 15).

Reproductive healthcare for women living with HIV addresses the social and physiological reproductive health considerations that affect people living with HIV who identify as women. Gender is an important construct to consider in the context of reproductive health for women living with HIV as it impacts multiple dimensions including access to ART, prevention of HIV transmission, stigma, disclosure, contraception, pregnancy intentions, access to healthcare and interactions with the healthcare system. Reproductive healthcare, including support for reproductive decision-making, contraceptive counselling and administration, abortion access, preconception counselling, and support during the post-partum period, is a facet of comprehensive health care for women living with HIV. The Programme of Action of the International Conference on Population and Development defines reproductive health as “a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity, in all matter relating to the reproductive system and to its functions and processes” (16). Sexual and reproductive health and rights are interconnected and therefore should be considered as an integrated and comprehensive construct. Women living with HIV have described services that do not fully address their needs for family planning, pregnancy planning and abortion services (17, 18). For the purpose of addressing these previously identified gaps in reproductive healthcare, this dissertation research, with its limited scope, focused on reproductive health needs and priorities.

Current organizational models of HIV care delivery often overlook reproductive healthcare (19). The majority of women living with HIV in Canada receive HIV and primary care from HIV specialized doctors or clinics, where reproductive healthcare may not be prioritized (5, 20). In one recent study, indicators of reproductive healthcare delivery represented the largest measured gap in care for women living with HIV in Canada (5). Gaps in reproductive healthcare for women living with HIV contribute to high rates of unintended pregnancies, higher risk of perinatal HIV transmission, and more experiences of HIV-related stigma during pregnancy and in the postpartum period (21, 22, 23, 24).

Equitable and evidence-based reproductive healthcare delivery for women living with HIV is needed to address gaps in care while also considering the gendered disparities in HIV care among people living with HIV in Canada. Given the evolving medical, epidemiological, and social HIV landscape, a deeper understanding of the contemporary reproductive healthcare needs of women living with HIV is needed.

1.2 Problem Statement

Although the importance of addressing sexual and reproductive health in HIV care is known (24) the current reproductive health needs and priorities of women living with HIV are poorly understood (25). Today, women living with HIV are more likely to become pregnant compared to the pre-ART years of the HIV epidemic (26). The increased incidence of pregnancy and childbirth, however, is mostly driven by unintended pregnancies (21, 27). An estimated 61% of pregnancies among women living with HIV in Canada are unintended, while the use of prescription contraceptive methods is lower compared to their use by HIV-negative women (28, 29, 30). Lower uptake of prescription contraceptive methods among women living with HIV suggests women may not be discussing their sexual behavior or pregnancy intentions with their healthcare providers, leading to missed opportunities for providers to support women's reproductive goals.

Supporting the reproductive goals of women living with HIV necessitates an understanding of current pregnancy intentions and their evolution. Previous estimates of pregnancy intentions among women living with HIV in Canada are from cross-sectional studies and prior to undetectable = untransmittable (U=U) messaging, meaning they may not capture contemporary pregnancy intentions or changes over time. The relationship between pregnancy intentions and pregnancy incidence among women living with HIV is also unknown. Providing healthcare that supports women's intentions to become pregnant or avoid pregnancy begins with dialogue between women and their healthcare providers in which women can share their reproductive goals. Discussions between women living with HIV and their healthcare providers, however, are not routine (20, 31). Moreover, the features of healthcare settings and the characteristics of healthcare providers that promote and support reproductive discussions have not been studied.

To address gaps in reproductive healthcare, an understanding of the contemporary reproductive health needs and priorities of women living with HIV is needed. This requires an understanding not only of pregnancy intentions and the factors that facilitate reproductive health discussions in healthcare settings, but also an understanding of the historical and present-day role of gender in HIV care delivery. Both historically and in the present-day, medical and social HIV research lenses have focused on men, leaving gaps in our understanding of women's experiences with care. Health service research for women living with HIV must consider the marginalization of women's voices and centre their needs, priorities, and perspectives.

1.3 Purpose and Specific Objectives

The purpose of this dissertation was to assess three distinct but related reproductive health considerations for women living with HIV: changes in pregnancy intentions, reproductive discussions with healthcare providers, and the importance of reproductive healthcare in HIV care that women consider satisfactory. This research focused on needs and priorities among women living with HIV rather than all people living with HIV because of gendered inequities that not only drive greater vulnerability to HIV infection and worse health outcomes among women compared to men but also contribute to the marginalization of women's voices in HIV research. Social and medical research lenses have, both historically and in the present-day, overlooked the experiences of women living with HIV, necessitating research approaches that focus on women's specific needs and priorities. This dissertation considered women living with HIV as experts in their lived experiences with reproductive and HIV healthcare.

To address the overall aim of this dissertation, the research addressed three distinct but related objectives.

1) To examine how the pregnancy intentions of women living with HIV change over time and whether pregnancy intention predicts future pregnancy incidence.
2) To identify determinants of women living with HIV discussing reproductive goals with a healthcare provider and determine whether women's comfort discussing their reproductive goals is a mediating factor.

3) To identifying factors influencing women’s satisfaction with HIV care and the relative importance of reproductive healthcare in women’s satisfaction.

1.4 Positionality

My social location, personal and professional identities and lived experiences shape my ontological and epistemological beliefs. I apply a critical research lens informed by my identities and experiences as a Black woman, a research trainee and a medical student to studying reproductive rights. I arrive at this work with the stance that an individual's reproductive rights are fundamental and should not be constrained by political, social, or economic inequities.

The intersecting facets of my identity, particularly gender and race, inform my relationship to the Reproductive Justice social movement. The movement arose from Black feminists' critique of feminist thinking around reproductive choice and its lack of acknowledgment of other marginalized identities intersecting with gender. As a woman not living with HIV, my lived experience with constraints on Reproductive Justice does not intersect with the marginalized experience of living with HIV, as it does for the women who participated in this research.

My developing identity as a clinician and healthcare provider in training evolved over the course of my PhD and shaped my interpretations and reflections of the implications of this work. While my healthcare provider perspective informed my reflections about gender and power in the interaction between women and their healthcare providers, the perspectives of more experienced providers who have been providing care to people living with HIV for decades were also included throughout the research process by other research team members. The research team included women living with HIV in different regions of Canada with diverse professional identities and lived experiences relating to reproductive rights. Some community advisory board members brought an advocacy lens to this work, also contributing to shaping my critical research lens. Many of the women living with HIV and researchers I collaborated with had years of experience in HIV research and advocacy, which informed the perspectives brought to this work.

1.5 Organization of the Dissertation

This dissertation consists of seven chapters plus appendices. In this chapter, I provide an overview of the problem this dissertation aims to address and the specific research objectives. In Chapter 2, I synthesize the literature that existed at the time this research was conducted on what was known about the experiences of women living with HIV in reproductive decision-making and navigating reproductive healthcare, situating the problem within the historical and present-day realities of women living with HIV and their accessing HIV and reproductive healthcare. I highlight what was missing from existing knowledge and how this dissertation addresses these knowledge-gaps. Chapter 3 describes the research methodology, including the theoretical frameworks underpinning this research, the study design, the methods, and the primary data source, the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS).

Chapter 4, published in *BMC Women's Health* (32), describes the contemporary pregnancy intentions of women living with HIV and examines the relationship between pregnancy intention and pregnancy incidence.

Chapter 5, published in *Sexual and Reproductive Health Matters* (33), examines the prevalence of women living with HIV discussing their reproductive goals with healthcare providers and investigates the roles of provider gender and patient comfort in determining whether these discussions occur.

Chapter 6, published in *the Journal of Personalized Medicine* (34), explores factors that influence women’s satisfaction with HIV care, along with the perceived relative importance of reproductive healthcare, from the perspective of women living with HIV.

In Chapter 7, I present a unifying discussion, summarizing the key findings, strengths, and limitations of the research and the implications for primary care research and practice.

2. Literature Review

Introduction

In this chapter, I examine gaps in understanding about the reproductive health needs of women living with HIV. This literature review situates the problem of unmet reproductive health needs, considering what was known at the time that this dissertation research was conducted about women living with HIV, experiencing HIV stigma, and navigating reproductive healthcare. As this dissertation research focuses on the experiences of women living with HIV in Canada, I focus on evidence from Canada and comparable healthcare contexts. I summarize advances in HIV care and the goals of HIV treatment, including the benefits of HIV prevention and antiretroviral therapy (ART) for people living with HIV (2.1). I argue that social determinants of health inequities among women living with HIV necessitate specific considerations in the care of women (2.2). I synthesize evidence on the role of HIV stigma on reproductive decision making for women living with HIV (2.3). I define reproductive healthcare for women living with HIV, arguing that a lack of prioritization of women-specific health needs contributes to unmet reproductive health needs (2.4). I present existing evidence on pregnancy intentions (2.5) and models of reproductive healthcare delivery for women living with HIV in Canada (2.6). Finally, I summarize the known reproductive healthcare and knowledge gaps and outline how the objectives of this dissertation aim to inform equitable reproductive healthcare delivery for women living with HIV (2.7).

Chapter 2 – Literature Review

2.1 HIV/AIDS: Advances in Treatment

Since the first cases of Acquired Immune Deficiency Syndrome (AIDS) were reported in 1981, an estimated 36.3 million people have died of the disease as of 2021 (35). In 1983, HIV, a retrovirus, was isolated and identified as the cause of AIDS (36, 37). HIV targets and destroys CD4+ T cells (CD4), weakening the immune system (38). Without treatment, HIV infection causes AIDS, which is fatal (39). AIDS is diagnosed when CD4 count is below 200 cells/mm or with the diagnosis of an AIDS-defining opportunistic infection, such as candidiasis, cryptococcosis, and Kaposi's sarcoma (40). Although there is currently no cure for HIV infection, ART targets HIV replication, preventing HIV infection from progressing to AIDS and reducing the risk of HIV transmission (41).

The UNAIDS estimates that 38 million people were living with HIV globally in 2019 (35), with prevalence of HIV increasing over time given the advancements in HIV treatment and medical care. The first ART, azidothymidine (AZT), was approved by the US Food and Drug Administration in 1987, six years after the first reported AIDS cases (42). AZT improved life expectancy for people living with HIV but was marked by eventual drug resistance among patients taking the medication for extended periods of time (43). The introduction of three-drug combination ART in 1996 significantly reduced morbidity and mortality, and transformed what it meant to live with HIV for those with access to treatment (44). Life expectancy of people living with HIV today approaches that of the HIV-negative population (11). People diagnosed with HIV, engaged in care, and on treatment can live long lives without ever progressing to AIDS (45, 46, 47). Consequently, HIV care has shifted from acute care management to chronic disease management. Healthcare for people living with HIV today must address co-morbidities, mental health, and sexual and reproductive health across the lifespan.

Empirical studies established the benefits of early ART initiation for the health of people living with HIV and to prevent HIV transmission (41). The HPTN 052 trial, conducted between 2007 and 2010, was particularly noteworthy as it crystalized the idea of treatment-as-prevention; final results published in 2016 reported early ART initiation led to a 93% reduction in HIV transmission risk to sexual partners compared to delayed ART initialization (41). Treatment-as-prevention is further supported by evidence demonstrating that sustained HIV suppression effectively eliminates the risk of sexual transmission (48, 49). This evidence was amplified in the undetectable equals untransmittable (U=U) campaign (50), which has been accepted and promoted by public health agencies and organizations globally, including Health Canada as of December 2018 (51). Sustained HIV viral suppression is also important in the context of reproductive health to lower the risk of perinatal HIV transmission during pregnancy and in childbirth and through infant feeding (52, 53). A study conducted in Canada found the perinatal transmission risk between 1997 and 2010 was 0.4% with appropriate maternal ART treatment and healthcare, demonstrating the improvements in HIV health outcomes in the area of effective treatments (4).

To achieve the health and prevention benefits of HIV treatment, engagement in care is key. The HIV care cascade describes the steps people living with HIV must navigate to access HIV care and achieve viral suppression (54, 55, 56). The steps in the HIV care cascade are HIV testing, linkage to HIV care, engagement in HIV care, initiation and adherence to ARTs, and viral suppression (57). The HIV care cascade provides a framework to analyze disparities in HIV care. Social and structural factors impact vulnerability to HIV, access to HIV healthcare, and, consequently, HIV health outcomes. Access to the benefits of ART depends on access to and engagement in healthcare.

Ample evidence, however, has demonstrated inequities in engagement in care and access to ARTs, with particularly striking gendered inequities in Canada (58, 59, 60, 61).

2.2 Social Determinants of Health Inequities Among Women Living with HIV

The gender distribution of people living with HIV has changed since the beginning of the HIV epidemic. Men who have sex with men remain the largest HIV exposure group in Canada, but women represent one-quarter of the estimated 62,050 people living with HIV and around 53% of people living with HIV globally (6, 7). In Canada, women accounted for 30% of new HIV diagnoses in 2019 (6).

Women living with HIV in Canada experience more barriers to healthcare access compared to men and are more likely to be lost at each of the steps of the HIV care cascade. Women are diagnosed with HIV at more advanced stages and have longer delays between diagnosis and linkage to care. Women living with HIV in North America are also less likely to be retained in care, adhere to ARTs, and achieve viral suppression (59, 62, 63, 64). Moreover, health outcomes among women living with HIV in Canada are worse compared to outcomes among men. In the general Canadian population, life-expectancy among women exceeds that of males (65), but among the population living with HIV, life-expectancy among women was an estimated 7 years less between 2000 and 2012 (11). These disparities are largely attributed to the intersection of gender and socio-structural determinants of health, including racism, sexism, classism, homophobia, and transphobia (66, 67). Furthermore, the early years of the HIV epidemic set a precedent for the social, medical, and research lenses to focus on HIV among men. The needs of women have been overlooked, contributing to gender disparities (68, 69).

These inequities intersect with other social determinants of health. For instance, in Canada, women account for 48.6% of new HIV cases in Indigenous communities, but only 20.4% in the non-Indigenous population (70). High rates of HIV in Indigenous communities are linked to the ongoing legacy of colonialism and racism, including intergenerational trauma from residential schools and the creation of reserves and communities isolated from healthcare services. These socio-structural factors create significant barriers to healthcare access for many Indigenous women. Results from a cross-sectional survey of African, Caribbean, and Black (ACB) women living with HIV in Canada found that racial discrimination was significantly associated with depression, reduced quality of life and reduced social support (71).

Additional examples of differences in the social positioning of women living with HIV can be seen in the correctional system. Although women represent only 6% of federally incarcerated people in Canada (72), a study of women living with HIV in Vancouver reported a 76% lifetime incarceration rate (73). Notably, the prevalence of HIV among women in prison is estimated to be 4.7% compared to 1.7% among men in prison (72). Moreover, Indigenous women are over-represented in Canada’s criminal justice system, accounting for 42% of incarcerated women (72) where Indigenous people in general represent 4.8% of the population in Canada (74), demonstrating the intersection of multiple axes of power in determining the social locations of women living with HIV.

The criminalization of HIV non-disclosure in Canada also profoundly shapes the sexual and reproductive experiences of women living with HIV (75). Hyper-surveillance of sexual and reproductive experiences due to criminalization of HIV non-disclosure further marginalizes and stigmatizes women living with HIV, creating barriers to HIV and sexual and reproductive healthcare

(76, 77). The health needs of incarcerated women and gender minorities are often further overlooked in the correctional system in favour of the needs of the much larger population of men (78). Incarceration can perpetuate HIV-related stigma among women living with HIV at the institutional and interpersonal levels, creating additional barriers to HIV care (79). The lack of access to health services often continues following release from correctional settings (61).

Immigration status can also be a barrier to HIV care for women in Canada, particularly for new immigrant women and women with precarious immigration statuses (80). Health disparities for immigrant women can function through several pathways, including poverty, lack of drug coverage, and unstable housing (81). Furthermore, the Canadian healthcare system is complex, with interwoven primary and tertiary health services. Navigating the healthcare system as a new immigrant to Canada can contribute to challenges accessing services and information on HIV prevention or treatment. Although many ACB women living with HIV in Canada are immigrants from HIV endemic countries, there are limited data available on where women contracted HIV. One study from Ontario estimated between 20% and 60% of women living with HIV acquire HIV post-migration, highlighting knowledge gaps on the HIV experiences of ACB immigrant women (82).

Globally, trans women experience a high prevalence of HIV infection (83). Although there has been some focus on HIV prevention among trans women, little attention has been paid to their healthcare needs and experiences after HIV diagnosis. The limited body of literature on the healthcare experiences of trans women living with HIV suggests they face greater barriers to HIV testing (80), lower retention in HIV care (84), lower prevalence of ART use (85), lower adherence to ARTs, and lower rates of viral suppression (86, 87, 88, 89). In the Canadian context, Lacombe-

Duncan et al. examined trans women's engagement in the HIV care cascade and found that violence, trans stigma and racism, substance use, lack of social support, and unstable housing were all significantly associated with lower engagement in the HIV care cascade (58). Additionally, women who identify as sexual or gender minorities experience higher racial and gender discrimination compared to heterosexual cisgender women (90), underscoring the importance of acknowledging the complex intersections of social identity.

For many women living with HIV, multiple marginalized social positions intersect, combined with discrimination based on these social positions. A critical epistemological lens is needed to analyze and critique the social-structural contexts that undergird power, privilege, and inequity (91). Challenges applying and modeling critical theory in quantitative research have contributed to a lack of studies explicitly examining how intersecting social positions influence women's experiences with HIV and reproductive healthcare (92). The application of novel approaches for quantitative modelling grounded in critical theory is needed to understand health inequities among women living with HIV.

2.3 HIV Stigma and its Intersections

HIV remains highly stigmatized in Canada and globally. People living with HIV risk experiencing rejection, disapproval, social isolation, and discrimination upon disclosing their HIV status (93). Living with HIV means living with stigma from multiple sources, including communities, individuals, and institutions, such as the healthcare system (94). Link and Phelan conceptualize stigma as a social process that uses the labeling of human differences, stereotyping, separation, and discrimination of labelled people to create and uphold power dynamics (95). HIV-related stigma is also linked with systems of racism, classism, and gender inequity (96), which shape power differentials in the healthcare system and the relationship between women living with HIV and their healthcare providers. These systems of oppression, when applied to powder dynamics in healthcare settings, may impact whether women living with HIV feel comfortable accessing health services or engaging in discussions with healthcare providers about their reproductive goals due to their fear of further stigmatization.

Fear of being stigmatized contributes to delays in treatment, coping difficulties, inadequate self-care, and chronic stress (80). Stress from HIV-related stigma has profound consequences extending to many areas of health, including ART adherence (97), HIV-related health outcomes (91), substance use, and mental health (93, 98). The internalization of negative views of HIV infection has been found to be intensified among women living with HIV and connected to low self-esteem and anticipation of stigmatizing experiences (94). Stigma has also been cited as a key barrier to patient-provider communication about U=U, potentially influencing healthcare provider decisions to withhold information about U=U or modify the messaging, such as suggesting that U=U applies in the context of condom use or that the risk of HIV transmission to sexual partners is “extremely low” or “negligible,” rather than “zero”/ “no risk”(99).

For women living with HIV, HIV-related stigma, dissuasive societal messaging about HIV and motherhood, and concerns about perinatal HIV transmission complicate reproductive decision making (100, 101). Women living with HIV face contradicting social expectations around pregnancy: as women, they are expected to become mothers, but as women living with HIV who are perceived as “dirty,” they are expected to be celibate and avoid pregnancy, expectations that Ingram and Hutchinson describe as a double bind (102). To further illustrate, a woman described her fear of stigmatization as a pregnant woman living with HIV in the following way: “I told [the doctor] I was not hauling my HIV-positive pregnant ass into the waiting room… because you sit in that waiting room, everyone knows you're positive, and I wasn't going to sit there pregnant and have everybody judge me and look at me and whatever” (103).

The combined effects of stigma from multiple sources, including healthcare providers, can influence reproductive discussions in healthcare settings by disempowering women. Persistent stigma associated with HIV, sexuality, pregnancy, and motherhood disempowers women living with HIV to initiate conversations with healthcare providers about their reproductive goals and make informed decisions driven by their pregnancy desires and intentions.

2.4 Reproductive Health among Women Living with HIV

Reproductive healthcare for women living with HIV addresses pregnancy avoidance and strategies to support healthy pregnancies from preconception to postpartum. It addresses the reproductive health considerations that affect HIV care and HIV considerations that affect reproductive health. The medical and social HIV lenses have historically focused on the needs of men who have sex with men. Consequently, poor understanding of women’s reproductive health needs and priorities, along with the organization of HIV health services not specifically designed around the needs of women, have contributed to unmet reproductive health needs in HIV care. Strategies to deliver healthcare to women living with HIV that address their contemporary pregnancy intentions and reproductive health priorities must consider the current context of HIV and reproductive healthcare delivery.

Although reproductive healthcare is an important component of primary care (104), women living with HIV in Canada describe having unmet reproductive healthcare and counselling needs (5). A third of women living with HIV who want to have a child have never discussed their pregnancy desires with their doctors (105). Furthermore, according to one study, a majority of women living with HIV in Canada had not discussed their reproductive goals (to avoid pregnancy or become pregnant) with a doctor in the past 3 years (5). To support reproductive healthcare globally, the WHO's consolidated guidelines on sexual and reproductive health and rights of women living with HIV outline eight components of sexual and reproductive health and rights: 1) psychosocial support, 2) healthy sexuality over the life course, 3) economic empowerment and resource access, 4) integration of sexual and reproductive health and rights and HIV services, 5) protection from violence and creating safety, 6) social inclusion and acceptance, 7) community empowerment, and 8) supportive laws and policies and access to justice (25). Addressing these components of care delivery requires that existing models of HIV care delivery adapt to better align with the needs and priorities of women, who have been overlooked in the design of HIV health services.

The interface between HIV specialist care and primary care is blurry (106). As HIV is now a chronic manageable condition accompanied by co-morbidities associated with aging and prolonged HIV treatment, HIV management and primary care are interwoven, as demonstrated in two studies. A survey of the organizational attributes of settings providing HIV care in Canada found many settings to be multidisciplinary and team-based, containing on-site healthcare providers with diverse training, including pharmacists, dietitians, social workers, and addiction counsellors (59). HIV specialists in Canada, however, still provide the bulk of HIV care. For instance, among a cohort of women living with HIV in Canada, 72% accessed primary HIV care in HIV specialized clinics between 2015 and 2017 (5). Although HIV-specific care settings surveyed performed well on indicators of HIV management, such as viral load monitoring, primary care settings (defined as a setting in which either a family physician or a nurse practitioner is present) performed better in cervical cancer screening and intrauterine device (IUD) insertion (19). The same study found 30% of HIV-specialized settings offered IUD insertion compared to 50% of primary care settings providing care to people living with HIV. Gaps in reproductive discussions, however, were observed across all care settings (5). Comprehensive care delivery often relies on referrals to specialists outside the clinics providing HIV care, such as obstetricians and gynecologists. Women living with HIV have expressed challenges with referrals to other health settings, including fear of stigma, confidentiality concerns, geographically inaccessible services, and repeated answering of sensitive questions with each new healthcare provider visited (103). Hence, referrals between providers require good communication to facilitate the corridor of care between services.

Clinics, particularly those in urban settings, have adopted approaches to help patients access services across different settings. Peer health navigation or pivot nurses have been used to guide, connect, refer, educate, and accompany people living with HIV through the healthcare system (107). In a non-HIV specific urban community clinic serving approximately 105 people living with HIV in Vancouver, British Columbia, peer navigators were part of the clinic's care management program. Notably, even in studies measuring the effect of these interventions, reproductive healthcare access is overlooked or not measured at all. For example, in a pre-post analysis measuring the effects of peer navigation and the implementation of the Chronic Disease

Management model on HIV health outcomes (108), syphilis screening was the only measured indicator of sexual and reproductive health studied.

Integrated care models that aim to provide a “one-stop shop” for all healthcare needs have also been implemented to support the delivery of comprehensive care. One application of an integrated healthcare delivery model for women living with HIV in Canada is demonstrated by the Oak Tree Clinic in Vancouver (109). The Oak Tree Clinic “is the only HIV clinic in Canada specifically designed for the needs of women and children.” The clinic integrates HIV and women’s healthcare in a setting where 500-800 women, along with their children and partners, access healthcare. The clinic illustrates one example of an approach to reproductive healthcare delivery for women living with HIV; however, disease and gender-specific clinics are not feasible in all settings. Clinics where women living with HIV access healthcare often provide care for diverse patient populations, including men who have sex with men, Indigenous people, new immigrants, people who use drugs, and many patients with multiple health needs. In these settings, models of care must respond to the diverse needs of patients accessing care at the clinic.

In response to challenges accessing care in non-HIV-specific clinical settings and the low numbers of women followed at HIV-specialized clinics in Canada, women living with HIV envisioned a model of care delivery designed to meet their comprehensive care needs. Women-centred HIV care, grounded in principles of person-centred and patient-centred care (110, 111), emerged as a model to address the comprehensive healthcare needs of women living with HIV. The model builds on basic care competencies while incorporating specific considerations: integrated and coordinated HIV and women’s care, peer-support and peer leadership in the design and delivery of care, and care that is responsive to social-structural barriers to care including HIV-related stigma. Its implementation in health settings has not been studied; however, implementation in more resource-limited settings has potential challenges. For instance, peer-support and peer-leadership systems might not be feasible in a rural primary healthcare setting providing HIV care to a small number of women. Considering the diverse settings and contexts in which women living with HIV access care, it is helpful to address women's reproductive care needs by understanding their priorities.

2.5 Contemporary Pregnancy Intentions and Decision-making for Women Living with HIV

Pregnancy intentions, as described by Ross, include intending to become pregnant, avoiding pregnancy, and desiring spaced pregnancies (112). Pregnancy intentions have uncertainty, can change over time, and are poorly understood among women living with HIV in Canada. Estimates of intentions to give birth in the future range from 25.8% among women living with HIV in British Columbia between 2003 and 2004 to 57% among women living with HIV in Ontario between 2007 and 2009 (113, 114, 115). These estimates, however, are from cross-sectional studies before U=U messaging started in 2016. Therefore, they do not capture contemporary pregnancy intentions or their dynamic nature. In a 2014 survey of women living with HIV in the United States who had recently given birth, about half acknowledged that their pregnancy was mistimed and half felt that before becoming pregnant, they did not want to have a baby (116). Coupled with low use of prescriptions for long-acting reversible and hormonal contraceptives among women living with HIV after U=U messaging began (29, 105), this evidence suggests a discrepancy between reproductive goals and realities.

The social importance of motherhood for women living with HIV has evolved. As life expectancy among people living with HIV has increased, so too have desires to have and raise children, making pregnancy planning more relevant. Although it is more common for women today to forego or delay childbearing, the persistent stigma associated with childlessness, infertility, and miscarriage in many cultures illustrate social messaging about the value of childbearing (117, 118). Furthermore, a study of primarily immigrant women living with HIV in Canada, published in 2018, found that motherhood was perceived as elevating women's social position and presumed health within their communities (119). Studies have shown that many women living with HIV view motherhood as important and pregnancy as a way of coping with HIV status by feeling like a "normal" woman (120). However, motherhood can also raise anxieties about HIV disclosure, perinatal HIV transmission, and the impacts of HIV-related stigma on their children (121).

In a study examining pregnancy-related decision-making among women living with HIV in Ontario, family support was associated with intentions to become pregnant (122). Findings also revealed gaps in our understanding of the barriers preventing women living with HIV from enacting their fertility intentions. Studies among women who have experienced intimate partner violence demonstrate that relationship power dynamics, social positioning, and marginalization influence women's reproductive choice or lack of choice (123, 124, 125, 126). Women living with HIV have disproportionately high rates of post-traumatic stress symptoms compared to the general population of women (127), with estimated rates of intimate partner violence being twice the national rate in the United States among women living with HIV (128). In addition to trauma experiences, financial instability and perceived poor health may reduce women's autonomy in realizing their reproductive goals and their intentions to conceive or avoid pregnancy (129). Cuca and Rose argue that stigmatization and the social situations of women living with HIV make it difficult to have true reproductive choice (130). Reproductive healthcare that understands and responds to these unique considerations can support reproductive choice for women living with HIV.

Although pregnancy planning clinical guidelines exist to support healthcare providers in counselling women living with HIV about family planning and safe conception, discussions about pregnancy intentions between women and their healthcare providers are not routine and can be stigmatizing (131). Reproductive discussions between women living with HIV and their healthcare providers allow providers to be aware of and support women's reproductive intentions. Factors that promote reproductive discussions between women living with HIV and their healthcare providers have not been investigated thoroughly. Moreover, although studies have explored the factors that shape pregnancy intentions, few studies have examined whether women's pregnancy intentions predict future pregnancy incidence. This information is useful to support healthcare providers in providing appropriate counselling and care that aligns with women's reproductive intentions.

Data from the United States indicate that pregnancy rates have increased since the introduction and widespread use of ART and are now similar to rates among HIV-negative women (132). Increasing birth rates, however, are driven mainly by unintended pregnancies (21, 27, 133). Previous studies have shown a diversity of pregnancy intentions among women living with HIV (21, 105, 134, 135, 136). In addition to pregnancy and family planning considerations, women living with HIV have unique reproductive health considerations related to increased risk of cervical cancer (135) and early menopause onset (136) that should be addressed as part of their primary health care (137, 138). However, reproductive healthcare delivery has not kept up with the rapidly evolving reproductive health needs of women living with HIV. In a survey of women living with HIV in Canada between 2013 and 2015, 69% of women who received reproductive care had not discussed their reproductive goals with a healthcare provider in the last three years (5). Supporting safe conception strategies and contraceptive uptake in HIV care requires communication between women and their healthcare providers. Existent literature suggests reproductive discussions are not routine. Studies have not, however, investigated the features of care, such as patient, provider, and structural factors that promote or inhibit these discussions.

In response to a shifting demographic of people living with HIV and the increasing incidence of pregnancy among people living with HIV, calls have been made to better integrate reproductive and family planning services into HIV care (139). Previous HIV health service research has focused on men, who represent a larger proportion of service users. Existing gendered health inequities among people living with HIV demonstrate the consequences of research and healthcare that does not redress the marginalization of women living with HIV. Consequently, to support the pregnancy intentions and reproductive health needs of women living with HIV, research must centre their perspectives, expertise, and experiences.

When pregnancy is not desired, contraceptives are a safe and effective means for women living with HIV to avoid or delay pregnancy (140, 141, 142, 143). Concerns about drug interactions caused by concurrent use of hormonal contraceptives and ARTs contributed, historically, to women living with HIV being offered fewer contraceptive methods than HIV-negative women (144). Available ART regimens today have no or minimal risk of drug-drug interactions with hormonal contraceptives (145). The safety of co-prescribing hormonal contraceptives and ART regimens has been endorsed by the WHO (145) and recommended in guidelines on the care of women living with HIV in Canada (144, 146). Prescription contraceptive use among women living with HIV remains lower compared to use among HIV-negative women (147). Women living with HIV are less likely to use long-acting reversible and short-acting hormonal contraceptive methods and are more likely to rely on condoms, despite the established greater safety and efficacy of these methods compared to condoms, which have high failure rates (13% for male condoms with typical use) (148). Unintended pregnancies can have severe adverse physical and psychological health outcomes, such delayed prenatal care and maternal depression (149). The discrepancy in prescription contraceptive uptake between women living with HIV and HIV-negative women highlights practices that are slow to adapt to advances in HIV care, namely newer ART regimens and U=U. Informed decision-making about safe and effective contraceptive uptake is supported through discussions between women living with HIV and their healthcare providers. The absence of these discussions contributes to missed opportunities for counselling and support for desired pregnancy, pregnancy avoidance, and reproductive health across the lifespan.

When pregnancy is desired, guidelines have been developed in Canada to support pregnancy planning and promote safer conception strategies among people living with HIV (150). These guidelines are supported by the large body of evidence cited earlier in this review demonstrating the effectiveness of ART adherence in improving the health of women living with HIV and preventing HIV transmission. Recommendations include offering reproductive health counselling to women living with HIV of reproductive age soon after HIV diagnosis and, on an ongoing basis, addressing pregnancy planning and preconception health issues, such as maintaining a healthy diet and lifestyle; cessation of smoking, alcohol, and drug use; understanding the risk of genetic disorders; and undergoing a prenatal screening (150). Additionally, guidelines address specific considerations for women living with HIV, namely, HIV viral suppression and psychosocial stressors related to pregnancy planning in the context of HIV, such as those brought on from HIV-related stigma and discrimination. However, it is unclear how widespread knowledge and uptake of these guidelines are by healthcare providers and women living with HIV.

Preconception planning must also address pregnancy-safe ART regimens, which are indicated to optimize women's health and to prevent sexual and perinatal HIV transmission during conception and pregnancy (151, 152). Additional considerations include access to fertility specialists and assisted reproductive technologies for women living with HIV, including women in same-sex relationships who want to become pregnant (150). In contrast to several countries in Europe, where people living with HIV have had access to assisted reproductive technologies since the early years of the HIV epidemic, (153) in Canada, access to such services for people living with HIV is limited by region and individual clinics, according to a survey conducted between 2007 and 2014 (154).

When pregnancy has occurred, as is the case for HIV-negative women, reproductive healthcare in Canada must support the rights of women living with HIV to decide on the outcomes of their pregnancies. Pregnant women living with HIV have unique care needs that must be considered to ensure a healthy pregnancy and childbirth. Prevalence of preterm birth, for instance, has been shown to be higher among women living with HIV (20%) compared to HIV-negative women (7%), even after adjusting for women's sociodemographic characteristics, substance use, and smoking status (155). Preterm birth is a leading cause of infant mortality in the

United States (156). A meta-analysis reported women living with HIV also have a higher risk of low birth weight babies (RR 1.62, 95%CI 1.41-1.86), babies born small for gestational age (RR 1.31, 1.14-1.51), and stillborn babies (RR 1.67, 1.05-2.66) compared to HIV-negative women (157).Despite the well-established importance of ART for reducing the risk of perinatal HIV transmission, studies have reported an increased risk of adverse pregnancy outcomes associated with earlier initiation of ART (157). These observational study findings, however, are susceptible to selection bias due to the exclusion of women living with HIV who delivered prior to initiating ART (158). Nevertheless, these potential pregnancy complications highlight the considerations that women living with HIV must navigate. Beyond pregnancy and delivery, there are also complications relating to infant feeding practices (159) and recommendations, which further complicate reproductive autonomy for women living with HIV.

2.6 Supporting Reproductive Health and Priorities and Satisfaction with Care Across the Lifespan

As the population of women living with HIV ages, new insights have emerged into how reproductive health needs evolve over the lifespan. Similarly to trends among HIV-negative women, women living with HIV are increasingly giving birth in their later reproductive years (133). Desires to delay childbearing are complicated by evidence indicating that infertility, abnormal menstruation, and early onset of menopause are more common among women living with HIV (160, 161, 162, 163). These additional reproductive health considerations are often overlooked in the absence of routine and integrated reproductive healthcare. Informing this new standard of care requires a better understanding of women's reproductive healthcare needs and priorities across the lifespan and an examination of how these fit within existing models of HIV care delivery.

The models and approaches to delivery of reproductive and HIV care are diverse in organization and practice but have significant room for improvement. Gaps in reproductive healthcare delivery point to the need and potential to better understand and respond to the needs and priorities of women living with HIV. The WHO defines the quality of care as "the extent to which health care services provided to individuals and patient populations improve desired health outcomes" (164). Satisfaction with care is a useful measure to study HIV care through the perspective of women living with HIV. Patient satisfaction is a patient-centred outcome that measures how patients compare their experiences receiving care with their personal subjective standards, which are shaped by values beliefs and expectations of the care experience. The construct of patient satisfaction has been used in previous research to improve the quality of healthcare by integrating patient perspectives (165, 166, 167). Evaluating features of care based on their importance to patient satisfaction with HIV care provides a pragmatic approach to tailoring services in response to patient priorities.

A mixed-studies review synthesizing factors promoting satisfaction with HIV care among people living with HIV in high income settings identified important features but did not address gendered care considerations or reproductive health (168). The findings from this review provide a starting point for understanding how to improve healthcare delivery but must be updated by addressing the gendered considerations in HIV care and centering the expertise of women living with HIV in Canada.

2.7 Summary of Knowledge Gaps

A review of existing literature on the reproductive healthcare experiences of women living with HIV highlights important knowledge gaps. The epidemiologic, scientific, and medical landscape of HIV has significantly changed reproductive health considerations for women living with HIV in recent years. Contemporary reproductive intentions are poorly understood. Previous studies measured pregnancy intentions cross-sectionally, which did not capture whether and how intentions change over time. Moreover, these studies happened before U=U messaging, which now represents a different reality of sexual and reproductive health for women living with HIV. Previous studies have also not examined whether pregnancy intentions predict future pregnancy outcomes. This information is crucial for providing appropriate reproductive counselling and support to women living with HIV.

Secondly, although previous studies have found that discussions about reproductive goals between women living with HIV and their healthcare providers are not routine, the effect of healthcare provider characteristics and women's comfort discussing reproductive goals on these discussions' occurrence has not been established.

Thirdly, to date, very few studies have examined the factors that contribute to women living with HIV feeling satisfied with their HIV care. A comprehensive approach is needed to explore how women's social contexts and health priorities shape their experiences with HIV and reproductive healthcare. A better understanding of the factors women perceive as most important to their satisfaction with HIV care is needed to design and adapt health services that work for women living with HIV and align with their reproductive health needs and priorities.

3. Methodology

This dissertation research assessed the reproductive health needs and priorities of women living with HIV in Canada from a critical health equity stance (169) and post-positivist epistemology (170). Post-positivist tradition asserts that researchers can approximate, but not precisely capture reality, which is relative and provisional (170). The use of multiple methods for knowledge creation extends from this critical epistemology, as it addresses research questions and triangulates evidence from multiple perspectives (171). In this chapter, I describe the theoretical frameworks and research approaches that guided this dissertation (3.1). I describe the study design, the primary data source, the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), and the methods used to address the three specific objectives (3.2).

3.1 Theoretical Frameworks and Research Approaches

3.1.1 Reproductive Justice

A reproductive justice theoretical framework informed this dissertation research. The reproductive justice framework was put forward by Black women activists in the United States in 1994 as a critique of reproductive "choice" and its narrow focus on abortion access (112). The framework, further elaborated on by Black, Indigenous, and other women of colour, focuses on three human rights:

1. The right to have a child under the conditions of one's choosing
2. The right not to have a child using contraception, abortion, or abstinence
3. The right to parent children in safe and healthy environments

Reproductive justice is a useful framework for assessing the reproductive health needs of women living with HIV, as it considers the entire scope of reproductive experiences, including structural inequities and intersectional oppression that constrain reproductive decision-making, family planning, pregnancy planning, and abortion access.

The scope of this dissertation research is informed by the scope of reproductive health services that address these facets of reproductive health. Specifically, this dissertation assesses women's access to counselling and information (reproductive discussions) and support for their evolving pregnancy intentions (relationships between intentions to avoid pregnancy or become pregnant and pregnancy incidence). The reproductive justice framework offers an expanded definition of reproductive "choice," recognizing rights-based approaches and the necessity of listening to women's voices in the design and delivery of reproductive healthcare to reconcile historical and present-day injustices and address contemporary needs and priorities (172). By adopting this expanded definition of reproductive choice, this dissertation research responds to the historic and contemporary marginalization of the voices and specific experiences of women living with HIV in HIV research and the design of health services. The framework provides a useful lens to study the shared and diverse reproductive healthcare experiences of women living with HIV in Canada, including women historically excluded from HIV research.

3.1.2. Social Determinants of Health

This dissertation research applies the social determinants of health framework described by McGibbon & McPherson (173), integrating intersectionality and complexity theory to understand the social and structural drivers of health inequities among women living with HIV. Within this theoretical framing, health inequities are driven by social determinants of health, including oppressive processes (sexism, racism, ableism, colonialism, classism, transphobia, homophobia, etc.) and geographical marginalization (urban versus rural), a reality for many women living with HIV. Additionally, many women living with HIV experience multiple forms of oppression and marginalization. Intersectionality theory allows us to view these intersections as interlocking and compounding. Intersectionality, a concept coined by Kimberlé Crenshaw (174), acknowledges power differentials between people of different social identities and the relationship between multiple compounding oppressed identities and inequities. Complexity theory builds on this framework by illuminating the interactions between complex adaptive systems (2). Here "complex" implies a diversity of elements in the system, and "adaptive" refers to the system's ability to learn and change in response to experiences. Given the diversity of organizational approaches within healthcare systems and the interactions (linkage, coordination, referral, integration) between health services (175), complexity theory provides a valuable conceptual perspective to study HIV care where the interface between primary and specialist care is complex and adapting.

Through McGibbon & McPherson's bridging of these theories, this dissertation research considers the role of social determinants of health and systemic oppression within healthcare and social services and their impact on the reproductive healthcare experiences of women living with HIV in Canada.

3.1.3 Participatory Research

The marginalization of women living with HIV in the design of HIV care delivery also contributes to the organization of services that do not fully understand or respond to their reproductive health needs. This research takes the position that centering the expertise of women living with HIV is critical to redressing injustices and delivering appropriate healthcare. This dissertation combines participatory research approaches and the principles of the Greater/Meaningful Involvement of People Living with HIV/AIDS (GIPA/MIPA). Participatory research aims to involve community members meaningfully in research impacting their community, drawing on the strengths and knowledge of the community and responding to their calls to action (176). In accordance with participatory research principles, GIPA/MIPA is grounded in respect for the rights and dignity of people living with HIV and a commitment to ensure their equal partnership in HIV research (177). Meaningful Involvement of Women Living with HIV (MIWA) emerged based on the need, described by women living with HIV, for approaches to redress women's marginalization from HIV research and healthcare, which largely centres men (8, 178). This dissertation operationalized participatory research approaches and MIWA principles through a community-based, collaborative approach, where the knowledge and experiences of women living with HIV guided the specification of research questions, development of methodologies, data collection, interpretation, and knowledge translation.

This dissertation aimed to move scientific knowledge and primary care practice towards greater health equity by considering the power dynamics between stakeholders and shifting power and leadership towards women living with HIV. This research aimed to capture the reproductive health needs of women living with HIV by centering the expertise of women living with HIV.

3.2 Study Design

Through multiple methods, the research pursued three distinct but linked research questions concerning the reproductive health needs and priorities of women living with HIV in Canada. The first two studies analyzed quantitative survey data collected as part of a larger project, the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), to investigate changing patterns in pregnancy intentions and in reproductive discussions between women living with HIV and their healthcare providers.

3.2.1 The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS)

CHIWOS is a longitudinal, community-based participatory study conducted in partnership with women living with HIV in British Columbia, Ontario, and Quebec (179). The main objective of CHIWOS was to address gaps in knowledge related to the use of women-centred HIV services and the impact of service use on the sexual, reproductive, and mental health of women living with HIV in Canada.

The formative phase of CHIWOS involved defining women-centred HIV care based on existing literature and the perspectives of women living with HIV (180). This formative phase informed the design of a longitudinal study with three data collection points between 2013 and 2018.

Instrument Development

The survey instrument was designed by working groups composed of women living with HIV, clinicians, researchers, and community representatives with different backgrounds in and experiences with HIV (181). Notably, women living with HIV participated in multiple stages of survey refinement. Where validated scales for variables of interest existed, these were included.

The survey was pilot tested for validity and reliability among a sample of women living with HIV (n=30) by comparing participants' responses at first completion and during a re-test 2–4 weeks later. The baseline survey consisted of 436 questions measuring 2,136 sociodemographic characteristics and medical and HIV-related health variables, such as healthcare and social support service use, sexual and reproductive health, stigma, discrimination, substance use, violence, emotional wellbeing, resiliency, and health-related quality of life. Follow-up surveys included questions identical to the baseline survey to allow for longitudinal analysis, as well as additional questions on social determinants of health and healthcare service use.

Recruitment and Eligibility

Women living with HIV were eligible to participate in CHIWOS if they (1) self-identified as women (inclusive of cis, trans, two-spirit, gender-queer, or questioning people who identified as women), (2) were 16 years of age or older, (3) were diagnosed with HIV, and (4) were living in Quebec, Ontario, or British Columbia at the time of the baseline survey. Peer Research Associates (women living with HIV hired and trained for the research project) led participant recruitment in clinics, AIDS service organizations, community settings, and on social media (181). Non-random, purposive sampling was conducted to reflect the geographic distribution of women living with HIV in British Columbia, Ontario, and Quebec. An estimated 82% of women living with HIV in Canada reside in these three provinces (182). Figure 3.1 illustrates target and actual recruitment numbers for each of the study provinces. Between October 2013 and May 2015, 1,422 women enrolled in CHIWOS and completed the baseline survey.

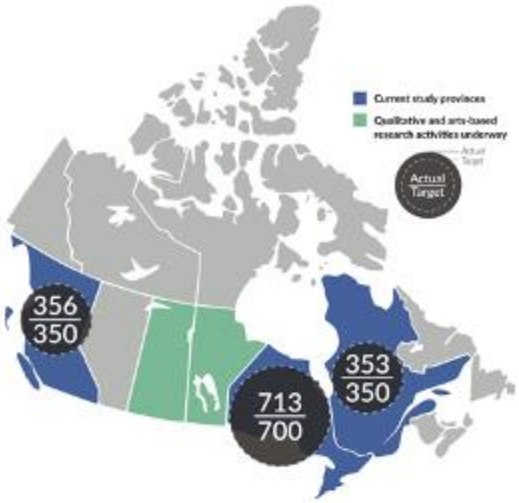


Figure 3.1 Target and Actual Recruitment for CHIWOS in the Three Study Provinces, British Columbia, Ontario, and Quebec (in Blue). Adapted from CHIWOS Provinces with Target and Actual Enrolment Numbers in Loutfy et al (181).

Data Collection

Participants completed computer-based surveys administered by Peer Research Associates. Surveys were conducted in-person, by phone, or by videoconferencing over Skype in either French or English, using the online software FluidSurveys (for the baseline and 18-month surveys) and Oracle (for the 36-month survey). Data collection occurred between 2013 and 2018. Total study retention over 36 months was 66%. A list of CHIWOS survey questions relevant to this dissertation research is provided in Appendix A.

Ethical Considerations

Ethics approval for CHIWOS was granted by the research ethics boards of Simon Fraser University, the University of British Columbia, the Providence Health Care Research Institute, , Women's College Hospital, the McGill University Health Centre, and participating clinics and AIDS service organizations. An honorarium of $50 was provided to participants for each CHIWOS study visit.

3.2.2 Fuzzy Cognitive Mapping

The third study aimed to inform strategies to address the gaps in reproductive healthcare identified in the first two studies, by examining factors that influence women's satisfaction with HIV care and the relative importance of reproductive healthcare. The study considered the interface and gaps between reproductive healthcare and HIV care. With two Peer Research Associates, I interviewed 23 women living with HIV in Quebec and British Columbia to understand the factors that promote their overall satisfaction with HIV care and whether aspects of reproductive healthcare (pregnancy intentions, discussions, non-stigmatizing approaches, reproductive rights, etc.) emerge as important consideration among these factors.

Fuzzy cognitive maps (FCMs) are graphical representations derived from constructivist psychology that capture expert knowledge of a system or problem (183, 184, 185). Fuzzy cognitive mapping, as a research method, is qualitative and semiquantitative. Maps are comprised of nodes, representing factors, joined by arrows, representing causal relationships between factors. Each arrow is assigned a weight representing the perceived strength of the causal relationship. A positive weight ($w_{ij} > 0$) indicates an encouraging relationship, while a negative weight ($w_{ij} < 0$) indicates an inhibitory relationship. These weights are "fuzzy" because they have an implied but not-specified degree of uncertainty. Consequently, weights cannot be interpreted probabilistically. Fuzzy cognitive maps are, therefore, conceptual or theoretical models, rather than predictive models (186). A major advantage of FCM is that it provides an accessible way to express knowledge and ideas across different cultures, languages, educational levels, and technological skills (186). Analysis focuses on the network of factors that affect an outcome of interest and the relative strength of direct and indirect causes of said outcome. FCM has been used to engage stakeholders in environmental management and urban planning (187, 188, 189, 190, 191), to identify stakeholder priorities (192), and in participatory health research to capture Indigenous knowledge (193, 194).

This dissertation posited a novel application for FCM as a tool to bridge social constructs with quantitative methods of investigation. Through FCM, women living with HIV constructed conceptual models based on their experiential expertise. These conceptual models can guide quantitative epidemiological studies through a translation into directed acyclic graphs (DAGs), which specify causal and counterfactual relationships (195).

Recruitment and Eligibility

Women were eligible to participate if, at the time of the study, they had been diagnosed with HIV, identified as women, were 18 years of age or older, were living in Quebec or British Columbia, and had access to a device with internet connection.

Data Collection

Individual interviews were conducted with 23 women living with HIV between December 2020 and March 2021. I developed an interview guide in French and English with input from two Peer Research Associates (Appendix B), and, together, we co-facilitated the interviews. We began by asking women to reflect on the healthcare they had received. We asked women to define their satisfaction with HIV care and to identify the factors that positively or negatively influenced their satisfaction with HIV care. Conscious of the role of the research-participant power dynamic, this step was purposely open-ended to allow participants to identify factors that were important to them rather than asking directly about the importance of reproductive healthcare, which could potentially influence its importance as a consideration. We asked women to identify all the causal relationships between factors and assign a weight between 1 and 5 indicating the strength of each relationship. At the end of the interview, women had the opportunity to review their final fuzzy cognitive map and make changes if necessary. Maps were drawn in real-time using the software yED. Interviews were conducted virtually over the videoconferencing platform Zoom to abide by physical distancing policies during the COVID-19 pandemic.

Ethical Considerations

Ethics approval for the third study was granted by the University of British Columbia, the Providence Health Care Research Institute, and the McGill University Health Centre. Informed consent was obtained from each participant before data collection. An honorarium of $25 and $50 was provided to participants of the fuzzy cognitive mapping interviews and member checking focus group discussions, respectively.

A summary of the study's aims and approaches is presented in Table 3.3.1. Data analyses specific to each study are detailed in Chapters 4, 5, and 6.

Table 3.3.1 Overview of Study Aims and Approaches

Aim	Methods	Key independent variables / domains	Key dependent variables / domains
(1) To examine how the pregnancy intentions of women living with HIV change over time and whether pregnancy intention predicts future pregnancy incidence	Quantitative descriptive and regression analysis of baseline, 18-, and 36-month survey data from cis-women living with HIV enrolled in CHIWOS (n = 284).	Pregnancy intention	Pregnancy in the 18 months following the survey
(2) To estimate the prevalence of women discussing their reproductive goals with any current healthcare provider and assess the role of the HIV care provider's gender and women's comfort	Quantitative mediation analysis of baseline and 18-month follow-up survey data from women (cis, trans, intersex, two-spirit, gender queer) living with HIV enrolled in CHIWOS (n = 533).	Gender of primary HIV care provider	Discussing reproductive goals with any current healthcare provider since last CHIWOS survey (outcome) Having a current healthcare provider with whom women feel comfortable discussing their reproductive goals (mediator)
(3) To assess the importance of reproductive healthcare in women's definition of satisfying HIV care	Individual fuzzy cognitive mapping interview with women living with HIV (n=23). Qualitative and quantitative data analysis. Three-member checking focus group discussions (n = 10)	Receiving reproductive healthcare	Satisfaction with HIV care

4. Manuscript 1: Patterns of changing pregnancy intentions among women living with HIV in Canada

4.1 Preamble

The contemporary pregnancy intentions of women living with HIV are often overlooked and poorly understood. Like HIV-negative women, women living with HIV have unintended pregnancies, but contraceptive uptake is lower among women living with HIV. While antiretroviral therapy has changed the landscape of HIV and reproductive health, previous research on pregnancy intentions among women living with HIV was conducted prior to U=U mention, reflecting a different time and reality in reproductive decision-making for this population. Additionally, the use of cross-sectional methods in previous research provided an incomplete picture of how women's pregnancy intentions evolve with time. When I conceptualized this analysis, no previous study had examined patterns of changing pregnancy intentions. Nor were there any studies examining whether pregnancy intention predicts future pregnancy incidence among women living with HIV. Understanding pregnancy intentions and their evolution is key to providing reproductive healthcare that aligns with the needs of women living with HIV.

This chapter presents the first of three manuscripts, which, taken together, assess contemporary reproductive health needs and priorities among women living with HIV in Canada from different but complementary angles. To address the knowledge gap in contemporary reproductive priorities among women living with HIV, this study examines patterns of changing pregnancy intentions and the association between pregnancy intention and pregnancy incidence. I analyzed longitudinal data from 284 women of reproductive age living with HIV and enrolled in

CHIWOS from 2013 to 2018. Of the 284 participants in the analytical sample, 281 identified as women, 0 identified as transwomen and 3 identified as "other." The findings reveal pregnancy intentions are diverse, dynamic and not strongly associated with subsequent pregnancy. The results emphasize the importance of recognizing, assessing and considering the evolution of reproductive decision-making in healthcare delivery for women living with HIV. The implications include a recognizable imperative for healthcare providers to engage in ongoing discussions with women living with HIV about their reproductive intentions and consider these intentions and their dynamic nature in care delivery. This implication led to the research questions informing Manuscript 2.

As the first study in a series of three complementary studies, this chapter lays a foundation for the subsequent chapters, further exploring the reproductive landscape and healthcare delivery needs for women living with HIV in Canada. This chapter was published in the journal *BMC Women's Health.*

Skerritt L, Kaida A, O'Brien N, Burchell AN, Bartlett G, Savoie É, Boucoiran I, Gormley R, Kestler M, Money D, Loutfy M, de Pokomandy A. Patterns of changing reproductive intentions among women living with HIV in Canada. BMC Women's Health 2021; 21(1):350

4.2 Title Page

Patterns of changing pregnancy intentions among women living with HIV in Canada

Lashanda SKERRITT[1], Angela KAIDA[2], Nadia O'BRIEN[3], Ann N. BURCHELL[4], Gillian BARTLETT[5], Édénia SAVOIE[6], Isabelle BOUCOIRAN[7], Rebecca GORMLEY[2,8], Mary KESTLER[9,10], Deborah MONEY[9,10], Mona LOUTFY[11], Alexandra DE POKOMANDY[1,6]

1. Department of Family Medicine, McGill University, Montreal, Canada
2. Faculty of Health Sciences, Simon Fraser University, Burnaby, Canada
3. Centre de recherche du Centre hospitalier de l'Université de Montreal (CRCHUM), Montreal, Canada
4. Department of Family and Community Medicine, Centre for Urban Health Solutions, Li Ka Shing Knowledge Institute, St. Michael's Hospital, Unity Health Toronto, Toronto, Canada
5. Department of Family and Community Medicine, University of Missouri, Columbia, USA
6. Chronic Viral Illness Service, McGill University Health Centre, Montreal, Canada
7. CHU Ste-Justine, Université de Montreal, Montreal, Canada
8. British Columbia Centre for Excellence in HIV/AIDS, Vancouver, Canada
9. Oak Tree Clinic, BC Women's Hospital and Health Centre, Vancouver, Canada
10. Faculty of Medicine, University of British Colombia, Vancouver, Canada
11. Women's College Research Institute, Women's College Hospital, Toronto, Canada

Corresponding author:

Alexandra de Pokomandy, MDCM, MSc Chronic Viral Illness Service
McGill University Health Centre - Glen Site 1001 Decarie Blvd., Rm D02.4110 Montreal, Quebec
H4A 3J1 Canada
Telephone 1-514-843-2090, Fax 1-514-843-2092
E-mail: alexandra.depokomandy@mcgill.ca

4.3 Abstract

Background: Women with an undetectable viral load can become pregnant and have children with no risk of HIV transmission to their sexual partners and low risk of transmission to their infants. Contemporary pregnancy intentions of women living with HIV in Canada are poorly understood, evidenced by high rates of unintended pregnancy and low uptake of contraceptives.

Methods: We used longitudinal survey data from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) to measure and compare pregnancy intentions (Yes *vs* No *vs* Unsure) at baseline, 18-months and 36-months follow-up (from 2013 to 2018) among women living with HIV of reproductive age (16–49 years) and potential. We used Sankey diagrams to depict changes in pregnancy intentions over time and multivariable logistic regression to examine the relationship between pregnancy intention within 2 years and subsequent pregnancy.

Results: At baseline, 41.9% (119/284) of women intended to become pregnant, 43.3% did not, and 14.8% were unsure. Across 36-months of follow-up, 41.9% (119/284) of women changed their pregnancy intentions, with 25% changing from intending to not intending to become pregnant and 13.1% vice versa. Pregnancy intentions were not strongly associated with subsequent pregnancy between baseline and 18-months (aOR 1.44; 95% CI 0.53, 3.72) or between 18 and 36-months (aOR 2.17; 95% CI 0.92, 5.13).

Conclusions: Our findings underscore the need for healthcare providers to engage in ongoing discussions with women living with HIV to support their dynamic pregnancy intentions.

4.4 Introduction

The reproductive landscape for women living with HIV has changed significantly [1, 2], such that it is now possible for women engaged in HIV care to become pregnant and have children with no risk of HIV transmission to their partners and an extremely low risk to future infants [3,4,5]. Medical advances have contributed to the increased incidence of pregnancy and childbirth among women living with HIV [6], driven mainly by unintended pregnancies [7, 8]. In a survey of women living with HIV in the United States who had recently given birth, about half reported that their pregnancy was mistimed, and half felt that before becoming pregnant, they did not want to have a baby [9]. Poor maternal and child health outcomes associated with unintended pregnancies [10] likely extend to women living with HIV and may be exacerbated by structural forms of oppression, including HIV stigma, a persistent and known barrier to healthcare access [11, 12].

Pregnancy intentions include intending to become pregnant, pregnancy spacing, avoiding pregnancy, or being unsure about pregnancy intention. Estimates of pregnancy intentions among women living with HIV in Canada are from cross-sectional studies prior to undetectable=untransmittable (U=U) messaging [13, 14]. Therefore, they do not capture contemporary pregnancy intentions or their dynamic nature. Although pregnancy planning clinical guidelines exist to support healthcare providers in counselling women living with HIV about family planning and safe conception, discussions about pregnancy intentions between women and their healthcare providers are not routine and can be stigmatizing [15, 16]. Among women living with HIV of reproductive age in Canada, 60% have never discussed their reproductive goals with a healthcare provider since being diagnosed with HIV [17]. Additionally, uptake of effective contraceptive methods among women living with HIV who report wanting to avoid pregnancy is low [18], and the range of contraceptive methods used is more narrow compared to HIV negative women [19], underscoring the need and opportunity to better understand and address the sexual and reproductive health needs of women living with HIV.

Demands for improving patient-provider communication through routine screening of pregnancy intentions are increasing [20,21,22,23,24]. Existing evidence and recommendations, however, are based on women's pregnancy intentions at one point in time and do not capture the dynamic complexity of reproductive decision-making. Further, few studies have investigated whether pregnancy intention predicts future pregnancy outcomes. The objectives of this study were to measure and compare the pregnancy intentions of women living with HIV in Canada over time and investigate the relationship between pregnancy intention within 2 years and subsequent pregnancy.

4.5 Methods

Study design and setting

We used longitudinal survey data from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), a longitudinal community-based participatory study [25] conducted by, for, and with women living with HIV in British Columbia, Ontario, and Quebec, where over 80% of women living with HIV in Canada reside [26]. In Canada, women living with HIV represent approximately 23% of people living with HIV [26]. HIV prevalence and incidence are higher among marginalized women, including women in poverty, women of Indigenous ancestry, women who identify as African, Caribbean, or Black, refugees and new immigrants, and sexual and gender minorities. For many women living with HIV, several of these marginalized identities intersect [27].

Participants

Between August 2013 and May 2015, 1,422 women enrolled in CHIWOS and completed the baseline survey. CHIWOS eligibility criteria included self-identifying as a woman (including cis, trans, two-spirit, gender-queer, or questioning people who identified as women), 16 years of age or older, diagnosed with HIV, and living in one of the study provinces. Women were recruited using a non-random, purposive sampling approach [28, 29]. Participants completed a computer-based survey administered by Peer Research Associates (women living with HIV who completed research training) [25]. Two follow-up surveys were administered 18 and 36 months after the baseline visit. Baseline data were collected between 2015 and 2016, 18-month follow-up data between 2016 and 2017, and 36-month follow-up data between 2017 and 2018. Total study retention over 36-months was 66%.

For this analysis, we excluded women who were 50 years of age or older at baseline or unable to become pregnant (self-reported infertility, menopausal, post-menopausal, male sex assigned at birth). We also excluded women with missing data on pregnancy intentions across the three follow-up visits, either because they preferred not to answer the pregnancy intention question or were lost to follow-up.

All participants provided written or verbal informed consent. Ethical approval was granted from all participating institutional Research Ethics Boards, including Simon Fraser University, University of British Columbia/Providence Health Centre, Women's College Hospital and McGill University Health Centre, and participating clinics and AIDS Service Organizations where requested.

Measures

Pregnancy intention was measured by the baseline, 18-month, and 36-month follow-up survey question "Do you intend to become pregnant in the future?", with responses categorized as "Yes," "No," or "Unsure." We also measured pregnancy intention within 2 years by asking women who responded "Yes" to the former question, "When in the future do you intend to become pregnant?". We then derived the following categories: "Intends to become pregnant within 2 years," "Does not intend to become pregnant within 2 years," and "Unsure."

At each follow-up visit, women were asked how many pregnancies they had since their last study visit (including currently being pregnant). Participants who reported being pregnant at least once since their last study visit were assessed as having a pregnancy.

When assessing the relationship between reported pregnancy intention at baseline and 18-months (exposure) and subsequent pregnancies reported at 18 and 36-months (outcome), we considered as confounders women's age, ethnicity, number of children, relationship status, educational attainment, and household income, as previous studies have identified these factors as strong determinants of both pregnancy intention and pregnancy outcomes [10]. The exposure and confounders were measured at the same time-points. Women who preferred not to answer the question about their relationship status (n=1) were categorized as 'single/ other'. We assumed that women who preferred not to answer the question about education (n=1) had not completed high school.

Statistical methods

Descriptive statistics were used to characterize the sample at baseline and to examine pregnancy intentions and subsequent pregnancy. Sankey diagrams [30] were used to depict longitudinal absolute (*n*) and relative frequencies (%) of pregnancy intentions at the three study visits. Sankey diagrams were also stratified by age category to account for differences in pregnancy intention between younger and older women.

Two separate multivariable logistic regression models were fit to investigate the relationship between pregnancy intention within 2 years and subsequent pregnancy between the baseline and 18-month visit (model 1) and between the 18-month and 36-month visit (model 2) while adjusting for potential confounders. Following recent calls to move away from reliance on statistical significance in interpreting research results [31], we adopted an approach to estimating proportions and measures of association, recognizing that *p* values should not drive the interpretation of statistical analyses. Based on previous literature [10, 13, 14, 32,33,34,35] and the expertise of clinicians and women living with HIV, we considered the following as potential confounders in our model: women's age, race/ethnicity, number of children, relationship status, education, and household income.

A sub-analysis was performed to compare reported live births and pregnancy terminations over the 36-month study period among women 35 years of age and younger to women over 36 years of age using descriptive statistics. We also compared live births and pregnancy terminations across baseline pregnancy intention. All analyses were performed using R: A Language and Environment for Statistical Computing (R Foundation for Statistical Computing, Vienna, Austria, 2019).

4.6 Results

Of the 1422 women living with HIV enrolled in CHIWOS, 284 were included in this analysis (20.0% of the total cohort). We excluded 398 participants who were 50 years of age or older, 15 who were postmenopausal, 14 who were assigned male sex at birth, 375 who reported being unable to become pregnant for other reasons, 6 who preferred not to answer questions on pregnancy intention, and 330 who were lost to follow-up (Figure 4.1).

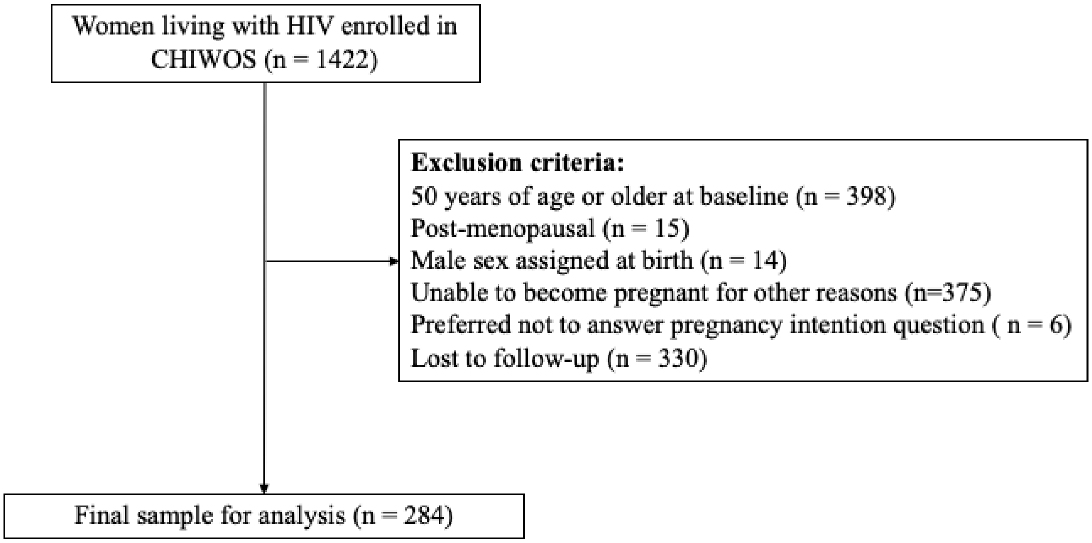


Figure 4.1 CHIWOS participant inclusion and exclusion criteria for analysis of pregnancy intentions

Baseline Characteristics of the study sample

At baseline, the median age was 36.0 years [interquartile range 31.0–40.0]. Women living in Ontario represented the largest proportion (46.1%), followed by Quebec (31.0%) and British Columbia (22.9%). The majority of women identified as African/Caribbean/Black (54.2%), had a high school education or higher (83.1%), at least 1 child (67.3%), an annual household income of less than CAD 20,000 (52.1%), identified as heterosexual (86.6%), and were currently on ARTs (85.2%) (Table 4.1)

Table 4.1 Baseline demographic characteristics of participants in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) included in these analyses (n = 284)

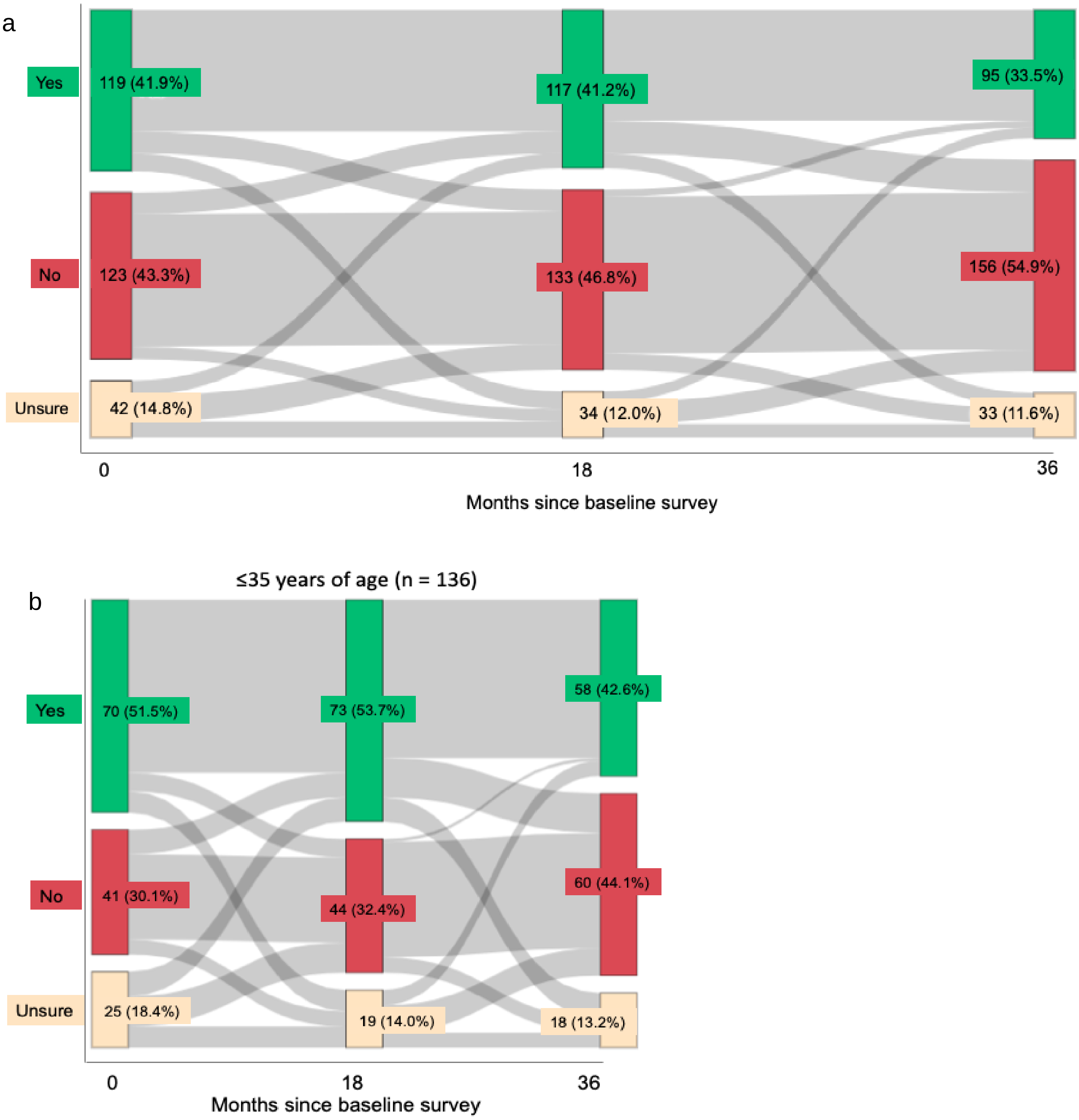
	Overall (N=284)
Age (years)	
Median [Q1, Q3]	36.0 [31.0, 40.0]
Ethnicity	
Indigenous	32 (11.3%)
African/Caribbean/Black	154 (54.2%)
White	79 (27.8%)
Other/Mixed	19 (6.7%)
Province	
British Columbia	65 (22.9%)
Ontario	131 (46.1%)
Quebec	88 (31.0%)
Education attainment	
Lower than high school	47 (16.5%)
High school or higher	236 (83.1%)
DK/PNTA	1 (0.4%)
Relationship status	
Married/Relationship/Common-law	117 (41.2%)
Single/Other/PNTA	131 (46.1%)
Separated/Divorced/Widowed	36 (12.7%)
Number of children	
None	93 (32.7%)
1 or 2	126 (44.4%)
3 or more	65 (22.9%)
Household income (CAD)	
<20K	148 (52.1%)
20K-40K	66 (23.2%)
>=40K	56 (19.7%)
DK/PNTA	14 (4.9%)
ART use	
Not currently but previously on ARTs	22 (7.7%)
Currently on ARTs	242 (85.2%)
Never on ARTs	19 (6.7%)
DK/PNTA	1 (0.4%)

	Overall (N=284)
Sexual orientation	
Heterosexual	246 (86.6%)
LGBTTQ	36 (12.7%)
DK/PNTA	2 (0.7%)

[Q1, Q3] first quartile, third quartile; DK/PNTA, don't know or prefer not to answer; CAD, Canadian Dollars; ART, antiretroviral therapy; LGBTTQ, Lesbian, Gay, Bisexual, Transgender, Two-Spirit and Queer

Pregnancy intentions and patterns of changing intentions

At baseline, 41.9% (119/284) intended to become pregnant in the future, 43.3% (123/284) of women reported that they did not intend to become pregnant in the future, and 14.8% (42/284) were unsure. At 18-months, 41.2% (117/284) intended to become pregnant in the future, 46.8% (133/284) of women did not intend to become pregnant in the future, and 12.0% (34/284) were unsure. At 36-months, 33.5% (95/284) intended to become pregnant in the future, 54.9% (156/284) did not intend to become pregnant in the future, and 11.6% (33/284) were unsure. Figure 4.2a depicts reported pregnancy intentions and changes between the baseline, 18-month, and 36-month surveys among all participants included in the analysis.


a
Yes
No
Unsure
119 (41.9%)
123 (43.3%)
42 (14.8%)
117 (41.2%)
133 (46.8%)
34 (12.0%)
95 (33.5%)
156 (54.9%)
33 (11.6%)
0
18
36
Months since baseline survey
b
≤35 years of age (n = 136)
Yes
No
Unsure
70 (51.5%)
41 (30.1%)
25 (18.4%)
73 (53.7%)
44 (32.4%)
19 (14.0%)
58 (42.6%)
60 (44.1%)
18 (13.2%)
0
18
36
Months since baseline survey

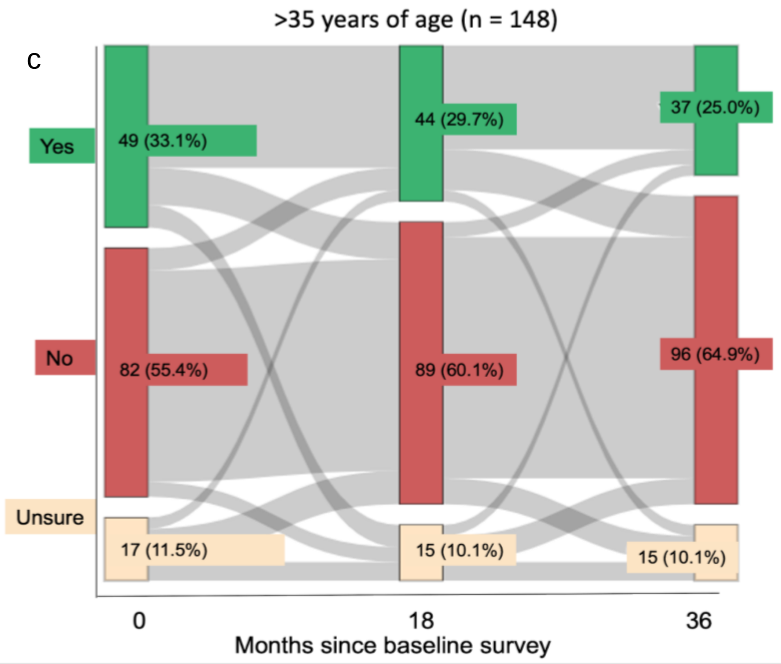


Figure 4.2. **a** Sankey diagram showing the proportion of participants who reported that they intended (green), did not intend (red) or who were unsure (beige) about whether to become pregnant in the future. The grey bars depict shifts in intention between surveys. The height of the grey bars is proportional to the number of participants. **b** Sankey diagram for women 35 years of age and younger (16–35 years of age). **c** Sankey diagram for women over 35 years of age (36–49 years of age)

Over the 36-month observation period, 58.1% (165/284) of women had no change in their pregnancy intentions. Among those who reported consistent pregnancy intentions, 86 (30.3% of total) intended to become pregnant throughout the study period, 74 (26.1% of total) did not, and 5 (1.8% of total) were unsure at each visit. Across 36 months, 41.9% (119/284) of women changed their pregnancy intentions, with 25% of changes from intending to not intending to become pregnant, and 13.1% from not intending to intending to become pregnant. Between baseline and 18-months and between 18 and 36-months, 29.6% and 26.8% of women changed their pregnancy intentions, respectively. Between baseline and 18-months, changes from being unsure to not intending to become pregnant accounted for 22.6% (19/84), the largest proportion, of changes in intention. Between 18 and 36-months, changes from intending to not intending to become pregnant accounted for 31.6% (24/76) of all observed changes. Among women 35 years of age and younger, 46.3% (63/136) changed their pregnancy intention over 36-months compared to 37.8% (56/148) among women over 35 (Fig. 2b, c).

Pregnancy intention and subsequent pregnancy

We assessed the relationship between women's pregnancy intentions within 2 years and pregnancies in the subsequent 18-months. Intention to become pregnant within 2 years was 23.3% (58/284) at baseline (Table 4.2) and 27.1% (77/284) at 18-months (Table 4.3). Between baseline and 18-months, 15.5% (9/58) of women who intended to become pregnant within 2 years did so, 12.5% (23/184) of women who did not intend to become pregnant became pregnant, and 14.3% (6/42) who were unsure became pregnant (Table 4.2). Between 18 and 36-months, 20.8% (16/77) of women who intended to give birth within 2 years did so, 11.0% (19/173) of women who did not intend to become pregnant had a pregnancy, and 5.9% (2/34) who were unsure became pregnant (Table 4.3).

Table 4.2 Association between baseline pregnancy intention within two years and pregnancy in the subsequent 18-months

Pregnancy intention	n (%) became pregnant in subsequent 18-months	OR (95%CI)	Adjusted[a] OR (95%CI)
Intends to become pregnant within two years (n=58)	9 (15.5%)	1.29 (0.53, 2.88)	1.44 (0.53, 3.72)
Does not intend to become pregnant within two years (n=184)	23 (12.5%)	Ref	Ref
Unsure (n=42)	6 (14.3%)	1.17 (0.41, 2.92)	1.10 (0.37, 2.92)

[a] adjusted for age category, ethnicity, number of children, relationship status at time of survey, education and household income

Table 4.3 Association between 18-month pregnancy intention within two years and pregnancy in the subsequent 18-months

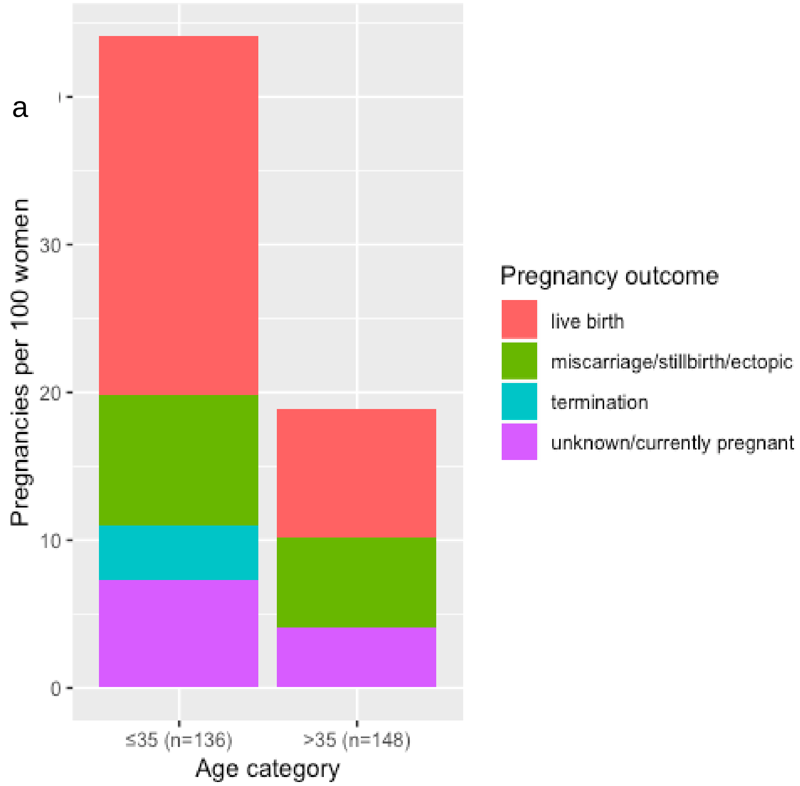
Pregnancy intention	n (%) became pregnant in subsequent 18-months	OR (95%CI)	Adjusted[a] OR (95%CI)
Intends to become pregnant within two years (n=77)	16 (20.8%)	2.13 (1.02, 4.41)	2.17 (0.92, 5.13)
Does not intend to become pregnant within two years (n=173)	19 (11.0%)	Ref	Ref
Unsure (n=34)	2 (5.9%)	0.51 (0.08, 1.87)	0.26 (0.04, 1.14)

[a] adjusted for age category, ethnicity, number of children, relationship status at time of survey, education and household income

After adjusting for potential confounders, there was no association observed between reporting an intention to become pregnant within 2 years at baseline and pregnancy in the subsequent 18-months (adjusted OR 1.44; 95% confidence interval 0.53, 3.72) or between being unsure at baseline and pregnancy by 18-months (aOR 1.10; 95% CI 0.37, 2.92) (Table 4.2). Intending to become pregnant within the next 2 years at the 18-month follow-up study visit was associated with 2.17 times higher adjusted odds of pregnancy by 36-months (95% CI 0.92, 5.13). Being unsure about pregnancy intention was associated with lower odds of subsequent pregnancy (aOR 0.26; 95% CI 0.04, 1.14) (Table 4.3). These relationships, however, were not statistically significant.

Sub-analysis: pregnancy outcomes

Figure 4.3 shows pregnancy outcomes over 36-months per 100 women by age category and baseline pregnancy intention. Among the 136 women aged 16–35 in our study, there were 60 pregnancies during the study period. Of those pregnancies, 33 ended in live births, and 5 were terminated. Among the 148 women aged 36–49, there were 28 pregnancies. Of those, 13 ended in live births, and none were terminated (Figure 4.3a). There were 44 pregnancies reported among the 119 women who intended to become pregnant at baseline, of which 25 ended in live births, and 3 were terminated. There were 30 pregnancies among the 123 women who did not intend to become pregnant at baseline, of which 13 ended in live births, and none were terminated. Among the 42 women who were unsure about their pregnancy intention, 14 became pregnant, 8 had live births and 2 pregnancies were terminated (Figure 4.3b).



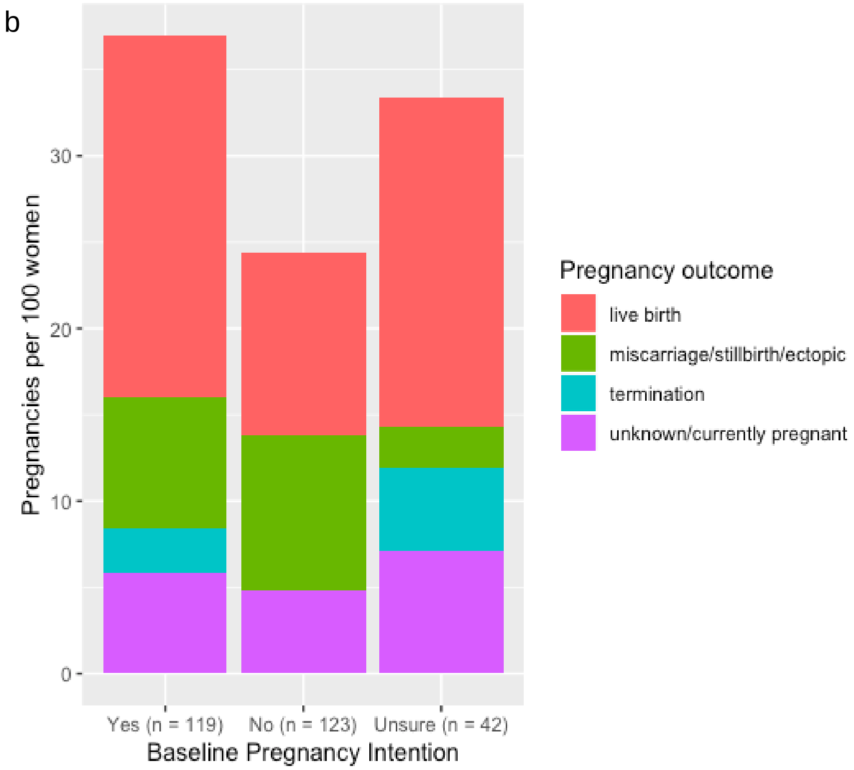


Figure 4.3 **a** Pregnancy outcomes per 100 women over 36-month by age category. **b** Pregnancy outcomes per 100 women over 36-months by baseline pregnancy intention

4.7 Discussion

Among this sample of women aged 16–49 years and of reproductive potential living with HIV in Canada, we observed diverse and dynamic pregnancy intentions over a 36-month follow-up period. Over one-quarter of women changed their pregnancy intention over 18-months, and 42% did so over 36 months. At baseline, 43% of women living with HIV did not intend to become pregnant in the future; however, only 26% reported not intending to become pregnant at all 3 study visits. Subsequent pregnancies were not strongly associated with initial pregnancy intentions, indicating the dynamic nature of pregnancy intention and underscoring the need for ongoing reproductive discussions between women and their healthcare providers.

Our finding that 43% of women intended to become pregnant at baseline is similar to that reported in a meta-analysis estimating that 42% of women living with HIV in high-income countries between 1997 and 2015 intended to become pregnant in the future [32]. The proportion was lower than that reported in a cross-sectional study of slightly older and mostly immigrant women living with HIV in Ontario between 2007 and 2009 [14], where 57% intended to give birth in the future. The proportion was higher than the 39% of women living with HIV in British Columbia surveyed in 2007 [13] who intended to give birth in the future. The study included a larger percentage of Indigenous women and single women compared to our analyses. These studies reported pregnancy intentions before the era of U=U and were cross-sectional.

Our longitudinal study revealed that intentions were dynamic, changing significantly over 36-months. The proportion of women not desiring pregnancy increased from 40% at baseline to 55% at the 36-month visit. Close to half of all observed shifts in pregnancy intentions throughout the study were changes from intending pregnancy or being unsure to not wanting to become pregnant. These results may be explained by increasing age [14] or pregnancies that occurred over that time, but also demonstrate that for many women living with HIV, reproductive health needs change over a few years. Only one-quarter of women in the study consistently reported not intending to become pregnant at each study visit. At baseline, around 20% of women were unsure whether they wanted to become pregnant in the future. A study published in 2013 of men and women living with HIV in Los Angeles found that 13% of study participants who responded “no” to the survey question “do you wish to have a/another child?”, also responded “yes” when asked “Would your desire to have a/another child change if you knew you could have a child with limited risk of transmitting HIV to your partner and the child” [36]. These results may reflect feeling inadequately informed to make pregnancy decisions given the changing reproductive landscape, particularly for women living with HIV [37,38,39,40,41,42].

Previous research has described the factors that shape pregnancy desires and intentions [13, 14, 32, 33]. Our results suggest that pregnancy intention at one point in time are not strongly associated with future pregnancy occurrence. Although intending to become pregnant in the future was positively associated with subsequent pregnancy, the observed relationship was not statistically significant. The weak observed relationship at baseline and 18-months may be explained by social desirability bias due to stigma related to HIV and motherhood [34, 43] but could also be explained by the larger social context of women's lives and factors that influence women's choice or lack of choice in becoming pregnant or avoiding pregnancy, such as relationships, health, employment, income and housing security [44]. Moreover, pregnancy terminations were more common among women who intended to become pregnant at baseline compared to women who did not, further demonstrating that the relationship between pregnancy intention and outcome is complex. A study of the sexual and intimate relationship experiences of women living with HIV in Canada found that women in long-term/unhappy sexual relationships or short-term sexual relationships were more likely to experience low levels of power equity [45]. Women in these relationships may not feel empowered to decide whether and when to have children. Low uptake of long-acting and preferred contraceptive methods among women living with HIV [19] may also explain the weak association between pregnancy intentions and outcomes. Unintended pregnancies are associated with an increased likelihood of negative feelings and experiences during pregnancy and in the postpartum period [46]. On the other hand, women living with HIV describe the fear and criminalization of HIV transmission to be a barrier to engaging in sexual relationships [47, 48], despite the emergence of evidence showing people living with HIV who are taking ART and have a suppressed viral load have effectively no risk of transmitting HIV to their sexual partners [1]. Women's pregnancy decisions occur within complex social contexts shaped by intimate relationship power inequity, economic precarity, HIV-related stigma, and HIV criminalization laws that all compete with their desires to avoid pregnancy or become pregnant. Healthcare providers should be aware of the social and structural factors that influence the relationship between pregnancy intention and pregnancy outcome. Despite the large proportion of women whose intentions changed over the study, analyses of data from the same cohort found that reproductive discussions are not routine and account for the largest measured gap in comprehensive healthcare for women living with HIV [17, 49]. Supporting the uptake of effective contraception and clinical follow-up is particularly important to help women living with HIV prevent unwanted and unplanned pregnancies [35] and improve uptake of long-acting and hormonal contraceptives, which has been observed to be lower among women living with HIV in Canada compared to the general population [19]. Women living with HIV have described the support and counselling received by their healthcare providers as instrumental to their decision-making [35, 44]. However, most women living with HIV receive care from HIV specialized settings where reproductive discussions are less likely to occur compared to non-HIV specialized settings [17]. According to primary care providers, competing health priorities are the main barrier to asking women about their pregnancy intentions [50]. Strategies for promoting these discussions include delegating from physicians to members of multidisciplinary care teams [51, 52], raising the topic of pregnancy at one visit and following up on at a subsequent visit [50], using waiting room tools to support patient agency initiating reproductive discussions, introducing comprehensive training on pregnancy intention discussions and periodic check-ins between healthcare providers in the same clinics to facilitate sharing of strategies and best practices [50]. Community and AIDS service organizations can also support these conversations and services by promoting empowerment and information about initiating reproductive discussions with healthcare providers.

Limitations and strengths

This study has limitations. We excluded women living with HIV who were missing longitudinal data on their reproductive intentions. Women lost to follow-up were less likely to be engaged in HIV care and more likely to have a detectable viral load (data not shown). According to previous studies, this population is less likely to desire to have children [33]. Moreover, persistent HIV-related stigma associated with pregnancy and motherhood may have led some women to report not intending to become pregnant or being unsure rather than reporting that they intend to become pregnant in the future. On the other hand, women living with HIV who desire to become pregnant in the future may be more likely to participate in research focused on Sexual and Reproductive Health among women living with HIV, which may have led to an overestimate of the proportion of women living with HIV who intend to become pregnant in the future. Our study was powered to detect only large associations between pregnancy intention and subsequent pregnancy. The small sample size should be considered in the interpretation of the estimated associations. Although these associations were not found to be statistically significant in this analysis, the direction of the association was positive and should be further investigated in future studies with larger sample sizes. Residual confounding and misclassification of covariates could have resulted in underestimating or overestimating the true effect of pregnancy intention on subsequent pregnancy because of incomplete adjustment [53]. This study was conducted in the context of universal healthcare coverage and in the global North. The findings may not extend to other contexts where financial and medical barriers may have a greater impact on pregnancy intentions and subsequent pregnancies.

This study has several strengths. Surveys were administered by PRAs, which may have made participants more comfortable answering sensitive questions. Recruitment strategies extended beyond clinics and aimed to include women less engaged in healthcare and research. Our prospective assessment of pregnancy intention overcomes biases inherent in previous studies that collected pregnancy intention data retrospectively [7, 32, 54, 55].

The findings from this study have important implications for family planning counselling. To support the contraceptive and pregnancy planning needs of women living with HIV, healthcare providers should not only ask women about their pregnancy intentions but should also aim to create non-stigmatizing, trauma-aware, and women-centred environments [52, 56], normalizing these discussions. Discussing reproductive goals once with women living with HIV is not sufficient to address changing pregnancy intentions. Nor is it sufficient to ask about pregnancy intentions at a pre-specified frequency. Rather than approaching conversations around pregnancy and family planning as a routine screening question, these discussions need to be left open so that women living with HIV can discuss their intentions as they evolve and receive the counselling that aligns with their evolving needs and considers the social contexts and power dynamics that influence their reproductive decision-making [56, 57].

Conclusion

This study demonstrates that women living with HIV have a diverse range of pregnancy intentions that change over time. It provides a crucial understanding of both the dynamic property of pregnancy intentions and the social contexts that influence the relationship between women's intentions and their reality. Healthcare providers should promote safe and non-judgemental spaces where women feel comfortable discussing their reproductive intentions as they evolve. Promoting open and ongoing discussions is needed to provide women living with HIV with the support and counselling they need.

4.8 References

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5. Manuscript 2: Discussing Reproductive Goals with Healthcare Providers Among Women Living with HIV in Canada: the role of provider gender and patient comfort

5.1 Preamble

The findings from Chapter 4 demonstrate the dynamic pregnancy intentions of women living with HIV in Canada. Over 36 months, 41.9% of women in the study changed their pregnancy intentions, and over one-quarter changed their intentions over 18 months. The patterns of changing intentions were diverse, with one-quarter of changes from intending to not intending to become pregnant and 13.1% from not to intending to become pregnant. Supporting these dynamic pregnancy intentions necessitates regular discussions between women living with HIV and their healthcare providers about women's pregnancy intentions and reproductive goals. While evidence suggests reproductive discussions between women living with HIV and their healthcare providers are not a routine part of care in Canada, little is known about the factors that influence whether these discussions occur.

In this chapter, I present the second study of my dissertation research. I examine the prevalence of reproductive discussions and the effect of healthcare provider gender and patient comfort on such discussions between women living with HIV enrolled in CHIWOS and their healthcare providers. Of 533 women included in the analysis, around one-third (34.3%) engaged in reproductive discussions with their healthcare providers over 18 months, indicating a need for improved communication and support to address women's reproductive health needs and priorities.

Given the important role of gender in HIV care delivery for women living with HIV, the effect of the healthcare provider's gender on reproductive discussions was of interest in this study. I analyzed the effect of healthcare provider gender on the occurrence of reproductive discussions. Women who receive care from a woman HIV care provider have a higher likelihood of engaging in reproductive discussions compared to women who receive care from providers who are men—about one quarter (25.9%) of women who had a man as a primary HIV provider discussed their reproductive goals between their baseline and 18-month study visits, compared to 46.3% of those who had a woman provider ($p < 0.001$).

I conducted a causal mediation analysis to better understand the causal mechanisms through which healthcare provider gender influences reproductive discussions. I estimated the direct and indirect effects of provider gender on reproductive discussion through a hypothesized pathway mediated by patient comfort. Unlike standard structural equation modelling-based approaches that make the strong assumption that no interactions exist between exposure and mediator variables, the mediation approach applied here allowed us to examine the interaction between the exposure (provider gender) and the mediator (comfort). I included an interaction term between the exposure and mediator to test my hypothesis that intervening on comfort may have a larger effect for a subgroup of women, namely women who receive care from a male healthcare provider. The results revealed that comfort explains a substantial portion of the total effect of the provider's gender on whether reproductive discussions occur. The interaction term in the model was not statistically significant.

Findings suggest that strategies to increase patient comfort may lead to an increased prevalence of reproductive discussions, fostering healthcare delivery that better aligns with the reproductive health needs of women living with HIV. This chapter was published in the journal Sexual and Reproductive Health Matters:

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5.2 Title Page

Discussing Reproductive Goals with Healthcare Providers Among Women Living with HIV in Canada: the role of provider gender and patient comfort

Lashanda SKERRITT[1]; Alexandra DE POKOMANDY[1,2]; Nadia O'BRIEN[1,2]; Nadia SOURIAL[1]; Ann N. BURCHELL[3,4]; Gillian BARTLETT[1]; Tibor SCHUSTER[1]; Danielle ROULEAU[5,6]; Karène PROULX-BOUCHER[2]; Neora PICK[7]; Deborah MONEY[7]; Rebecca GORMLEY[8,9]; Allison CARTER[10]; Mark H. YUDIN[11]; Mona LOUTFY[12,13]; Angela KAIDA[8]; CHIWOS research team

1. Department of Family Medicine, McGill University, Montreal, QC, Canada
2. Chronic Viral Illness Service, McGill University Health Centre, Montreal, QC, Canada
3. Department of Family and Community Medicine, St. Michael's Hospital, Toronto, ON, Canada
4. Department of Family and Community Medicine, University of Toronto, Toronto, ON, Canada
5. Centre de Recherche du Centre Hospitalier de l'Université de Montréal (CR-CHUM), Montreal, QC, Canada
6. Département de Microbiologie, Infectiologie et Immunologie, Montreal, QC, Canada
7. Oak Tree Clinic, BC Women's Hospital; Vancouver, BC, Canada
8. Faculty of Health Sciences, Simon Fraser University, Burnaby, BC, Canada
9. British Columbia Centre for Excellence in HIV/AIDS, Vancouver, BC, Canada
10. Kirby Institute, Faculty of Medicine, University of New South Wales, Sydney, NSW, Australia
11. Department of Obstetrics and Gynecology, St. Michael's Hospital, University of Toronto, Toronto, ON, Canada
12. Women's College Research Institute, Women's College Hospital, Toronto, ON, Canada
13. Faculty of Medicine, University of Toronto, Toronto, Canada

Corresponding author:
Angela Kaida, PhD
Associate Professor and Canada Research Chair in Global Perspectives in HIV and Sexual and Reproductive Health
Faculty of Health Sciences, Simon Fraser University
Blusson Hall Rm 10522, 8888 University Drive, Burnaby, B.C. V5A 1S6
Tel: 778-782-9068 Email: kangela@sfu.ca Twitter: @akaida

5.3 Abstract

Antiretroviral therapy effectively prevents sexual and vertical transmission of HIV. Yet, some women living with HIV report having unmet needs for reproductive health care. This study measured the prevalence of women discussing reproductive goals with any current healthcare provider and assessed the effect of the current HIV care provider's gender on such discussions and whether comfort was a mediator. We analysed baseline and 18-month survey data from 533 women living with HIV enrolled in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) (2013–2017), a community-based participatory study, restricting the analysis to participants aged 16–45 years. We used causal mediation analysis to estimate direct and indirect effects of the gender of one's HIV care provider on reproductive discussions, incorporating mediating and interaction effects of women having any provider with whom they felt comfortable discussing reproductive goals. Between the baseline and 18-month follow-up surveys, 34.3% (183/533) of women discussed their reproductive goals with a healthcare provider. Having a woman HIV care provider was associated with a 1.18 excess relative risk (ERR) of discussion (95%CI: 0.15, 2.20). The mediating effect of comfort was primarily explained by the fact that those participants with women providers felt more comfortable discussing their reproductive goals compared to participants with men providers, accounting for 66% (95%CI: 32%, 99%) of the total effect. Findings support that HIV provider gender affects women's comfort and whether they discuss reproductive goals, which must be acknowledged and addressed in care delivery.

5.4 Introduction

Due to advances in HIV treatment and medical care, people are living longer, healthier lives with HIV compared to the early years of the epidemic.[1] Several studies have also established that there is effectively no risk of HIV transmission through sex without a condom when a person living with HIV is on antiretroviral therapy (ART) and has a consistently suppressed viral load.[2–4] Additionally, with appropriate treatment and care, women living with HIV can become pregnant and have children with a very low risk of perinatal HIV transmission (0.4% in Canada).[5–7]

These advances have resulted in changes to the reproductive desires, behaviours, and outcomes of women living with HIV.[8–12] Updates to treatment guidelines, including recommendations for safer conception and contraception, have emerged to support the sexual and reproductive health and rights of people living with or affected by HIV.[13] In one Canadian province (Ontario), an estimated 63% of women of reproductive age living with HIV intended to give birth in the future.[14] These reproductive intentions translate to more pregnancies compared to the earlier years of the HIV epidemic.[10,12]

Despite these trends, women living with HIV report having unmet needs for reproductive health care.[15–17] In a Canadian cohort of women living with HIV, 25% reported becoming pregnant after HIV diagnosis, with 60.8% of these pregnancies being unintended.[18] The World Health Organization (WHO) recommends “dual protection” (long-acting, reversible contraception plus condoms) for women living with HIV to prevent sexual and perinatal transmission of HIV.[19] Less than 20% of women living with HIV in Canada practise WHO-defined dual protection, and 40% practised an expanded definition of dual protection (long-acting, reversible contraception plus either condoms or a suppressed HIV viral load).[17] The range of contraceptive methods used by women living with HIV is also more limited compared to women in the general Canadian population.[17] Among women living with HIV, studies suggest that awareness about safer conception methods[20,21] and the prevalence of receiving pre-conception counselling are low.[21] The Canadian HIV Pregnancy Planning Guidelines,[22] the WHO consolidated guideline on sexual and reproductive health and rights of women living with HIV,[23] and community-driven guidelines[24] offer guidance about reproductive counselling and support for women living with HIV. They recommend that healthcare providers initiate discussions about reproductive goals on a regular basis, asking about women's preferred number, spacing, and timing of biological children, or whether women prefer to avoid pregnancy altogether. Nevertheless, existing data suggest that such discussions are not routine; a retrospective study of women of reproductive age living with HIV in Ontario found that 51% reported ever discussing pregnancy planning with a healthcare provider since HIV diagnosis.[21]

A systematic review conducted in 2011 found that the practice of discussing reproductive goals may vary with healthcare provider characteristics such as training, sex, gender, age, and cultural differences affecting provider approaches to sexual health-related discussions with patients.[25] More women HIV care providers in the United States reported assessing the reproductive intentions of their female patients compared to men HIV care providers (57% [95% CI: 48-–65%] vs 40% [95% CI: 31-–50%]).[26] As reproductive discussions can be initiated by either the healthcare provider or the patient, we hypothesise that such differences may be explained by gender differences in providers prioritising reproductive counselling, and/or by women living with HIV feeling more comfortable initiating reproductive discussions with women healthcare providers. To inform strategies to support discussions between women living with HIV and their healthcare providers about their reproductive goals, the objectives of this study were to (1) estimate the prevalence of women discussing reproductive goals with any current healthcare provider, (2) assess the effect of their current HIV care provider's gender on discussing reproductive goals, and (3) determine the role of patient comfort as a mediator of the effect of provider gender on reproductive discussions.

5.5 Methods

Study design

We analysed baseline and 18-month follow-up survey data from The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), a multi-site longitudinal study following 1422 women living with HIV in three Canadian provinces (British Columbia, Ontario, and Quebec). The methodological approach, described in greater detail elsewhere,[27] followed the tenets of community-based participatory research. The study was approved by the Research Ethics Boards (REBs) at Women's College Hospital (Ontario), Simon Fraser University (BC), University of British Columbia/ Providence Health (BC), McGill University Health Centre (Quebec) and the independent REBs of other study sites. All participants provided written informed consent prior to enrolment.

Study sample and recruitment

Eligible participants identified as women (cis- and trans-inclusive), were 16 years of age or older, had been diagnosed with HIV, and were living in one of the three study provinces at the time of recruitment. Recruitment occurred between 2013 and 2015 through HIV clinics, AIDS service organisations, online and "word-of-mouth" peer networks.[28] A non-random, purposive sampling approach was used to reflect the geographic distribution of women living with HIV in each study province, and to recruit more trans women and women less engaged in health care and HIV research. This allowed the analysis of health care access and outcomes for these specific vulnerable populations.

Inclusion and exclusion criteria

For this analysis, we restricted the sample to cis- and trans-women who completed both the baseline and 18-month follow-up surveys and who were of reproductive age (16–45 years) at baseline. We further excluded women who reported at baseline that they had not accessed HIV medical care in the past year, as they were missing information about the gender of their HIV care provider. We also excluded those who reported at the 18-month visit that discussing reproductive goals was “not applicable” to them because they were unable to conceive and those who preferred not to answer the question (*n*=3).

Data collection

Data collection occurred via peer research associate-administered web-based surveys conducted in-person, by phone or by skype.[29] Surveys were administered in English or French using the online software FluidSurveys™. Baseline surveys were administered between 2013 and 2015. The 18-month follow-up survey was completed between 2015 and 2017.

Measures

A mediation diagram of the relationship between gender of the HIV care provider (exposure) and discussions (outcome) was constructed based on evidence from the literature and input from HIV care providers (Figure 5.1). The mediator and confounders of the exposure-outcome relationship were identified from the diagram. We hypothesised that women's comfort discussing reproductive goals is a mediator (variable in the causal pathway) between provider gender and discussions.

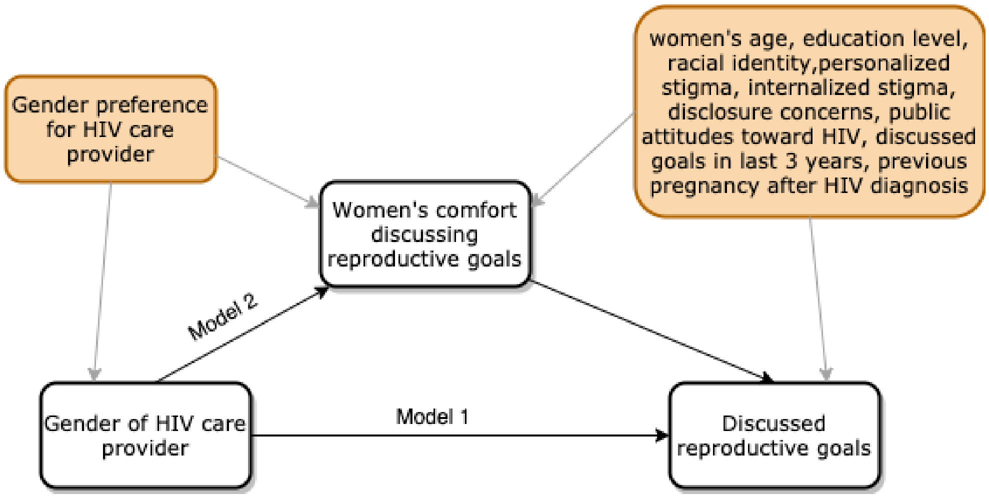

Figure 5.1 Mediation diagram for the hypothesized effect of HIV care provider gender on discussing reproductive goals.

Notes: Exposure = gender of women's healthcare provider, measured at baseline (woman vs man); Mediator = comfortable discussing reproductive goals, measured at baseline (yes vs no); Outcome = discussed reproductive goals between the baseline and 18-month follow-up surveys, measured at 18-month follow-up. Confounders of the exposure → mediator relationship: Having a gender preference for one's HIV care provider; Confounders of the mediator → outcome relationship: women's age, education level, racial identify, HIV stigma (personalised, internalised, disclosure concerns, public attitudes), had a discussion about reproductive goals with a healthcare provider in last 3 years, having at least one pregnancy since being diagnosed with HIV

Outcome: Discussing reproductive goals

The outcome was measured at the 18-month study visit, based on participants' responses to the question, "*Since your last CHIWOS interview, have you discussed your reproductive goals with a healthcare provider?*" "Reproductive goals" were defined as women's preferred number, spacing, and timing of biological children or not wanting children. Responses were dichotomised into "yes" and "no". We collapsed the responses "no" and "don't know" (*n*=1) as not remembering reproductive discussions was considered equivalent to not having the discussion in terms of information retained from the exchange with a healthcare provider.

Exposure: Gender of primary HIV care provider

The exposure was the gender of the primary HIV care provider (healthcare provider who primarily prescribes HIV medicines, follows CD4 count, viral load, etc.), which was identified from participants' response to the baseline question "*What is the gender of your primary HIV care provider?*" Response options were "woman", "man", "trans person", "don't know", and "prefer not to answer".

Mediator: Women's comfort discussing reproductive goals

We considered women's comfort discussing their reproductive goals with a healthcare provider as a mediator (Figure 5.1) and measured comfort at baseline. Participants were asked, "*Do you currently have a healthcare provider with whom you feel comfortable talking to about your reproductive goals?*" Responses were dichotomised into "yes" and "no", combining "no", "don't know" (*n*=9) and "prefer not to answer" (*n*=2). We assumed that women preferring not to answer the question about comfort discussing reproductive goals in a peer-administered survey likely indicated a lack of comfort discussing reproductive goals with a healthcare provider.

Confounders

We measured confounders of the exposure (gender of the HIV care provider)-mediator (women's comfort discussing their reproductive goals with their healthcare provider) relationship. Women indicated their preference for the gender of their HIV care provider: "I prefer my HIV doctor to be a woman", "I prefer my HIV doctor to be a man / no preference or other". As patients in Canada can choose their HIV healthcare provider, this was done to account for women potentially seeking out women HIV care providers due to gender preference and comfort.

We measured confounders of the mediator (comfort)-outcome (discussions) relationship: women's age (10-year intervals), education level (lower than high school, high school or higher), and race/ethnicity (Indigenous, African/Caribbean/Black, or white), HIV-related stigma, having discussed reproductive goals with a healthcare provider in the three years preceding the baseline survey, and reporting a pregnancy since HIV diagnosis. HIV-related stigma was included in the model to account for its effect on women's comfort in discussing their reproductive goals and its effect on reproductive discussions. We used the validated shortened HIV Stigma Scale (HSS)[30] to measure four HIV-related stigma dimensions: (i) personalised stigma measures experiences of enacted stigma through rejection and isolation; (ii) concerns disclosing HIV status; (iii) negative self-image measures internalised stigma; and (iv) public attitudes measures perceived stigma. HIV-related stigma dimensions were dichotomised to high and low stigma with the sample median as the cut-off. Previous discussions were included in the model to adjust for decreased likelihood of subsequent reproductive discussion if one had occurred recently. All confounders were measured at baseline.

Statistical Analysis

Guided by the mediation diagram (Figure 5.1), we used two multivariable logistic regression models to estimate odds ratios (and 95% confidence intervals): Model 1, a confounder-adjusted model, was fitted to the data to quantify the association of the exposure (provider gender), mediator (comfort), and their interaction on the outcome (discussions). Including an interaction term allowed us to identify whether strategies to intervene on comfort may have a larger impact on women who receive care from providers of one gender over another. Model 2 is a confounder-adjusted model estimating the association between the exposure and mediator.

To complement the mediation analysis using the logistic regression models, we used the med4way package[31] in Stata version 15.1 (StataCorp, 2017) to quantify the decomposed effect of HIV care provider gender on reproductive discussions, considering mediation (variable in the pathway between exposure and outcome) and interaction (effect of exposure on outcome varying across another variable) effects. The med4way package uses parametric regression models to calculate contrasts in decomposed effects.[31] For a binary mediator and outcome, two logistic regression models were fitted: a model for the outcome as a function of the exposure, the mediator, their interaction and confounders and a second model for the mediator as a function of the exposure and confounders. This approach to mediation analysis allowed us to decompose the total effect, while considering interaction effects between the exposure and mediator and nonlinearity in our model. We applied methods described by VanderWeele[32] to decompose the effect into four distinct components: the effect due to mediation only (pure indirect effect), the effect due to interaction only (reference interaction), the effect due to mediation and interaction (mediated interaction), and the effect due to neither mediation nor interaction (controlled direct effect). Our model assumes a counterfactual framework.[32] The four components of the decomposition are illustrated (Figure 5.2). Estimates are reported as excess relative risk: Excess Relative Risk (ERR) = Risk Ratio (RR) −1.

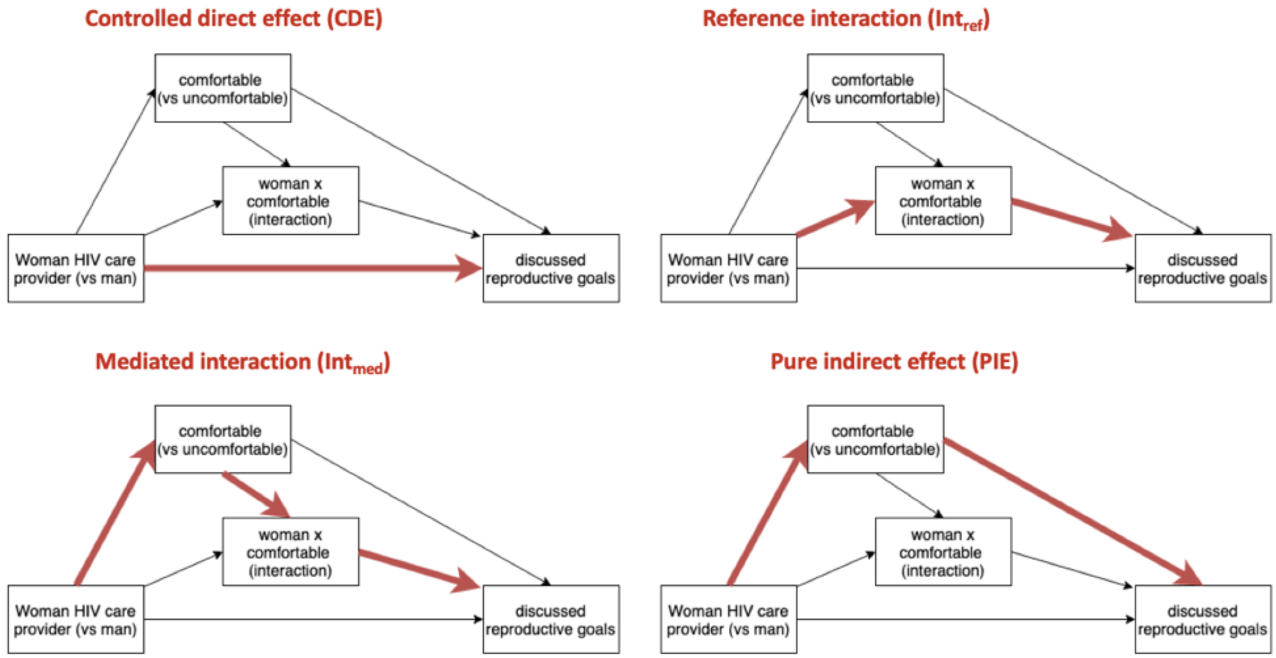

Figure 5.2 Summary of 4-way decomposition in causal mediation analysis
Notes: Bolded arrows represent each of the four components of the decomposition

5.6 Results

Sample characteristics

A total of 1422 women living with HIV completed the baseline CHIWOS survey and 1252 completed the 18-month follow-up survey for a retention rate of 88%. For the present analysis, we excluded participants over the age of 45 years (n=571), participants who did not access HIV medical care in the previous year (n=59), participants who responded that discussing reproductive goals was not relevant to them as they could not have children (n=154) or who preferred not to answer the question about reproductive discussions (n=3), and participants who were lost to follow-up at the 18-month visit (n=102), yielding a final analytic sample of 533 participants (37.5% of the enrolled cohort).

Table 5.1 shows the baseline characteristics of the 533 included participants. Women had a median age of 35 [IQR: 31.40] and identified as Indigenous (21.0%), African, Caribbean or Black (36.4%), white (37.3%), and mixed or other race (5.3%). Most participants (85.2%) identified as heterosexual, were taking ART (78.2%), and reported an undetectable HIV viral load (75.2%). Regarding healthcare provider gender, 40.2% received HIV care from a woman provider and 59.9% from a man. Women's reported reproductive intentions included not intending to become pregnant in the future (41.3%), intending to become pregnant (28.5%), and being unsure (20.6%).

Table 5.1 Baseline characteristics of participants in the analytical sample (n=533)

Characteristic	**Median [IQR] or n (%)**
Province of residence	
British Columbia	114 (21.39)
Ontario	307 (57.60)
Quebec	112 (21.01)
Age at baseline (years)	35 [31, 40]
Racial and/or ethnic background	
Indigenous	112 (21.01)
African, Caribbean, Black	194 (36.40)
White	199 (37.34)
Mixed / Other	28 (5.25)
Sex assigned at birth	
Male/ Other	5 (0.94)
Female	531 (99.06)
Gender identity	
Woman	525 (98.50)
Transwoman	4 (0.75)
Other	4 (0.75)
Sexual orientation	
Heterosexual/ Straight	454 (85.18)
LGBTTQ/DK/PNTA	79 (14.82)
Highest level of formal education	
Lower than high school/DK/PNTA	69 (12.95)

High school or higher	464 (87.05)
Household annual income (CAD)	
<$20,000	302 (56.66)
$20,000-$40,000	112 (21.01)
>40,000	100 (18.76)
DK/PNTA	19 (3.56)
Incarceration history	
Never	385 (72.23)
Ever/ DK/PNTA	148 (27.77)
What is your current legal status in Canada	
Canadian Citizen	397 (74.48)
Landed Immigrant/ Permanent Resident	80 (15.01)
Refugee	39 (7.32)
Other/DK/PNTA	17 (3.19)
Relationship status	
Married/Relationship/Common-law	198 (37.15)
Single	280 (52.53)
Separated/Divorced/Widowed	55 (10.32)
Gender of current HIV provider	
Woman	214 (40.15)
Man	319 (59.85)
Ever discussed reproductive goals with a healthcare provider since HIV diagnosis	
No/DK	235 (44.09)
Yes	249 (46.72)
Unable/don't want children	46 (8.63)
PNTA	2 (0.38)
Intention to become pregnant in future	
No	220 (41.28)
Yes	152 (28.52)
DK	110 (20.64)
PNTA/Missing	51 (9.57)
Number of children	
0	233 (43.71)
1 to 2	199 (37.34)
3 to 4	80 (15.01)
5 or more	21 (3.94)
Pregnancy after HIV diagnosis	
Yes	69 (12.95)
No	464 (87.05)
Country of birth	
Canadian born	315 (59.10)
Foreign born/ DK/PNTA	218 (40.90)
Current ART use	
Currently on ART	417 (78.24)
Not currently/ DK/ PNTA	116 (21.77)
Most recent viral load results	
Undetectable (below 50 copies/mL)	401 (75.23)

Detectable (over 50 copies/mL)	95 (17.82)
DK/PNTA	37 (6.94)
Most recent CD4 count	
<200 cells/mm3	22 (4.13)
200-500 cells/mm3	132 (24.77)
>500 cells/mm3	288 (54.03)
DK/PNTA	91 (17.07)

LGBTTQ, Lesbian, Gay, Bisexual Transgender, Two-Spirit, Queer; DK/PNTA, don't know, prefer not to answer; ART, antiretroviral therapy

Reproductive discussions

At baseline, approximately half (46.7%) of women had discussed their reproductive goals with a healthcare provider since being diagnosed with HIV. Subsequently, at the 18-month follow-up survey, 34.3% (183/533) of women reported having discussed their reproductive goals with a healthcare provider since baseline. A quarter of women reported discussing their reproductive goals at both timepoints (136/533), while 21.5% (115/533) reported discussions at baseline only, 7.3% (39/533) at follow-up only, and 37.3% (200/533) at neither baseline nor follow-up. About a quarter (25.9%) of women who had a man as a primary HIV provider discussed their reproductive goals between their baseline and 18-month visits, compared to 46.3% of those who had a woman provider ($p<0.001$). Among women whose primary HIV provider was a man, 36.4% reported having a healthcare provider with whom they felt comfortable discussing their reproductive goals, while 70.6% of women with a woman primary HIV provider reported that they had a provider with whom they felt comfortable discussing their reproductive goals ($p<0.0001$).

Table 5.2 presents the confounder-adjusted logistic regression Model 1, with outcome being discussing reproductive goals between the baseline and 18-month follow-up study visits. Having a woman HIV care provider was not associated with discussing reproductive goals when the model was adjusted for comfort and other covariates (aOR=0.72; 95%CI: 0.33, 1.57). Comfort was associated with higher odds of discussing reproductive goals (aOR=2.24; 95%CI: 1.30, 3.87). Among women who reported feeling comfortable, having a woman provider was not associated with reproductive discussions (aOR=0.92; 95%CI: 0.37, 2.29). Among women who reported not feeling comfortable discussing their reproductive goals with a current provider, having a woman provider was associated with lower odds of such discussions (aOR=0.16; 95%CI: 0.05, 0.47). In Model 2, we analysed factors associated with our hypothesised mediator comfort discussing reproductive goals (Table 5.3). We observed that women whose primary HIV care provider was a woman had 4.18 times higher odds (95%CI: 2.70, 6.49) of reporting feeling comfortable discussing their reproductive goals with a current care provider after adjusting for covariates.

Table 5.2 Multivariate logistic regression results for Model 1 (outcome: discussed reproductive goals with a healthcare provider between baseline and 18-month follow-up)

Variable	aOR (95%CI)	p-value
Woman HIV care provider (ref. man)	0.72 (0.33, 1.57)	0.415
Comfortable*	0.92 (0.37, 2.29)	0.859
Not comfortable*	0.16 (0.05, 0.47)	0.001
Comfortable (ref. not comfortable)	2.24 (1.30, 3.87)	0.004
Education (ref. lower than HS)	1.35 (0.73, 2.50)	0.339
Personalized stigma (ref. low)	0.62 (0.39, 0.98)	0.043
Negative self-image (ref. low)	0.87 (0.55, 1.38)	0.547
Disclosure concerns (ref. low)	1.04 (0.63, 1.75)	0.861
Public attitudes (ref. low)	1.30 (0.83, 2.03)	0.252
Prefer woman provider (ref. man/ no preference)	1.38 (0.81, 2.35)	0.231
Age[a]	0.76 (0.56, 1.02)	0.071
Indigenous (ref. white/ACB)	0.72 (0.40, 1.29)	0.262
ACB (ref. white/Indigenous)	0.98 (0.61, 1.57)	0.923
Previous discussion within last 3 years (ref. no)	2.13 (1.56, 2.92)	<0.001
Pregnancy after HIV diagnosis (ref. no)	1.47 (0.84, 2.60)	0.180

*measure of interaction between HIV care provider gender and comfort discussing reproductive goals. [a]coded at intervals of 10 years.
Note: ACB, African, Caribbean, and/or Black

Table 5.3 Multivariate logistic regression results for Model 2 (mediator modelled as the outcome: comfort discussing reproductive goals with current healthcare provider)

Variable	aOR (95%CI)	p-value
Woman HIV care provider (ref. man)	4.18 (2.70, 6.49)	<0.001
Education (ref. lower than HS)	1.17 (0.67, 2.06)	0.579
Personalized stigma (ref. low)	1.15 (0.74, 1.80)	0.535
Negative self-image (ref. low)	0.68 (0.43, 1.07)	0.093
Disclosure concerns (ref. low)	0.63 (0.38, 1.04)	0.069
Public attitudes (ref. low)	1.17 (0.77, 1.78)	0.470
Prefer woman provider (ref. man/ no preference)	0.74 (0.44, 1.24)	0.249
Age[a]	0.91 (0.69, 1.21)	0.532
Indigenous (ref. white/ ACB)	0.79 (0.47, 1.31)	0.359
ACB (ref. white/ Indigenous)	2.20 (1.40, 3.47)	<0.001
Previous discussion within last 3 years (ref. no)	1.34 (1.00, 1.80)	0.048
Pregnancy after HIV diagnosis (ref. no)	1.59 (0.89, 2.85)	0.116

[a] coded at intervals of 10 years

Note: ACB, African, Caribbean, and/or Black

Table 5.4 presents the total effect of primary HIV care provider gender on discussions decomposed into a controlled direct effect (if everyone was uncomfortable, how much would gender of HIV care provider affect discussions), reference interaction effect (effect of having a woman provider modified by comfort and in the absence of mediation), the mediated interaction (effect of comfort on discussions, where the effect of comfort varies when the provider is woman vs man), and the pure mediated effect (effect of woman provider on discussions due to mediation through comfort only). The total effect of having a woman primary HIV care provider, when the mediator is set to its natural value, corresponded to a 1.18 (95%CI: 0.15, 2.20) excess relative risk (ERR) of reproductive discussion. When fixing the mediator, the controlled direct effect of provider gender is attenuated to −0.18 ERR (95%CI: −0.58, 0.22). The reference interaction between the effects of having a woman provider and comfort was associated with a 0.59 ERR (95%CI: −0.02, 1.19) of reproductive discussion. The mediated interaction was associated with a 0.49 ERR (95%CI: −0.03, 1.02) of reproductive discussion. The pure indirect effect of provider gender through comfort was associated with a 0.28 ERR (95%CI: 0.06, 0.50) of reproductive discussion. Mediation accounted for 66% (95%CI: 32%, 99%) of the total effect of healthcare provider gender on reproductive discussions.

Table 5.4 Mediation and interaction of comfort and effect of gender of healthcare provider on reproductive discussions (4-way decomposition)

Component	**Interpretation**	**Excess Relative Risk[a] (95%CI)**	**p-value**	**Proportion attributable (95%CI)**
Total effect	Effect of provider gender on discussions	1.18 (0.15, 2.20)	0.024	100%
Controlled direct effect	Effect of provider gender due to neither mediation nor interaction	-0.18 (-0.58, 0.22)	0.367	-15% (-55%, 24%)
Reference interaction	Effect of provider gender due to interaction only	0.59 (-0.02, 1.19)	0.058	50% (19%, 81%)
Mediated interaction	Effect of provider gender due to mediation and interaction	0.49 (-0.03, 1.02)	0.065	42% (18%, 66%)
Pure indirect effect	Effect of provider gender due to mediation only	0.28 (0.06, 0.50)	0.012	24% (-5%, 52%)
Total % mediated		-	-	**66% (32%, 99%)**

[a] adjusted for education, personalized HIV-related stigma, negative self-image related to HIV stigma, disclosure concerns, public attitudes towards HIV, preferring a woman HIV care provider, age, race/ethnicity, specialty of HIV care provider, previous discussions, previous pregnancy since HIV diagnosis.

5.7 Discussion

Among women of reproductive age living with HIV in the cohort, at baseline, 46.7% had discussed their reproductive goals with a healthcare provider since being diagnosed with HIV. Subsequently, 34.3% discussed their reproductive goals over the 18-month observation period. This finding supports previous studies reporting that women living with HIV experience gaps in reproductive health care.[15,16,21,26,33,34] Also consistent with previously published research,[15,26] women who received HIV care from a woman HIV provider were more likely to have discussed their reproductive goals with a healthcare provider. In our analyses, this included discussions with the primary HIV care provider or any other healthcare provider through referral or other means. We were able to deconstruct the effect of HIV care provider gender, revealing that the effect of HIV care provider gender on reproductive discussions operates principally through an indirect pathway mediated by women's comfort discussing their reproductive goals.

The estimated controlled direct effect was not significant, implying that, hypothetically, if all women had equal comfort discussing their reproductive goals, there would be no association between the gender of women's providers and whether or not reproductive discussions occurred. That more discussions were reported by women whose provider was also a woman can be primarily explained by differences in women's comfort. Given the intersecting challenges associated with sexuality, reproduction, motherhood, trauma, HIV-related stigma,[35] as well as racism and other forms of oppression that many women living with HIV face, women may feel more comfortable discussing these topics with an HIV care provider who is a woman[36] or asking that provider for a referral to another provider with whom they are more comfortable.

The substantive pathway through women's comfort highlights a point of interest for future interventions aimed at increasing reproductive discussions between women and their healthcare providers. Promising strategies include integrating women's reproductive health care in the delivery of HIV care[16,37,38] and increasing women's comfort discussing their reproductive goals. An integrated model of HIV care where allied healthcare providers are easily accessible[37] would facilitate reproductive discussions. A pre-post retrospective comparison of attendance at family planning clinics in Nigeria found that attendance at these clinics increased after the implementation of training for providers and formalised referrals between family planning and HIV clinics.[39] In general, HIV care providers of all genders should be capable of providing reproductive health care and counselling to women living with HIV. However, women's comfort discussing their reproductive goals may vary with the gender of their provider and social and cultural experiences.[40,41] Targeted training for care providers who identify as men may also help to educate them about initiating these discussions while addressing the comfort needs of women living with HIV.

Strategies to support women's comfort may include promoting self-efficacy,[42] creating a safe and supportive clinic environment, and signalling that reproductive discussions are welcome. Providers should also be aware of provider-patient and gendered power relations that exist in clinical encounters and approach these discussions accordingly.[43] The introduction of signs in clinic offices, waiting rooms or online[44] with information about pregnancy planning and contraceptives can help to signal that care providers at the clinic support the sexual and reproductive health and rights of women living with HIV. Annual reproductive discussions should also be part of routine

HIV care to help normalise these discussions, potentially increasing comfort for both patients and providers.[25]

This study is not without limitations. First, recall bias and social desirability bias may have led to misreporting of reproductive discussions in the past three years, gender preference for HIV care provider, and comfort discussing reproductive goals. Second, women who reported that they were unable to have children were excluded from the analysis, and information on why they were unable to have children is unknown. Hence, reproductive health counselling may still be relevant. Third, participants lost to follow-up, who represent a more marginalised population, were excluded from our analysis which may have led to an overestimation of the proportion who discussed their reproductive goals between baseline and follow-up. This also limits the generalisability of our findings. Fourth, we did not account for changes in healthcare provider over the study period. Our analysis measured reproductive discussions with any healthcare provider as opposed to with the primary HIV care provider; hence, we cannot conclude whether the effect of having a woman HIV care provider contributes to discussions with that provider or facilitating discussions with other healthcare providers involved in women's health care. We were, however, able to account for women living with HIV accessing health care in various settings by measuring reproductive discussions that occurred with any healthcare provider. Additionally, we did not measure participant and healthcare provider knowledge about reproductive health care for women living with HIV and safer conception strategies. Healthcare provider specialty or training may have influenced the initiation of reproductive discussions, however, reliable data on provider specialty was not available for inclusion in our model.[45] We measured healthcare provider gender and women's comfort discussing reproductive goals at the same time point; consequently, the direction of association cannot be inferred. Reproductive discussions may still be relevant for women who reported being unable to conceive, leading to an overestimation of the proportion of women living with HIV who discussed their reproductive goals with a healthcare provider. Estimations of excess relative risk may be biased by the rare outcome assumption leading to an underestimation of the indirect effect.[46] Finally, there may be unmeasured confounders that were not considered in our model, including post-exposure confounders of the mediator-outcome relationship. We included previous reproductive discussions as a confounder in our model; however, previous discussions may be a post-exposure confounder of the mediator-outcome relationship, which may have led to model bias.

Previous studies have described gaps in the delivery of reproductive health care for women living with HIV. In this study, we empirically assessed the relationships between healthcare provider gender, patient comfort, and discussing reproductive goals. Through the application of components of the causal framework, the longitudinal design of our study, and measured confounders, we are able to estimate the causal mechanism between healthcare provider gender and reproductive discussions. We highlight a potential avenue for interventions aimed at the delivery of reproductive health care. Further research is needed to better understand the concept of comfort and strategies that promote comfort discussing reproductive goals among women living with HIV. These strategies are needed to support the family planning, preconception, contraceptive, abortion, and sexual health needs of this population.

5.8 References

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6. Manuscript 3: Factors and priorities influencing satisfaction with care among women living with HIV in Canada: A Fuzzy Cognitive Mapping study

6.1 Preamble

In Manuscript 1, I delve into the contemporary pregnancy intentions of women living with HIV in Canada, highlighting the dynamic nature of pregnancy intentions. Notably, the manuscript emphasizes the need for ongoing discussions between women living with HIV and their healthcare providers to support their evolving pregnancy intentions adequately. Manuscript 2 builds upon the findings of Manuscript 1 by exploring the role of provider gender in supporting reproductive discussions in the healthcare setting. The findings from Manuscript 2 identify comfort as a critical mediator in the pathway between provider gender and reproductive discussions. The study emphasizes the role of patient comfort in improving reproductive healthcare delivery for women living with HIV, and concludes with a discussion on the need to better understand the concept of comfort from the perspective of women living with HIV.

Finally, Manuscript 3, presented in this chapter, complements the preceding manuscripts by further examining and expanding the concepts identified in the earlier chapters from the perspective of women living with HIV. I focus on women's satisfaction to better understand the features of care that contribute to feeling safe, comfortable and satisfied with HIV care. Using Fuzzy Cognitive Mapping, a participatory research approach, this study integrated existing literature and the perspective of women living with HIV to identify the factors contributing to satisfaction with HIV care and their relative importance. We conducted 23 individual Fuzzy

Cognitive Mapping sessions with women living with HIV. Data collection stopped after 23 interviews, as at this sample size, mapping sessions did not yield new insights into factors influencing satisfaction with HIV care. In addition to applying a participatory approach to the analysis and interpretation of mapping findings, we conducted member checking focus group discussions with a subset of study participants. The member checking discussion involved presenting preliminary findings from the analysis of participants maps and collecting participants interpretations of the data. The study identified factors not previously captured in the literature on satisfaction with HIV care, demonstrating how women's perspectives prove a more comprehensive understanding, particularly of how gender shapes care needs and priorities for women living with HIV. This chapter was published in the *Journal of Personalized Medicine.*

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6.2 Title Page

Factors and priorities influencing satisfaction with care among women living with HIV in Canada: A Fuzzy Cognitive Mapping study

Lashanda SKERRITT[1], Angela KAIDA[2], Édénia SAVOIE[3], Margarite SÁNCHEZ[2,4], Iván SARMIENTO[1], Nadia O'BRIEN[5]; Ann N BURCHELL[6], Gillian BARTLETT[1,7], Isabelle BOUCOIRAN[8]; Mary KESTLER[9], Danielle ROULEAU[5], Mona LOUTFY[10], Alexandra DE POKOMANDY[1,3,11]

1. Department of Family Medicine, McGill University, Montreal, QC;
2. Faculty of Health Sciences, Simon Fraser University, Burnaby, BC;
3. Chronic Viral Illness Service, McGill University Health Centre, Montreal, QC;
4. Viva Women, Vancouver, BC;
5. Centre de recherche du Centre hospitalier de l'Université de Montréal, Montreal, QC;
6. Department of Family and Community Medicine, Faculty of Medicine, University of Toronto, Toronto, ON;
7. Department of Family and Community Medicine, University of Missouri, Columbia, USA;
8. Centre Hospitalier Universitaire Sainte-Justine and School of Public Health, Université de Montréal, Montreal, QC;
9. Oak Tree Clinic, Vancouver, BC;
10. Women's College Research Institute, Toronto, ON;
11. Research Institute of the McGill University Health Centre, Montreal, QC;

Correspondence:
Alexandra de Pokomandy, MDCM, MSc Chronic Viral Illness Service
McGill University Health Centre - Glen Site 1001 Decarie Blvd., Rm D02.4110 Montreal, Quebec
H4A 3J1 Canada
Telephone 1-514-843-2090, Fax 1-514-843-2092
E-mail: alexandra.depokomandy@mcgill.ca

6.3 Abstract

Engagement along the HIV care cascade in Canada is lower among women compared to men. We used Fuzzy Cognitive Mapping (FCM), a participatory research method, to identify factors influencing satisfaction with HIV care, their causal pathways, and relative importance from the perspective of women living with HIV. Building from a map of factors derived from a mixed studies review of the literature, 23 women living with HIV in Canada elaborated ten categories influencing their satisfaction with HIV care. The most central and influential category was 'feeling safe and supported by clinics and healthcare providers,' followed by 'accessible and coordinated services' and 'healthcare provider expertise.' Participants identified factors that captured gendered social and health considerations not previously specified in the literature. These categories included 'healthcare that considers women's unique care needs and social contexts,' 'gynecologic and pregnancy care,' and 'family and partners included in care.' The findings contribute to our understanding of how gender shapes care needs and priorities among women living with HIV.

6.4 Introduction

In Canada, access to care and antiretroviral therapy (ART) has transformed HIV into a manageable chronic condition. Despite these advances, vast inequities in healthcare access, retention in care, HIV clinical outcomes and overall health and survival for people living with HIV persist [1,2]. In particular, although women represent one-quarter of people living with HIV in Canada [3], HIV programming has not adequately responded to their unique and evolving social and health priorities across the life course [4]. The lack of services that respond to the needs and priorities of women living with HIV has manifested in worse HIV-related outcomes among women compared to men across the HIV care cascade, including lower engagement in care, worse ART adherence and shorter life expectancy [1,2]. Gendered health inequities are further exacerbated by healthcare services that overlook the specific care needs and priorities of women living with HIV, resulting in delayed cervical and breast cancer screenings, missed opportunities for family planning counselling [5–7], and neglect of other sexual and reproductive health priorities [7]. These gaps in care are corroborated by women’s description of feeling overlooked in healthcare because of a lack of women-specific services [4].

Underlying the gendered inequities in HIV care and outcomes are multiple complex social and structural factors. To best meet women’s health care needs, healthcare services transformation should be anchored in the gendered priorities that shape patient satisfaction with care. A literature review synthesizing findings from articles reporting perceptions, experiences of, or satisfaction with healthcare services among people living with HIV identified seven themes [8]: 1) healthcare provider-patient relationship, 2) HIV specialist knowledge, 3) continuity of care, 4) health service access, 5) access to information and support, 6) co-ordination between healthcare providers, and 7) patient involvement in decision-making. The review did not, however, examine the role of gendered health considerations in satisfaction with care or the relative importance of different features of care by gender. This gendered lens is critical as perceptions of the clinic environment and care providers impact engagement with care among women living with HIV [9]. Meanwhile negative experiences, including experiencing or anticipating stigma and discrimination, are associated with poorer engagement in HIV care and adherence to ART [10,11]. Women's perceptions of their care environments effect not only HIV outcomes, but also sexual and reproductive health, an aspect of care particularly neglected. Women living with HIV who report feeling comfortable with healthcare providers are more likely to discuss their reproductive goals with their care providers [12]. Although frameworks recognizing the need for gendered care approaches exist [13,14], few studies have examined the care preferences and priorities of women living with HIV. Integrating these priorities and evidence-based care recommendations can maximize the care engagement, health and wellbeing of this population [15]. Understanding patient priorities and the causal relationships between aspects of care and satisfaction can also inform the implementation of interventions.

Satisfaction with care is a useful construct as it captures expectations of and experiences with healthcare [15]. Features of care that influence satisfaction from the perspective of women living with HIV remain poorly understood. Re-examining these features of satisfaction with care from the perspective of women living with HIV and determining the relative importance of these considerations can inform healthcare delivery that better aligns with their needs and redresses the historic marginalization of women in the design and delivery of HIV care [16]. The aim of this study was to identify relevant factors influencing women's satisfaction with HIV care, the relative importance of these factors to women living with HIV, and the causal relationships between these factors and satisfaction.

6.5 Materials and Methods

Theoretical framework

This study was guided by the social determinants of women's health framework described by McGibbon and McPherson [17]. Through this framework, the social determinants of women's health inequities are understood by bridging theories of social determinants of health, intersectionality theory and complexity theory. These theoretical frameworks informed our use of a mapping study design to capture and analyze the compounding effects of gender, oppression and power systems on healthcare priorities and experiences with healthcare. Given its known associations with care engagement, health outcomes, and patient experience, we considered patients' satisfaction with care as a critical indicator of appropriate health service delivery. We aimed to centre the priorities of women, acknowledging the role of gender and power dynamics in shaping the healthcare experience. The framework informed our interpretation of the identified factors influencing satisfaction with care. When examining each factor, we considered the role of gender and its intersections on women's healthcare expectations and perceptions.

Participatory research approach

We applied a participatory research approach, which aims to meaningfully involve community members in research impacting their community by responding to their priorities and drawing on their strengths and knowledge [18]. In this study, we considered women living with HIV as experts in their experiences with their HIV care [16]. Our research approach grounded existing evidence in the experiential expertise of women living with HIV. Two Peer Research Associates (PRAs), women living with HIV with research training and experience were partners throughout the research process, including the study design, interview guide development, mapping facilitation and data collection, data analysis and interpretation of findings.

Fuzzy Cognitive Mapping

We used Fuzzy Cognitive Mapping (FCM)[19] to identify factors influencing satisfaction with HIV care among women living with HIV in Quebec and British Columbia, Canada. FCM is a systematic process of knowledge creation that generates a concept map representing stakeholder understanding of causal relationships. The resulting map is a directed graph with nodes and numerically weighted arrows that model causes, effects, and the strength of causal relationships. FCM is a commonly used tool for stakeholder engagement in environmental studies and urban planning [20,21] and has been used in participatory health research to capture Indigenous knowledge [19,22,23], and to ground published knowledge and literature reviews in stakeholder understanding [24]. The use of visual language in FCM supports its use across different languages, cultures, and education levels. In this study, we used FCM to collate different sources of causal understanding, namely literature evidence and stakeholder knowledge.

Study participants and recruitment

A combination of convenience and purposive sampling was used to recruit participants to this study. Women living with HIV who were 18 years of age and older, spoke English or French, and were living in the study provinces of Quebec or British Columbia were eligible to participate. PRAs [25] and study investigators approached potential participants from their networks, through clinics, and contacted previous participants of the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), a community-based participatory research project that followed women living with HIV in Canada between 2015 and 2018 [26]. Participants were contacted by phone, email, or in person and invited to participate in the mapping sessions. We recruited participants of diverse ages, immigration experiences, rural and urban geographic locations, and reproductive health experiences (previous pregnancies, pregnancy intentions, menopausal status, and current contraceptive use). Recruitment took place between December 2020 and March 2021. We stopped recruitment when data saturation was reached, defined by the research team as the point at which no additional factors arose.

This study received ethics approval from the McGill University Health Centre, the Simon Fraser University, and the University of British Columbia Research Ethics Boards. All participants provided informed verbal consent. We provided a 25CAD honorarium to interview participants and an additional 50CAD honorarium to participants who attended the follow-up group discussion. An overview of the study process is illustrated in Figure 6.1

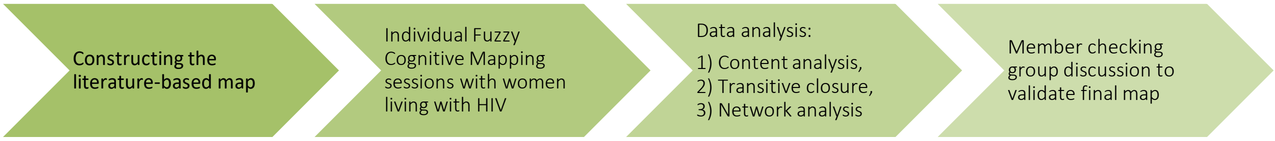


Figure 6.1. Study process overview

Data collection

Step 1. Constructing the literature-based map

We presented a synthesis of published evidence in the form of a map that women living with HIV used as an initial common ground to discuss factors they considered relevant to their satisfaction. The lead author constructed a map of themes influencing satisfaction with HIV care among people living with HIV based on findings from a mixed-studies review by Cooper et al, published in 2016 [8]. This review synthesized evidence from 23 studies (N = 2,719) exploring aspects of care associated with satisfaction among people living with HIV in Australia, Canada, the Netherlands, the UK, and the US between 1996 and 2015. Men living with HIV represented 61% of participants of the included studies reporting gender. The review, however, did not examine gendered care priorities or how gender shapes satisfaction with HIV care. For this project, a map summarizing themes from the literature review served as a starting point for women living with HIV to build their individual map following a standard protocol described below. The literature-based map presented factors and unweighted directed pathways towards satisfaction with HIV care.

Step 2. Fuzzy Cognitive Mapping sessions

Through individual interviews, participants adjusted the literature-based map to represent their personal perspective. A PRA and the lead author co-facilitated the individual mapping sessions in

French or English per participant preference. Each participant completed a brief demographic questionnaire. The PRA guided the interview and mapping process, while the lead author illustrated the map in real time and took notes of the discussion. The facilitators explained the process of Fuzzy Cognitive Mapping to the participant, presented the literature-based map, guided participants in developing their map, using a predefined qualitative interview guide. The guide invited women to first reflect on the healthcare they had received or were receiving and define satisfaction with HIV care. “In this interview, we would like you to reflect on that healthcare that you’ve received or are receiving. Was it OK? Was it the right care for you? Is it the right care for other women like yourself? If not, what could have made it better?”

The PRA facilitator then guided participants in the stepwise construction of their map. First, women were asked an open-ended question to elicit their understanding of the outcome, satisfaction. “What does satisfaction with HIV care mean to you?” The PRA facilitator asked women to adjust the map by adding or removing factors that positively or negatively influence their satisfaction with HIV care. “What factors do you believe positively or negatively influence your satisfaction with HIV care?” After arriving to a final list of factors, the PRA facilitator asked women to identify all the causal relationships between factors. “For each factor, one at a time, please identify all the causal relationships between that factor and others (meaning this factor causes another factor or vice-versa).” The PRA facilitator asked women to assign a weight between -5 and +5 indicating the strength and direction of the relationship. “Please assign a weight between -5 and +5 indicating how strong the relationship is and whether the influence is positive or negative.” Positive weights indicated that an increase in the originating factor would increase the landing factor, and negative weights the opposite. Values closer to -5 and +5 indicated stronger influences, and values closer to 0 corresponded to weaker ones. At the end of the interview, the PRA facilitator asked women to review their Fuzzy Cognitive Map and make any necessary changes before confirming the final version. “Is there anything you would like to change in your final map?”

We used the graph editing software yED [27] to draw the maps in real time during the interviews. Interviews were conducted virtually over the videoconferencing platform Zoom. Interview content was audio-recorded and transcribed verbatim. The lead author also took notes during each interview to capture important observations and meanings around participants definition of factors and their relationships. After each interview, a reflexive debrief was conducted between the mapping co-facilitators to note the interview experience and any issues relevant to the data collection process. Individual interviews varied in length from 35 minutes to 2 hours.

Data analysis and interpretation

Qualitative analysis of the listed factors influencing satisfaction with HIV care

FCM yielded both qualitative and quantitative data. Following methods described by Erlingsson and Brysiewicz [28], we conducted qualitative content analysis to condense the factors from the individual maps into categories. The lead author developed the first level of aggregation using a pattern correspondence table to collapse factors of similar meaning across individual maps [19]. For example, the factors “family and partners included in care,” “mom is included in care,” “family involved in care at the clinic,” “care and resources at clinic extended to family,” were standardized as “family and partners included in care.” This process of standardizing factors was ongoing and iterative. The final three participants identified factors consistent with those in the previous 20 interviews. We considered data saturation reached and stopped the data collection after 23 interviews. The lead author and two PRAs then conducted content analysis identifying categories from the standardized factors. The categorization of factors and their meanings were validated with input from other members of our multidisciplinary research team members, which included HIV clinicians and researchers.

Quantitative analysis of assigned weights representing the strength of associations

The individual maps were first presented as individual adjacency matrices. The matrices had an equal number of columns and rows, with each row and column corresponding to the standardized factors identified across all the maps. Each matrix cell corresponded to an arrow connecting two factors, from the row to the column. The cell value equalled the weight of that arrow assigned by the participant in the corresponding map. Cells had a zero value if the relationship was not on the map. We normalized the weights by dividing them by 5 to put them in the -1 to +1 range. We analyzed each participant's matrix using Transitive Closure, a tool derived from graph theory and available in Python version 3.7 and CIETmap [29]. Transitive closure recalculates the matrices by identifying the effects that one factor has on others through direct and indirect paths. The resulting transformed matrix specifies the strongest influence between nodes across the direct and indirect paths, where the strength of an indirect path equals the strength of the weakest relationship in the pathway.

From the 23 transformed matrices, we calculated the average weight of factor-level relationships. We used the categorization from the content analysis to condense the factor-level relationships into a category-level matrix. The category-level weights equalled the relative sum of the average weights of factor-level relationships with that category. The weight of the relationship between categories equaled the sum of the mean weights from each factor in the outgoing category to each factor in the incoming category. The sum was then divided by the maximum cumulative weight across all categories in the average matrix to obtain relative values between -1 and +1.

Network analysis

In addition to calculating the strength of the influences on satisfaction with HIV care, we also described the categories using indegree and outdegree centrality. For each category, we summed the absolute weights of incoming (indegree) and outgoing (outdegree) arrows as measures of centrality. A higher sum would indicate a higher centrality measure.

Member-checking group discussions to validate results

We conducted three virtual member checking [30] group discussions with nine mapping participants to establish trustworthiness in the results. They confirmed their agreement with the analysis results and provided additional interpretations of the categories and their relative importance. These discussions contributed to the final framing of the research findings and recommendations.

6.6 Results

Of 26 women living with HIV approached to participate, 23 agreed to participate in the individual mapping sessions. Table 6.1 presents the characteristics of study participants. Median age was 47 years [IQR: 19, 66], with a median 20 years living with HIV. The majority of women identified as cisgender, heterosexual/straight, white, with completed post-secondary education and did not live with a partner. Two-thirds of women had a household income above $20,000CAD. Nine (39%) participants had a pregnancy since their HIV diagnosis, 17% intended to become pregnant in the future, and 26% reported any contraception use in the last six months (including hormonal contraceptives, long-acting reversible contraceptives, male/female condoms, or other methods).

Table 6.1. Participant characteristics

Characteristics	Overall (n=23)
Age, Median [Min, Max]	47 [19,66]
Years living with HIV, Median [Min, Max]	20 [10, 36]
Gender	
Cis woman	21 (91.3%)
Genderqueer	2 (8.7%)
Ethnicity	
African/ Caribbean/ Black	8 (34.8%)
Indigenous	2 (8.7%)
Asian	1 (4.3%)
White	12 (52.2%)
Sexual orientation	
Bisexual/ Lesbian/ Queer	5 (21.7%)
Heterosexual	18 (78.3%)
Relationship status	
Married/ Common-law/ In a relationship	9 (39.1%)
Single/ Separated/ Divorced/ Widowed	14 (60.9%)
Education	
Post-secondary or higher	16 (69.6%)
Secondary or lower	7 (30.4%)
Household annual income, <20,000CAD	7 (30.4%)

Characteristics	Overall (n=23)
Pregnancy since HIV diagnosis	9 (39.1%)
Intends to become pregnant in the future	4 (17.4%)
Contraception use in last 6 months	6 (26.1%)
Post-menopause	11 (47.8%)

Factors influencing satisfaction with HIV care

The literature-based map included seven factors associated with satisfaction with HIV care (Figure 6.2). Women adjusted this map, identifying 79 factors influencing satisfaction with HIV care directly or indirectly and 1083 relationships (arrows) connecting these factors. The 79 factors included those from the literature-based map and new factors added by participants. We condensed the 79 factors into 10 categories. In Table 6.2, we present the final classification of factors in each category, including factors retained from the literature-based map and factors added by participants. ‘Accessible and coordinated services’ and ‘healthcare provider expertise’ were themes from the literature-based map retained in the final map but were further expanded by additional factors added by participants. The remaining 8 categories reflected constructs with new or different meanings than those from the literature review. The final categories were 1) feeling safe and supported by healthcare providers (HCPs) and clinics, 2) accessible and coordinated services, 3) healthcare provider expertise, 4) care that considers women’s unique care needs and social contexts, 5) empowerment/self-care/self-advocacy, 6) focus on mental well-being, 7) peer support and community involvement in care, 8) gynecologic and pregnancy care, 9) inclusion of family and partners in care, 10) care that adapts with aging.

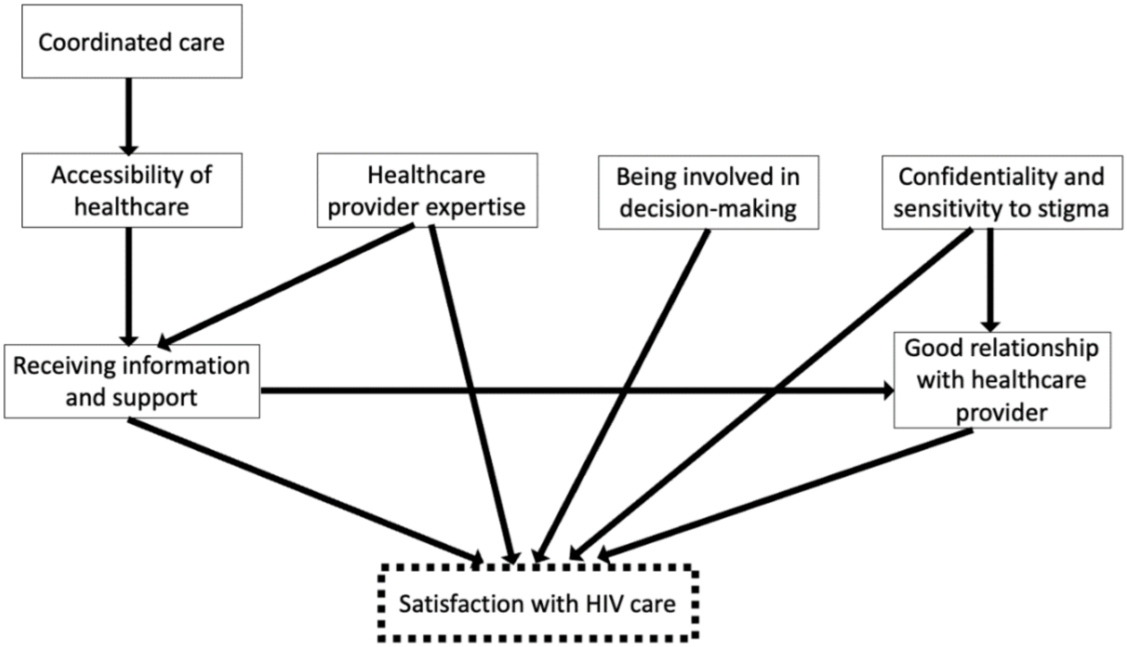


Figure 6.2. Literature-based map synthesizing findings from Cooper et al. on the factors that influence satis-faction with HIV care among people living with HIV

Table 6.2. Categorization of factors influencing satisfaction with HIV care among women living with HIV. Factors retained from the literature-based map in grey.

Final category	Factors
Feeling safe and supported by HCPs and clinics	1. Good/excellent relationships with HCPs 2. Receiving information and support from HCPs and clinics 3. Confidentiality and sensitivity to stigma 4. Access to genuine support 5. Follow-up from HCPs and receptionists 6. Culturally sensitive care 7. Caring, kind, genuine social worker/support, nurse practitioner 8. Reminders for appointments outside of clinic 9. Dentist comfortable treating people with HIV 10. Outreach workers at clinic 11. Building relationships with healthcare team 12. Honesty from HCP; trusting relationship 13. HCP advocacy 14. Female HCP 15. Respect from HCP and community 16. Not being treated differently when accessing non-HIV care 17. Using kind and considerate language 18. Continuity with HCP and social workers 19. Not being judged for pregnancies or lifestyle 20. HCP being good listeners; feeling heard; Questions and concerns being addressed 21. Regular monitoring of CD4 count and viral load 22. No judgement from reception when cancelling appointments 23. Welcoming, family-friendly, trans-inclusive waiting room 24. Addressing side effects of ARTs 25. Disclosure of HIV status to HCPs

	26. Less confidentiality in rural settings
Accessible and coordinated services	1. Accessibility of healthcare 2. Coordinated healthcare services 3. Receiving HIV medication while incarcerated 4. HCPs that work as a team; communicate with each other 5. No waitlist to access clinic services 6. COVID-19 pandemic interfering with access to services 7. Easy transportation to/from appointments 8. Resources and care all in one place (Holistic) 9. Accessing services over the phone/ remote 10. HCP going above and beyond to be accessible 11. HCP available for non-HIV healthcare resources 12. Close geographical distance/ transportation to/from clinic 13. Being able to see a doctor 14. Clinic ensuring primary care is happening 15. Links to non-HIV specialists 16. Complementary healthcare rather than medication 17. No delayed access to ARTs due to lack of insurance for immigrants
Healthcare provider expertise	1. HCP with expertise in HIV 2. Pharmacists essential part of care team to prevent drug interactions and manage side effects 3. Adequate training of nurses and doctors (incl. HIV, women's health, and reproduction)
Empowerment/self-care/self-advocacy	1. Collaborative approach between me and my HCP 2. COVID-19 pandemic interfering with spiritual practices 3. Feeling empowered by HCP to self-advocate 4. Having the option in advance to refuse or accept trainee HCPs in in-person appointments 5. Training on self-care 6. Exercise as part of care 7. Celebration of health milestones 8. No doom and gloom attitude 9. Belief in self and prayer 10. Patience and confidence in myself and my strength
Care that considers women's unique care needs and social contexts	1. Considers the social contexts of women living with HIV 2. Person-centred care 3. HCP focused on my needs and concerns 4. Research on HIV and women 5. Access to women-specific treatments 6. HCP considers my history and context 7. Care that adapts to my unique needs 8. Care that considers my health in the context of the COVID-19 pandemic
Focus on mental well-being	1. Mental health and social services integrated in clinic 2. HIV-knowledgeable psychiatrist
Peer Support; Community involvement in care	1. Peer vetted referrals to non-discriminatory services 2. COVID-19 pandemic interfering with social support 3. Community/peer support groups 4. Collaborative approach between medical and community 5. Meaningful Involvement of Women Living with HIV/AIDS (MIWA) 6. Disability insurance as barrier to community engagement & support
Gynecologic and pregnancy care	1. Receiving gynecologic care 2. Supportive pregnancy care 3. Being given options during pregnancy (e.g., abortion)
Inclusion of family and partners in care	1. Inclusion of family and partners in care
Care that adapts with aging	1. Healthcare that adapts with aging 2. Focus on cognitive function changing with aging

Figure 6.3 presents the summary map with the 10 final categories influencing satisfaction with HIV care, the highest weighted category-level relationships, and weights after transitive closure. The final map shows the two categories that closely reflected themes from the literature-based map as well as the categories that were distinct from initial themes presented in the literature. 'Feeling safe and supported', 'Accessible and coordinated services' and 'Healthcare provider expertise' most strongly influenced satisfaction directly, while the remaining categories primarily influenced satisfaction indirectly, through their effects on 'Feeling safe and supported.'

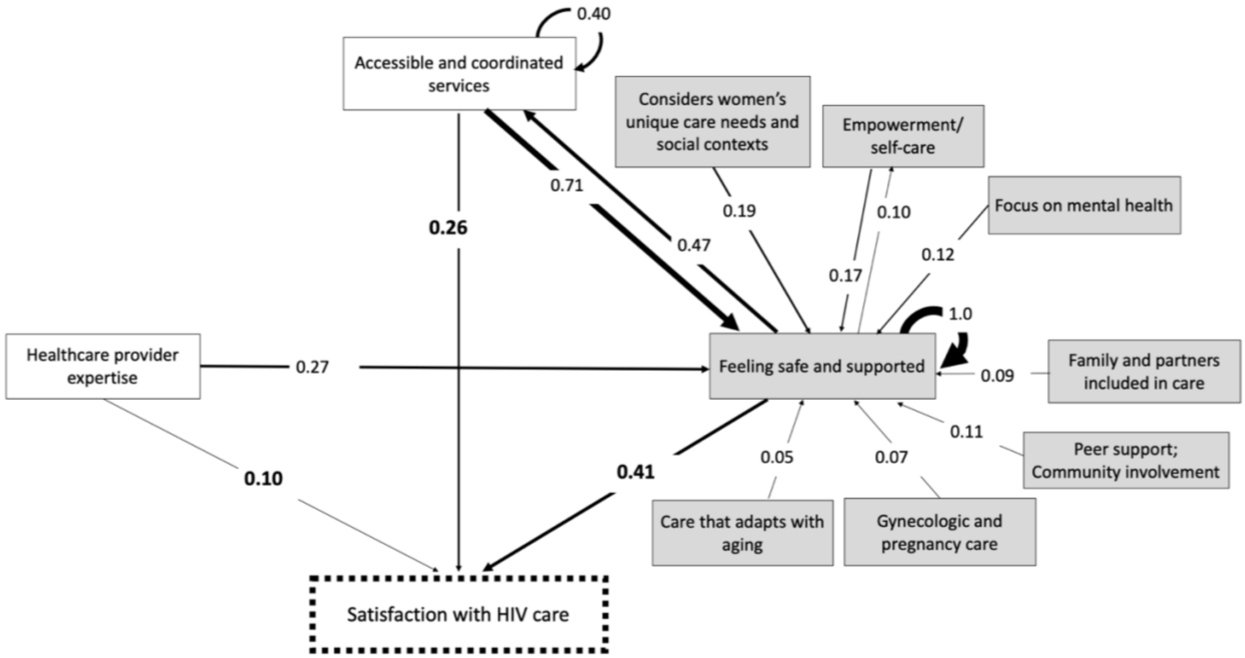


Figure 6.3. Summary Fuzzy Cognitive Map of category-level relationships showing the three highest weighted direct influences and the highest weighted indirect influences on satisfaction with HIV care. Weights closer 1 indicate stronger influences. Grey boxes represent new constructs added to the literature-based map.

Table 6.3 lists the category weights on satisfaction with HIV care and their relative weighted importance in the scale -1 to +1. The weights account for both direct and indirect pathways through which the categories influence satisfaction with HIV care.

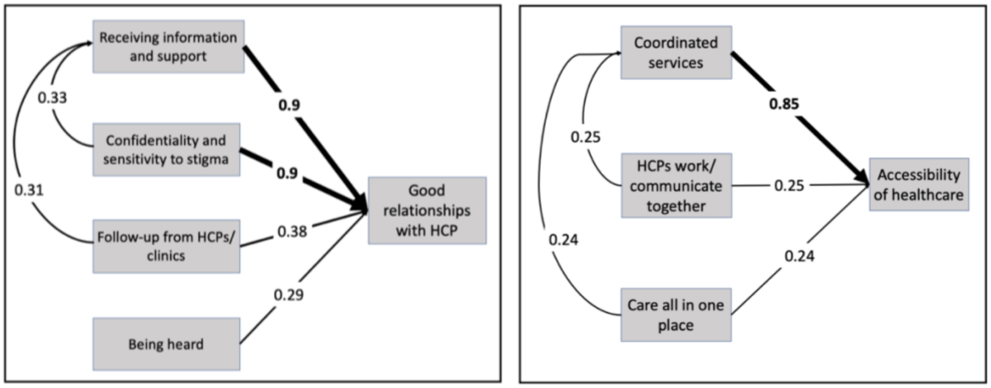
Table 6.3. Categories influencing women's satisfaction with HIV care and their relative category weightings considering direct and indirect pathways

Category	Weight
1. Feeling safe and supported by HCPs and clinics	0.41
2. Accessible and coordinated services	0.26
3. Healthcare provider expertise	0.10
4. Care that considers women's unique care needs and social contexts	0.06
5. Empowerment/self-care/self-advocacy	0.05
6. Focus on mental well-being	0.03
7. Peer Support; Community involvement in care	0.03
8. Gynecologic and pregnancy care	0.03
9. Inclusion of family and partners in care	0.02
10. Care that adapts with aging	0.02

Feeling safe and supported by healthcare providers and clinics

Providers' and clinics' attention to patients' feelings of safety and support had the most important influence on satisfaction with HIV care according to participants. The category 'Feeling safe and supported by HCPs and clinics' included 26 factors (Table 6.2) corresponding to the care environment and approaches centring patients' need to feel secure and cared for with kindness, compassion and without judgement. The category combined constructs retained from the literature-based map, namely, good relationships with HCPs, receiving information and support, confidentiality, and sensitivity to stigma. Participants also added new factors, such as the importance of genuine support, culturally sensitive care, and the absence of judgement for cancelling clinic appointments. Many factors added by the participants reflected the gender-specific experience or needs, such as participants' preference for female HCPs, not being judged for pregnancies or lifestyle, and having a welcoming, family-friendly, trans-inclusive waiting room in the clinic.

'Feeling safe and supported' directly influenced satisfaction with HIV care but, as Figure 6.3 shows, it also functioned indirectly by increasing access to services. The strong internal dynamics between factors in the category are reflected by a self-pointing arrow from 'feeling safe and supported' onto itself. Figure 6.4a illustrates the factor-level relationships within 'feeling safe and supported'. These internal dynamics were mainly attributed to the reinforcing relationships between five factors: 1) having good/excellent relationships with HCPs, 2) receiving information and support from HCPs and clinics 3) confidentiality and sensitivity to stigma, 4) follow-up from HCPs and clinic, and 5) feeling heard during appointments. The two most influential factor-level relationships were the effect of receiving information and support and confidentiality and sensitivity to stigma on having excellent relationships with healthcare providers.



(a) (b)

Figure 6.4. Self-pointing arrows in the final map at the factor level. The strongest internal dynamics between factors within the categories (a) feeling safe and supported and (b) accessible and coordinated services. Weights closer to 1 indicate higher influences.

Accessible and coordinated services

'Accessible and coordinated services' had the second strongest influence on satisfaction. The category consisted of 17 factors (Table 6.2). In identifying these factors, participants discussed the importance of timely and coordinated care and treatment, particularly when accessing care from multiple services and providers. Participants identified communication between providers and access to various services at one site as important for avoiding stigmatizing experiences in non-HIV specialized healthcare settings.

Strong internal dynamics were observed within this category, as depicted in Figure 6.4b by the self-pointing arrow. These internal dynamics were mainly attributed to the important relationships between four factors: (1) accessibility of healthcare, (2) coordinated healthcare services, (3) having healthcare providers who communicate with each other, and (4) having resources and care located in one place. The most influential factor-level relationship within this category was the effect of coordinated healthcare services on the accessibility of healthcare. Participants discussed the importance of accessibility and coordination to reduce or mitigate barriers to services and treatment.

Healthcare provider expertise

The category 'healthcare provider expertise' was composed of three factors, (1) provider expertise in HIV, (2) having a pharmacist as part of the care team and (3) adequate training of nurses and doctors (including knowledge of women's health and reproductive health in the context of HIV). The third factor capturing participants challenges in receiving both HIV and equitable women's health care. As shown in Figure 6.3, 'healthcare provider expertise' influenced satisfaction directly and indirectly through its effect on women's feelings and safety and support. Women cited their challenges accessing quality care in settings outside of HIV-specialized clinics, where healthcare providers had less knowledge about women's particular care needs and stigma concerns.

Additional categories influencing satisfaction with HIV care

In addition to 'Feeling safe and supported' the final map contained seven other categories that were distinct from constructs in the literature-based map. Women cited 'empowerment and self-care' as influencing satisfaction by contributing to their self-advocacy and consequently having their specific needs and concerns met. Women identified care that 'considers women's unique health needs and social contexts' as important to their satisfaction, describing care approaches and treatments supported by research on HIV and women, and that also considers patient health and social needs and concerns that are specific to women. Care that 'focuses on mental well-being' included mental health and social services available at clinics or access to mental health experts with knowledge on HIV to address trauma and violence. 'Peer support and community involvement in care' referred to peer vetted referrals to services, peer and social support groups, and the meaningful involvement of women living with HIV and community in health service decision-making. 'Gynecologic and pregnancy care' captured the importance of receiving gynecologic care, supportive pregnancy care and support for pregnancy decisions, including termination. In describing the importance of 'family and partners included in care' women described clinics where their young children could also receive care and where partners or family members can access resources and information. The final important category for participants was 'care that adapts with aging'. This category including aging and changes in cognitive function that accompany aging.

Network analysis

‘Feeling safe and supported’ had the highest indegree centrality, meaning it was the most important effect among all the relationships in the map both for the number of arrows pointing towards it and the strength of those arrows (indegree centrality score of 2.78). The second most important effect in the category map was ‘accessible and coordinated services’ (indegree centrality score of 1.47). The importance of these two categories as relevant effects on the maps was even higher than the importance of the main outcome ‘satisfaction with HIV care’ (indegree centrality score of 1). Outdegree centrality also identified ‘feeling safe and supported’ and ‘accessible and coordinated services’ as the most important influences, not only on satisfaction but also on other categories on the map.

6.7 Discussion

In this study, we used a participatory research approach to identify factors influencing satisfaction with HIV care and examine the relative importance of these factors from the perspective of 23 diverse women living with HIV in two Canadian provinces. Ten categories influencing satisfaction with HIV care were identified. ‘Feeling safe and supported’, ‘accessible and coordinated services’ and ‘healthcare providers’ expertise’ most strongly influenced satisfaction and captured constructs consistent with the literature. In addition, women living with HIV identified, defined, and elaborated on social and health considerations that also shape their satisfaction with care. These categories were care that considers women’s specific needs and social contexts, empowerment/self-care/self-advocacy, care that focuses on mental well-being, peer support and community involvement in care, gynecologic and pregnancy care, the inclusion of family and partners in care, and finally care that adapts with aging. Six out of ten categories included gender-specific factors, despite the interview guide not specifically asking how women perceived their gender to affect their care. This finding highlights the importance of gendered considerations in shaping women's care needs and satisfaction with healthcare delivery. Understanding the features of care that influence women's satisfaction, their relative importance and causal mechanisms is essential for designing services that meet women's care needs. Our study was unique in its novel use of FCM to integrate existing literature and the experiential expertise of women living with HIV. Our results contribute to the literature on HIV care delivery by presenting a complex picture of how women-specific factors shape the healthcare priorities of a sample of women living with HIV.

Feeling safe and supported in healthcare settings was the most important and central consideration in participants' satisfaction with HIV care. Although this category included constructs consistent with existing literature [8], participants elaborated further, identifying additional factors that define feelings of safety and support in healthcare. Participants weighted communication of information and resources and confidentiality and sensitivity to stigma as contributing strongly to their relationships with their healthcare providers. These findings align with previous studies that identified patient-provider communication as important for care engagement [31,32] and resilience, particularly for more marginalized populations living with HIV [33]. Interpersonal aspects of care that respond to known structural barriers to care for women living with HIV also emerged as significant. Participants described the importance of provider and clinic sensitivity to stigma, a known barrier to accessing HIV care [34]. Fear of HIV-related stigma has been found to impact interactions with HIV clinics and staff [35]. The importance of patient-provider relationships, including those developed with female healthcare providers, has been shown to affect health outcomes, such as discussing reproductive goals with healthcare providers and sexual and perinatal wellbeing among women living with HIV [12,36]. Healthcare provider gender has been shown to predict health outcomes outside of HIV care [37,38]. Women living with HIV who have good relationships with their care providers may be more likely to remain engaged in and feel safe, supported, and satisfied with their HIV care.

Accessible and coordinated services and healthcare provider expertise represented the second and third most important considerations in women's satisfaction with HIV care. These considerations are consistent with the literature on aspects of care valued by people living with HIV [8]. Clinic distance, long wait times and inconvenient clinic hours have been cited as barriers to healthcare access in studies with people living with HIV [39]. Engagement in HIV care is lower among women compared to men [40]. Through FCM, women in this study described how the coordination of services, communication between providers and the provision of multiple services at one clinic increase their access to care. Consistent with previous research, participants also identified healthcare provider expertise as important to their satisfaction. Healthcare for people living with HIV includes HIV management but also the management of multiple health conditions, co-morbidities, and reproductive health [41]. The complexity of care considerations requires multidisciplinary approaches, often including non-HIV specialized care providers and clinics. Stigma in non-HIV specialized clinics is a known barrier to accessing services [4,31]. Stigma contributes to the avoidance of healthcare, delays accessing treatment and treatment nonadherence among people living with HIV [42–46]. Women living with HIV identified the importance of care providers with adequate knowledge of HIV to prevent enacted stigma in healthcare encounters.

Women living with HIV described gendered health considerations that shape their satisfaction. Gendered considerations emerged in larger categories influencing satisfaction such as women feeling safe and supported. Women identified female healthcare providers and the absence of judgment of sexual and reproductive health behaviours as contributing to their feelings of safety and support. While 'feeling safe and supported' included gender-specific factors, other categories were completely shaped by gender. Women's unique needs and social contexts emerged as a category defined by gender. Previous literature has described how gender can inform women-specific HIV services and aspects of HIV care [13]. In this study, women living with HIV described the need for healthcare to recognize their gendered social contexts as with unique and complex histories. Women outlined the multiple mechanisms through which their social contexts influence satisfaction, including through empowerment, mental health, peer and community support needs, the involvement of family or partners in care, gynecologic and pregnancy care needs, and the evolution of care across the life course. These considerations should be interpreted through an intersectional lens, recognizing that health priorities are shaped by diverse and overlapping social and structural factors [47–49]. Gender, socioeconomic, and racial inequities intersect to inform patient healthcare needs and interactions with healthcare providers. These inequities also give rise to gaps in research on the care priorities of women living with HIV [50]. Given the prevalence of intersectional stigma in women's experiences navigating HIV healthcare, [10,11,51] healthcare must go beyond service provision. According to women living with HIV in our study, satisfying care must also responds to the gendered social contexts of women living with HIV.

Limitations

We did not collect data on clinical health outcomes or engagement in HIV care. Our sample did not include trans women; therefore, the findings may not capture the unique care priorities among this population. Future research should examine how gender shapes satisfaction with care among people living with HIV of diverse genders. Our literature review synthesis and construction of the literature-review map did not include PRA perspectives. Through mapping interviews, we aimed to integrate the perspectives of women living with HIV in existing literature. Data collection was limited to women living with HIV in two Canadian provinces, but the social contexts and demographics, including immigration status and racial identity of women living with HIV differ significantly in these two provinces [26]. Additionally, the study took place within the context of universal healthcare delivery. Findings may not extend to other settings, particularly where healthcare is delivered through different models, such as private delivery.

Strengths

Our recruitment strategy aimed to engage structurally marginalized women and underserved communities. Around half of participants identified as non-white, around one-fifth identified as a gender minority and 30% as low income, reflecting diversity in socioeconomic status. In this study, we asked women living with HIV to update existing literature to reflect factors influencing their satisfaction and to weigh the importance of relationships between factors. Although previous studies identified aspects of care valued by people living with HIV, our findings illustrated how gendered health and social considerations shape women's satisfaction with HIV care. Our results and interpretations are grounded in women's understanding of the causal relationships between their care priorities and satisfying HIV care.

Conclusions

Women living with HIV emphasized the importance of care approaches that increase their feelings of safety and support. The role of gender in shaping satisfaction with HIV care supports the view that all healthcare should be provided through a person-centred approach that considers gender along with other health and social contexts, which additionally shape the healthcare experience. The findings of this study revealed the importance of relationship- and trust-building with healthcare providers as a priority for women living with HIV, consistent with principles of person-centred and women-centred HIV care [4,52]. Efforts to improve HIV care and health outcomes for women living with HIV must integrate women's gendered priorities and perspectives in designing and delivering health services [53]. Our findings illustrate a systematic approach to developing conceptual maps grounded in literature and stakeholder expertise. The results can guide future research and health services that consider the role of gender and its intersection in the care needs and priorities of women living with HIV.

6.8 References

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7. Discussion

7.1 Overview

This dissertation aimed to assess the reproductive healthcare needs and priorities of women living with HIV, conceptualizing reproductive health through a reproductive justice framework. Three complementary studies conducted in partnership with women living with HIV furthered our understanding of contemporary reproductive healthcare needs and strategies to address gaps in current healthcare delivery. Additionally, the application of social determinants of health and participatory research lenses enabled an assessment of reproductive health needs and priorities that considered the historical and present-day marginalization of women living with HIV in research and the design of healthcare services. The findings of this dissertation indicate the importance of the healthcare environment in determining whether reproductive health is addressed in HIV care. The dissertation identified features of care that promote the satisfaction of women living with HIV, revealing the role of safety and support, a perspective not addressed in previous research. In this chapter, I discuss how the findings from the three manuscripts contribute to the broader literature on reproductive healthcare delivery for women living with HIV and describe the findings' research, policy, and clinical practice implications.

7.2 Summary of Key Dissertation Findings

Key Dissertation Findings

1. Pregnancy intentions among women living with HIV are diverse and dynamic.

2. Healthcare provider gender affects whether women living with HIV discuss their reproductive goals. This largely functions through women's comfort with their care provider.

3. Feeling safe and supported in the care environment was the most important and central consideration in women's satisfaction with HIV care. Satisfaction was also shaped significantly by gendered social and health considerations.

7.2.1. Contemporary Reproductive Health Needs Among Women Living with HIV

In the first study, presented in Chapter 4, I examined patterns of changing pregnancy intentions over 36 months among 284 pre-menopausal women living with HIV between 16 to 49 years of age (median age 36 years [IQR: 31-40]) who reported their pregnancy intentions at CHIWOS during all three survey waves. Among this sample, pregnancy intentions varied. At baseline, 42% of women intended to become pregnant in the future, 43% did not, and 15% were unsure. Notably, within 18 months, around 25% of participants changed their reproductive intentions from intending to not intending to become pregnant and vice versa. After 36 months, 40% of participants reported different pregnancy intentions compared to baseline. The findings highlighted the need for ongoing discussions between women living with HIV and their healthcare providers to support pregnancy intentions as they evolve.

Addressing contemporary reproductive health needs demands better, more consistent integration of HIV and primary care: pregnancy and family planning support that aligns with women's goals, promotes healthy pregnancies, prevents unintended pregnancies, and supports reproductive rights (196). Consistent with a reproductive justice framework (112), sustaining reproductive rights includes supporting reproductive autonomy, sexual health needs, parenting decision-making, and menopause management (138, 163, 197). The contemporary reproductive goals of women living with HIV change over time, requiring a longitudinal approach to reproductive healthcare delivery from menarche to menopause. To support the dynamic pregnancy intentions of women living with HIV, ongoing reproductive discussions should be prioritized. Furthermore, emphasis should be placed on addressing women's comfort with their care providers. As the findings of this dissertation show, comfort is a key mediator influencing whether women engage in reproductive discussions.

Most women living with HIV in Canada access HIV care from HIV-specialized settings (5). Despite regular interactions with care providers, previous studies have shown women who receive care from a specialist are less likely to discuss their reproductive goals compared to women who receive care from a family physician (5). Moreover, as previous studies suggest, reproductive healthcare often places emphasis on pregnancy prevention (22, 198). While pregnancy prevention is important for women who wish to avoid pregnancy, findings from this dissertation research demonstrated diverse and changing pregnancy intentions. As reported in Chapter 4, 42% of women living with HIV reported an intention to become pregnant and 15% were uncertain at baseline, demonstrating the importance of support and counselling that aligns with women's individual goals. On the other hand, although non-HIV specialized primary care providers and settings may be more likely to address comprehensive reproductive health, women living with HIV describe these settings as stigmatizing (24). Strategies are needed to destigmatize sexual and reproductive healthcare for women living with HIV.

The second study, presented in Chapter 5, applied a mediation analysis that highlighted the important role of women's comfort in determining whether women living with HIV discuss their reproductive goals with their healthcare providers. Between the baseline and 18-month follow-up surveys, about one third of participants discussed their reproductive goals with a healthcare provider. While family planning options have expanded for women living with HIV in recent years, women continue to face challenges accessing supportive reproductive healthcare (96, 120, 199). A healthcare delivery approach that reduces gaps between HIV and primary care and is responsive to the evolution of reproductive health needs would reduce missed opportunities for reproductive discussions between women living with HIV and their care providers. While previous guidelines focused on preventing mother-to-child transmission of HIV, more recent guidelines have aimed to better address the broader reproductive health needs of women living with HIV (150). These guidelines, however, assume reproductive goals are static and do not focus on reproductive health priorities. Furthermore, guidelines often target specific healthcare provider specialties, but fail to address the need to support patients in their navigation of services delivered across different care providers and clinical settings, a reality for many women living with HIV.

7.2.2. Creating Safe Healthcare Environments for Reproductive Discussions

Marginalized groups, including 2SLGBTQI+ people, people with disabilities, ethnic or racialized minorities, and people from low socioeconomic classes face stigma and discrimination related to their sexual and reproductive health. For example, the erasure of the sexual and reproductive health of women with disabilities has been described through discourses of desexualization and infantilization (200). Discourses related to the sexual and reproductive behaviour of Black and Indigenous women have been used to question their parenting abilities and justify the separation of Indigenous parents in Canada from their children through Federal policies. Indigenous and Black families are more likely than White families to be subjected to child welfare investigations, and Indigenous and Black children are more likely to be placed in protective care (201).

Stigma and discrimination towards marginalized groups have informed reproductive healthcare practices. Society's perception of women living with HIV as promiscuous, irresponsible, and dirty has led to societal expectations that women living with HIV should not have children (101, 129). Non-consensual and coerced sterilization of women living with HIV, a direct reproductive rights infringement, has been documented globally (202). A study from Chile found widespread forced sterilization of women living with HIV (203): among the population of women living with HIV who were sterilized, 12.9% had been sterilized without consent, including the case of a woman who was unaware that she was sterilized during a cesarean section. An additional 29% of sterilized women living with HIV had consented to sterilization under coercion.

Fear of stigma and judgement, particularly in non-HIV specialized settings represent additional barriers to reproductive healthcare access for women living with HIV (79, 199, 204, 205). Conscious and unconscious biases and assumptions about the care needs and priorities of women living with HIV can negatively impact the quality of care provided. Non-consensual disclosure of HIV status and privacy violations have been cited by Black women living with HIV in the United States as contributing to shame, guilt, and mistrust of healthcare providers and the healthcare system (206). Anticipated stigma in healthcare settings has also been found to hinder engagement in HIV care (207, 208). These factors can hinder women's willingness to discuss sexual and reproductive health topics in the healthcare setting. Destigmatizing approaches are therefore crucial for addressing reproductive healthcare.

A previous study examined social-structural factors associated with women living with HIV having their sexual and reproductive health priorities met by primary HIV care providers (209). They found that sexual, gender, and minority identity and HIV-related stigma experiences were negatively associated with having needs met, while accessing women-centred services was associated with having needs met. This dissertation research elaborates on the previous literature by being the only study known to attempt to map the direct and indirect causal pathways between features of healthcare delivery and reproductive health outcomes in Canada among women living with HIV. Using causal mediation analysis, I describe not only that women were more likely to discuss their reproductive goals if receiving HIV care from healthcare providers who were women, but also that this was significantly mediated by women's comfort with their providers. Participants receiving HIV care from a woman provider had 4.22 times higher adjusted odds (95%CI: 2.74, 6.55) of feeling comfortable discussing their reproductive goals. Women who reported currently having a healthcare provider with whom they felt comfortable discussing their reproductive goals had 2.21 times higher adjusted odds (95%CI: 1.28, 3.82) of discussing their reproductive goals between baseline and 18 months, suggesting that interventions that improve patient comfort could help to increase the prevalence of discussions and to better support pregnancy intention and reproductive goals as they evolve. These findings highlight the importance of creating a comfortable environment for marginalized patients to discuss sensitive or stigmatized topics with their healthcare providers.

The same analysis found women receiving care from a woman HIV care provider were more likely to report feeling comfortable discussing their reproductive goals. Among women whose primary HIV provider was a woman, 70.6% of participants reported feeling comfortable, compared to 36.4% of participants whose provider was a man. While healthcare providers who identify as men can still provide excellent care, they may need to be more conscious about prioritizing building rapport, fostering a safe space, and creating a comfortable environment for patients to support these discussions. Strategies mentioned in the manuscript to address comfort include normalizing the subject through implicit and explicit clinic messaging and promoting patient self-efficacy so patients feel empowered to share their goals.

7.2.3. The Role of Gender in Shaping Women's Satisfaction with HIV Care

Creating safe and supportive environments and normalizing conversations about sexual and reproductive health are critical steps for de-stigmatizing these areas of healthcare for women living with HIV. These approaches can help to reduce the stigma that women living with HIV often experience in the healthcare setting and support their self-determination. By providing safe environments where sexual and reproductive health and rights are normalized, healthcare providers can support women living with HIV to make informed decisions about their bodies and futures. This may help to reduce shame, isolation, and discrimination, while promoting overall health and well-being. By reframing healthcare approaches around self-determination, reproductive justice, and sexual pleasure rather than deficits, such as risks of HIV transmission, healthcare providers can help to create a more equitable and inclusive healthcare system. The findings from the first two studies pointed to the importance of the care environment, including comfort with care providers, in supporting the reproductive health of women living with HIV.

The third study, presented in Chapter 6, aimed to determine the important factors and causal pathways that influence women's satisfaction with HIV care, through a gendered lens. In this study, I used fuzzy cognitive mapping to ground existing evidence on satisfaction with HIV care in the knowledge and expertise of 23 women living with HIV in two Canadian provinces. Using an iterative process to integrate existing literature and new insights from the experiential knowledge of women living with HIV, we found that a safe and supportive care environment was the most important and central consideration in women's satisfaction with care. This novel use of fuzzy cognitive mapping contributed to our theoretical understanding of how satisfaction is shaped by gendered social and health considerations, including women's unique social and health contexts, empowerment and self-care, partners and family involvement in care, and care that evolves with women's needs over the life course. Considering the important role of gender in shaping satisfaction, the study results advance our understanding of the priorities of women living with HIV. This understanding is essential for providing health services that reduce gendered disparities in HIV care. Findings from this dissertation support the need for care approaches that create a safe and supportive environment for self-determination and self-efficacy.

7.2.4. Aligning Services with the Needs of Marginalized Groups

Pregnancy is often the catalyst for women living with HIV to seek out and access the information and support they need. Still, this approach misses opportunities to support women living with HIV in reproductive decision-making, safe conception planning, and family planning. The first study revealed that pregnancy intentions were not strongly predictive of future pregnancies, suggesting other considerations may be more important drivers of pregnancy incidence among women living with HIV. Findings from the second study indicate that reproductive discussions to support women's reproductive goals depend on how comfortable women feel engaging in those discussions with healthcare providers. The reproductive decisions made by women living with HIV may at times be perceived within the healthcare system or in society as counter to social norms and expectations (120, 129, 130, 198, 199). These discussions may be difficult for women living with HIV to engage in with their care providers. These findings align with previous research indicating that the high prevalence of trauma experiences among women living with HIV demands trauma-aware approaches to healthcare delivery (210). A greater focus on patient comfort on the side of the provider can foster safe spaces for these discussions.

While evidence-based clinical guidelines have emerged to help destigmatize aspects of sexual and reproductive health and rights for women living with HIV (25), barriers to reproductive healthcare extend beyond the simple disclosure of wanting a child or seeking contraception. Issues accessing reproductive healthcare are one manifestation of the larger complex social, cultural, personal, and relationship contexts that influence women's reproductive intentions and priorities. As previously discussed, these intentions and priorities may diverge from societal expectations, making it more challenging for women living with HIV to openly articulate their needs to a healthcare provider. Furthermore, excluding women's voices in the design of health services has contributed to an absence of reproductive healthcare in HIV care and disempowerment in reproductive self-determination. Not only have women living with HIV been excluded from our understanding of comprehensive HIV care needs, but social and structural barriers also challenge women's voices from being heard in healthcare settings (211). Addressing the factors influencing women's reproductive intentions requires a patient-centred, trauma-informed approach.

A patient-centred approach is touted as a central tenet of primary care practice (110, 212). Within family medicine and primary care, many physicians, however, are not trained or comfortable providing sexual and reproductive healthcare to women living with HIV, who represent a small percentage of the patient population seen in family medicine. Women living with

HIV are further overlooked due to social marginalization. Even among more experienced or specialized providers, sexual and reproductive health and rights have not historically been a significant consideration in healthcare delivery for this population (103). Addressing the reproductive care needs of women living with HIV requires better collaboration between primary and specialized care providers.

Another barrier to reproductive healthcare delivery identified in this dissertation is the intersection of social and medical hierarchies. As previously discussed, healthcare providers have historically dismissed women's reproductive autonomy, needs, and priorities through practices such as forced or coerced sterilization. The findings in Chapter 5 highlight the role of gendered power dynamics in healthcare settings. Healthcare provider-patient gender discordance was associated with decreased likelihood of women feeling comfortable discussing reproductive goals. This association demonstrates the role of gendered power dynamics in establishing trust and comfort with care providers and consequently delivering appropriate reproductive care. In a study of women living with HIV accessing care in British Columbia, Canada, sexual minority identity and gender minority status were associated with lower odds of having reproductive health priorities met (209). Gendered power dynamics in clinical settings also intersect with other power axes and social locations to influence self-determination and access to supportive reproductive healthcare. Many women living with HIV are located at the intersection of power imbalances related to their race, sexual orientation, ability, and socioeconomic status, which all influence one another and affect women's ability to seek and receive the healthcare that aligns with their priorities (211).

7.3 Unique Contributions of this Dissertation and Limitations

7.3.1. Contributions to Participatory Methodology

As previously elaborated in the Methodology chapter, this dissertation research took place within the larger community-based participatory research project, CHIWOS. The participatory approaches developed as part of that project have been described in the literature (103, 213). The use of fuzzy cognitive mapping through a gendered lens in this dissertation research represents a novel approach to the systematic integration of existing literature with the experiential expertise of women living with HIV. Through fuzzy cognitive mapping, I was able to capture stakeholder perspectives on the role of gendered social and health considerations in HIV-positive women's pregnancy intentions, reproductive health-seeking behaviour, and satisfaction with care, filling a gap in existing literature. Fuzzy cognitive mapping allowed for the creation of a visual representation of the complex relationships between various factors that influence satisfaction with healthcare among women living with HIV. This approach also provided a nuanced and contexualized understanding of the interactions between individual social and structural factors that affect women's access to and utilization of reproductive healthcare services. The application of participatory approaches involving the co-construction of the research process with women living with HIV, including data analysis, grounded and contextualized the scientific findings and contributed to the trustworthiness of the data. Preliminary findings were presented to study participants through member-checking focus group discussions to ensure further trustworthiness, validating the constructed sense-making maps that show the importance of relationships. This method offers a unique and valuable contribution to health equity research by demonstrating an innovative approach to studying the intersection of gendered social determinants of health.

The methods used in this dissertation offer researchers an example of a participatory approach to constructing and analyzing the qualitative and quantitative data generated through fuzzy cognitive mapping. The fuzzy cognitive mapping data were constructed and analyzed in collaboration with Peer Research Associates. We combined individual maps, which required qualitative content analysis. This led to the generation of categories describing groups of related factors. Although this approach may be more time-consuming for researchers, and has the potential to be taxing on participants, it augments the richness and contextualization of the data and interpretations. To mitigate potential participant fatigue, we began the map construction by asking participants to first generate factors and specify their causal relationships. Next participants began by assigning weights to the relationships they deemed were most important. In a few instances, participants became a bit fatigued, and we ended the interviews before every relationship was weighted. By having the most important relationships weighted first, we ensured these weights would be accurately represented in the quantitative analysis. Any missing quantitative data, which were imputed, represented those less important to participants.

The dissertation findings can guide future studies, informing survey designs, measurement of important variables, and informing causal models and interpretations. The maps can be used to communicate study findings to other stakeholders, such as healthcare providers, administrators, and those involved in organizing and funding healthcare services. The methodological approach outlined provides a systematic approach that researchers can use to integrate stakeholder perspectives and existing literature, grounding evidence in stakeholder knowledge and experiences.

7.3.2. Methodologic Implications of the COVID-19 Pandemic

A portion of this dissertation research occurred during the COVID-19 pandemic. The pandemic impacted research practices, particularly in the realm of qualitative research methods, which often rely on in-person interactions and observations. Like many researchers conducting qualitative research during the pandemic, I adapted the research protocols of this dissertation to accommodate physical distancing requirements.

The fuzzy cognitive mapping interviews and focus groups were conducted using virtual platforms. This approach allowed us to reach participants who might have been excluded from the research had the interviews and focus groups occurred in person. These included women living with HIV in more geographically remote areas, those with disabilities, and those with mobility limitations. We used video conference platforms to maintain social interaction while adhering to physical distancing guidelines imposed during the COVID-19 pandemic. Furthermore, we interviewed participants who preferred to remain anonymous by using only the audio feature of our video conferencing platform. This flexibility expanded the population of women who were willing to participate in our qualitative study.

In addition to virtual data collection methods, I adapted our qualitative data analysis approach. Traditional methods of qualitative data analysis often include in-person coding and team meetings to discuss, interpret, and categorize latent content (214). In the case of this dissertation research, meetings to discuss and consolidate codes occurred using virtual and asynchronous platforms. We took advantage of cloud-based tools to support our research team which included members from across Canada to share and collaborate on data analysis remotely. We complemented these approaches with regular virtual conference meetings with the research team where we would participate in reflexive discussion and iteratively adjust our codes and categories.

The shift to virtual methods of data collection and analysis in this dissertation posed several challenges that required careful considerations and measures to address. Ensuring the privacy, safety, and confidentiality of participants and their data was paramount. To achieve this, a range of protective measures were implemented by members of the research team. We were sensitive to the risks of HIV disclosure in email correspondence with participants. In invitation emails and videoconferencing organization with participants and Peer Research Associates, we avoided using language that could potentially lead to nonconsensual HIV disclosure if these emails were read by people other than the study participants. Prior to the videoconferencing calls, we emphasized the importance of our research team and participants conducting the calls in areas where discussions would not be overheard by others in their surrounding environments, again to mitigate the risk of unintentional disclosure or breaches of confidentiality. We took precautions including using secure video conference platforms and providing participants with instructions on how to ensure their privacy during virtual interviews. Furthermore, secure video conferencing platforms were carefully selected to ensure participant confidentiality during virtual interactions and minimize the risk of unauthorized access.

Many of the tools and approaches adopted in this dissertation research can improve collaboration between research team members and can support collaboration between diverse research teams, including engaging more marginalized populations in participatory research. For example, asynchronous and remote research platforms engage patient-partners through more flexible work hours and demands. Additionally, we connected our Indigenous participants in British

Columbia and Quebec with an Indigenous Elder to ensure follow-up after interviews that often touched on sensitive topics. Remote connection widened the options for engagement for patient-partnership and study participation.

7.3.3. Limitations

Limitations of this dissertation include the absence of transwomen and the small sample of Indigenous women in the fuzzy cognitive mapping study. Previous research using qualitative, quantitative, and mixed methods approaches (58) has examined the experiences of transwomen living with HIV accessing HIV and gender-affirming healthcare in Canada. The goal of this dissertation was not to generalize findings to all women living with HIV, but rather to describe the factors that contribute to satisfying HIV care among a sample of diverse women living with HIV and identify the mechanisms which these factors lead to satisfaction. The findings, however, may not represent the unique health considerations or experiences of trans or Indigenous women. Additional research is needed to ensure that these unique experiences are represented in our understanding of the realities of reproductive healthcare among trans and Indigenous women in Canada.

This dissertation focused on the perspectives and care priorities of women living with HIV. Healthcare providers are also key stakeholders in healthcare delivery but were not surveyed or interviewed as part of this research, as the aim was to centre voices historically excluded from research and healthcare. Future studies should examine care priorities from the perspective of healthcare providers, comparing how patient and provider priorities align or diverge and how this affects gaps in reproductive healthcare delivery. Healthcare provider perspectives would also help elucidate the reasons for the observed differences in patient comfort when discussing reproductive goals with healthcare providers who are women versus men.

Despite the important findings that emerged through the use and integration of social determinants of health, intersectional, and reproductive justice theoretical framings, their application was limited. For instance, although the important variables examined quantitatively in Chapter 4 and 5 reflected axes of social power, such as gender differences between patients and providers and comfort with providers, the statistical analysis did not parse the intersectional effects of different power axes across multiple intersections (92), as this was not our aim. Furthermore, while this dissertation contributes to our understanding of contemporary reproductive healthcare needs and priorities among women living with HIV, other aspects of reproductive health—for example, infant feeding—were relatively unexplored. In the Global North, clinical practice guidelines recommend women living with HIV formula feed their infants, whereas in the Global South healthcare agencies recommend women living with HIV breast feed their infants to reduce risks of illness from contaminated water used in formula preparation (159). This has complex social implications, particularly for women living with HIV who immigrate from the Global South to the North, where cultural practices and expectations complicate their decisions on which recommendations to follow. These issues raise important health policy considerations related to support for women's reproductive autonomy. While infant feeding practices were not the focus of this dissertation research, it is relevant in the contemporary reproductive health landscape for women living with HIV in Canada, particularly at the intersection of gender, HIV, and culture (215). Other aspects relevant to discussions around reproductive health needs and priorities might include support for infertility treatment and care. However, this was outside the scope of this dissertation.

7.4 Implications for Health Research, Policy, and Practice

7.4.1. Research Contributions

This dissertation research is the first known study examining pregnancy intentions longitudinally among a cohort of women living with HIV in Canada, and it revealed significant fluidity in intentions that need to be considered in healthcare delivery. Situated within the current literature on features of the healthcare environment that centre women's health needs, the findings support research into women living with HIV and their contemporary reproductive health needs and priorities. Reproductive health includes a broad range of considerations. The dissertation also describes frameworks and methodology that may be useful for future research aimed at understanding the experiences of women living with HIV in decision-making around other aspects of reproductive healthcare.

Future research should aim to further study the concepts of comfort and safety as they pertain to healthcare providers and healthcare settings. Feeling comfortable with a healthcare provider was an important predictor of reproductive discussions. Comfort functioned as a mediator, and hence a point of intervention for healthcare providers, particularly those who identify or present as men. Future work should investigate interventions that increase women's feelings of comfort in engaging in reproductive discussions and should develop strategies to evaluate patient safety and support in the context of healthcare delivery. This is particularly relevant for healthcare delivery for women living with HIV given the high lifetime prevalence of trauma in this population (210).

This dissertation combined reproductive justice and social determinants of health frameworks along with community-based participatory approaches. The application of these frameworks allowed an examination of power-dynamics in the reproductive healthcare experiences of women living with HIV. The frameworks elucidated the role of patient-provider relationships in the delivery of care and grounded existing evidence within the context of women's lived experiences and knowledge, a context sparsely captured in the literature.

The reproductive justice framework considers not only the rights to have children under the conditions of one's choosing or not have children but also the right to parent children in safe and supportive environments. Questions pertaining to how health service delivery supports the parenting rights of women living with HIV were beyond the scope of this dissertation, despite their relevance to reproductive health. Through this framework, this dissertation research interpreted reproductive self-determination as a marker of health equity. This dissertation focused on pregnancy intentions and pregnancy planning. This framing of reproductive health and rights through the reproductive justice framework is also consistent with a critical health equity stance (169). This stance focuses on the social-structural determinants of health, rather than conceptualizing health as a function of individual characteristics and behaviours. Healthcare that acknowledges these stigmatizing experiences, and aims to redress them though information support and nonjudgmental healthcare, supports reproductive justice for women living with HIV.

This dissertation applied a social determinants of health framework that acknowledges the notion of intersectionality. As previously described in this dissertation, intersectionality is an appropriate social theory to contextualize the healthcare experiences of women living with HIV who navigate multiple marginalized identities. The theorizing—including the application of a reproductive justice lens, participant recruitment, data collection, and interpretations—considered the intersectional social determinants of reproductive healthcare needs. Consistent with intersectional health equity theory, previously elaborated by Bowleg (216), our conceptualization of intersectional determinants of health assumes that many intersecting axes cannot be teased apart and attempting to do so would lead to inaccurate interpretations of the role of gender in reproductive health needs and priorities for women living with HIV. Further intersectional theorizing in this dissertation and in future research might explore the intersections of gender with race or immigration experiences. For example, future research may examine reproductive health priorities among immigrant African, Caribbean, and Black women and those born in Canada or between gender minority Indigenous women and cis Indigenous women.

7.4.2. Health Policy Implications

This dissertation has several implications for health policy aimed at improving health equity. The findings from this dissertation are grounded and contextualized in the experiences of marginalized communities, whose needs are not sufficiently addressed by existing healthcare system design.

The first policy implication pertains to reproductive healthcare guidelines for women living with HIV, including safe conception and family planning. As previously mentioned, existing guidelines have either focused narrowly on reducing HIV transmission risk, excluded the voices of women living with HIV, or have considered reproductive intentions among women living with HIV as static (217). This dissertation research adopted a reproductive justice lens considering reproductive needs and priorities more broadly, centred the experiential expertise of women living with HIV, and considered the dynamic nature of reproductive decision-making. In fact, the findings from this dissertation research have already been cited in two recently published guidelines, the first aimed at developing a national action plan to advance the sexual and reproductive health and rights of women living with HIV in Canada (218) and the second aimed at supporting healthcare providers in counselling patients on aspects of reproductive health (146). The guidelines aimed to address gaps in reproductive discussions, which were identified in this dissertation research, and to advance the provision of healthcare delivery that aligns with the priorities of women. Recommendations include ongoing reflexivity and attentiveness to and disruption of power imbalances between women living with HIV and their care providers to foster more egalitarian relationships (218). The findings from this dissertation, which described diverse and dynamic pregnancy intentions, were directly cited as a need for integrating ongoing discussions about HIV-positive women's reproductive desires in clinical care and the need to anticipate the risk of unintended pregnancy when prescribing ART regimens to avoid potential teratogenic side effects (146).

The second policy implication of this dissertation relates to the importance of training and supporting healthcare providers in patient-centred care. Training should emphasize creating environments where marginalized patients feel safe and comfortable disclosing sensitive and stigmatized topics and ensuring patients have access to evidence-based counselling and care. Additionally, policymakers play an important role in supporting reproductive justice by addressing the social and structural barriers that prevent marginalized populations from accessing reproductive healthcare. Health policy should consider the intersectional stigma faced by marginalized communities. Meaningful engagement of marginalized populations from diverse backgrounds, experiences, and circumstances is needed in the design, organization, implementation, and evaluation of health services. Peer support models have previously been described in the literature to support the meaningful engagement of women living with HIV in healthcare and research (107, 179). These models can be adapted to engage women at intersections of systemic racism, colonialism, sexism, and poverty. Furthermore, public policy can help challenge normative conceptions about the types of people who are afforded their reproductive rights and those deemed ‘unfit.’

7.4.3. Contributions to Health Service and Primary Care Delivery

In Canada, primary care settings are conceptually the main point of access for comprehensive health services. An opportunity exists to address gaps in reproductive healthcare for women living with HIV, through better integration of sexual and reproductive healthcare and HIV care in primary care settings. The findings of this dissertation have pragmatic relevance for health services delivery, particularly the provision of sexual and reproductive healthcare through primary care for women living with HIV. High rates of unplanned pregnancies and changes in pregnancy intentions underscore the need for regular discussions between patients and their healthcare providers about their reproductive goals. Primary care providers are well positioned to address sexual and reproductive health through counselling or appropriate referrals; however, adequate awareness about sexual health in the context of HIV is essential to ensure non-stigmatizing and evidence-based support, as previous studies have demonstrated that HIV care providers’ biases negatively impact patient care (24, 207).

Clinical guidelines have already been developed to support healthcare providers in the provision of evidence-based care and are accessible for primary care providers and other specialists providing care to women living with HIV (25, 150, 151). In response to the need for non-stigmatizing healthcare, results from this dissertation build on existing knowledge on women-centred healthcare (219) by identifying strategies for care providers to foster an environment where women living with HIV feel their needs are prioritized. Primary care providers play a critical role in reproductive decision-making for women living with HIV and, given the importance women in this research placed on safety and support, they should aim to establish a non-judgmental relationship with patients to destigmatize HIV and sexuality in the healthcare context. Providers should also keep in mind that reproductive goals are dynamic and regularly revising reproductive discussions is needed to account for changing reproductive intentions.

Primary care providers may be a first line of support in reproductive decision-making for women living with HIV. Healthcare providers should be aware of the role of stigma and power dynamics in reproductive decision-making and self-determination (130). The findings from this dissertation extend and have broader implications in primary care and the delivery of sexual and reproductive healthcare for patients living with chronic health conditions, such as physical or mental disabilities, where sexuality and reproduction are also often stigmatized or overlooked (200). The results of this study provide insights that may be relevant for improving the integration of sexual and reproductive health and primary care for these patients.

Women living with HIV value comfort and non-stigmatizing relationships with their healthcare providers, which support seeking, and remaining engaged in, healthcare. As revealed by this dissertation's findings, feeling safe and supported by clinics and healthcare providers is the most important factor influencing satisfaction with HIV care. Considering the high prevalence of trauma among women living with HIV (127), the role of safety and comfort is consistent with previous studies that support the need for trauma-informed approaches to healthcare delivery (210, 220). By establishing trusting relationships with their patients, primary care providers can help to address disparities in healthcare delivery and health outcomes for women living with HIV and other marginalized populations. These relationships between women and their care providers can help support self-efficacy and facilitate the navigation between different healthcare providers and services (221).

7.5 Conclusions

The three studies comprising this dissertation research provide greater insight into the contemporary reproductive health realities faced by women living with HIV in Canada. By examining the intersection between stigma, marginalization, and health service organization, this research highlights the challenges women encounter in accessing healthcare that aligns with their goals and needs. An important contribution of this dissertation stems from its unique approach to engaging women living with HIV actively in the knowledge-generation process. By co-constructing strategies alongside women living with HIV, this research not only identifies and contextualizes current gaps in reproductive healthcare but also offers pragmatic solutions grounded in the experiential expertise of women living with HIV. This approach offers implications for patient care, epidemiologic, and health systems research by emphasizing the importance of grounded evidence in the knowledge and experience of marginalized populations. Healthcare that prioritizes patient safety and comfort can help to address the stigma that impedes appropriate sexual and reproductive health care for these populations. Research underpinning these healthcare approaches should be grounded in the knowledge and experience of marginalized populations to ensure strategies address inequities in health service delivery for marginalized groups in Canada.

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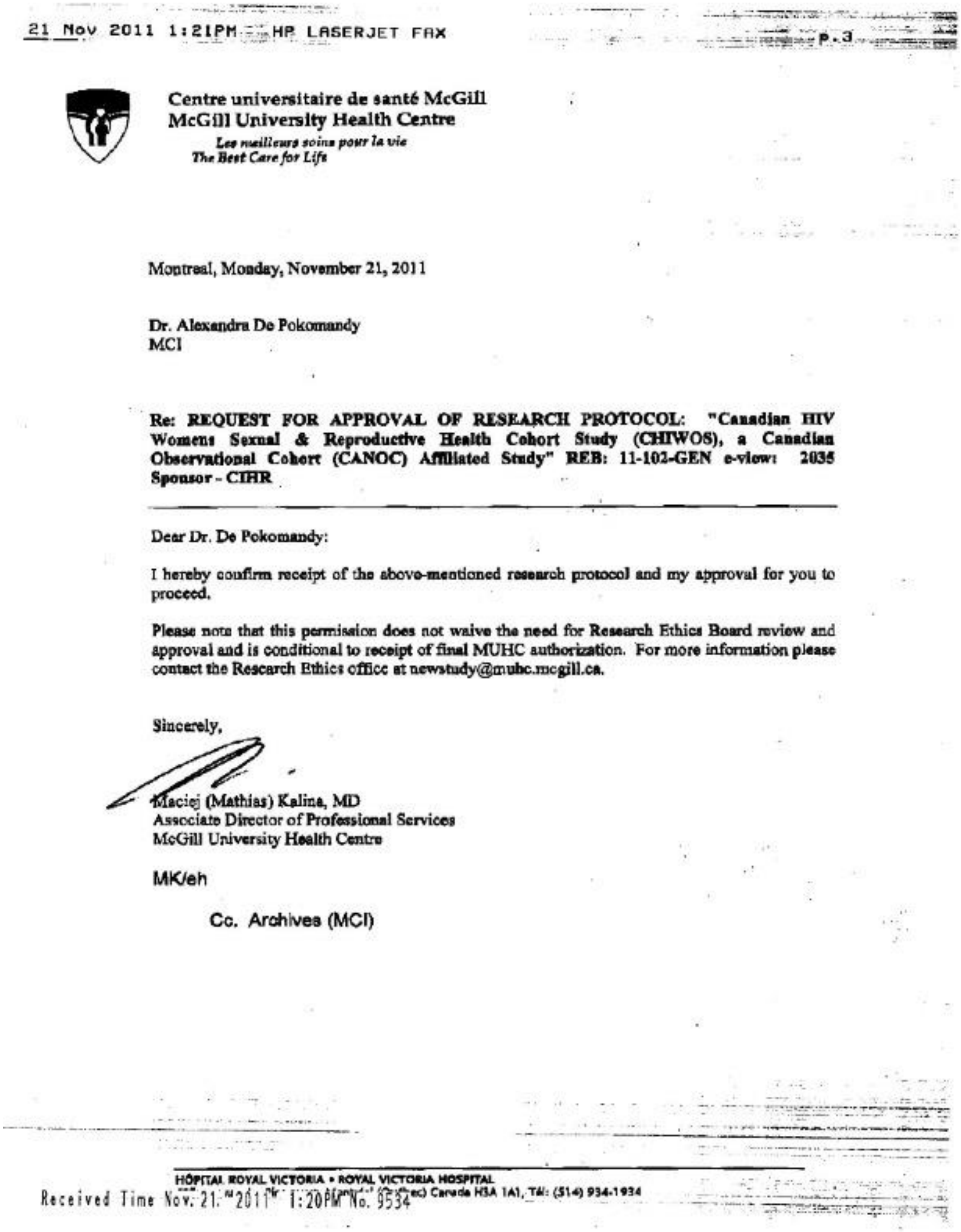
Appendices

Appendix A: Ethics approvals

CHIWOS study ethics approval



Centre universitaire de santé McGill
McGill University Health Centre
Les meilleurs soins pour la vie
The Best Care for Life

Montreal, Monday, November 21, 2011

Dr. Alexandra De Pokomandy
MCI

Re: REQUEST FOR APPROVAL OF RESEARCH PROTOCOL: "Canadian HIV Womens Sexual & Reproductive Health Cohort Study (CHIWOS), a Canadian Observational Cohort (CANOC) Affiliated Study" REB: 11-102-GEN e-view: 2035 Sponsor - CIHR

Dear Dr. De Pokomandy:

I hereby confirm receipt of the above-mentioned research protocol and my approval for you to proceed.

Please note that this permission does not waive the need for Research Ethics Board review and approval and is conditional to receipt of final MUHC authorization. For more information please contact the Research Ethics office at newstudy@muhc.mcgill.ca.

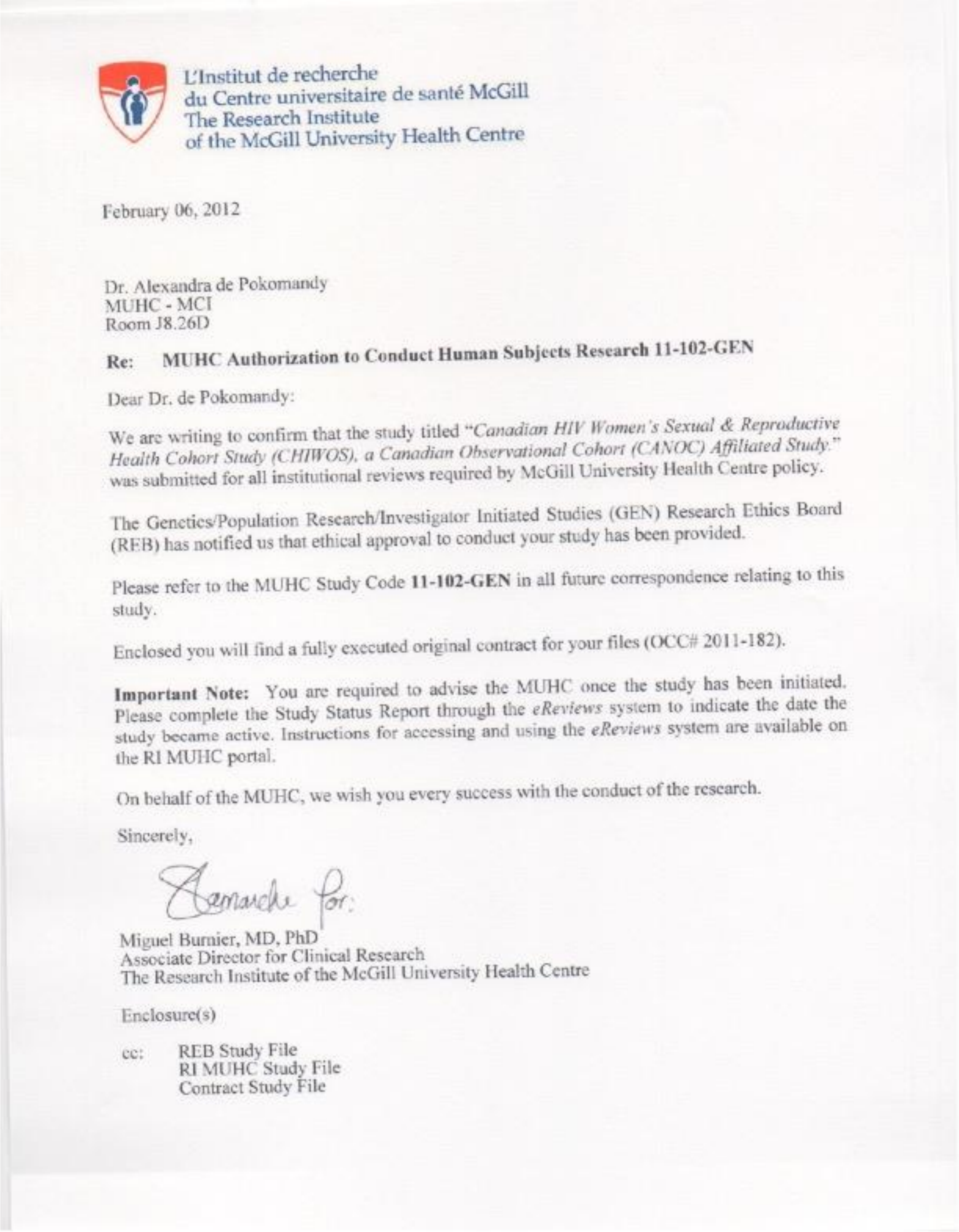
Sincerely,

Maciej (Mathias) Kalina, MD
Associate Director of Professional Services
McGill University Health Centre

MK/eh

Cc. Archives (MCI)

Received Time Nov. 21. 2011 1:20PM No. 9534



L'Institut de recherche
du Centre universitaire de santé McGill
The Research Institute
of the McGill University Health Centre

February 06, 2012

Dr. Alexandra de Pokomandy
MUHC - MCI
Room J8.26D

Re: MUHC Authorization to Conduct Human Subjects Research 11-102-GEN

Dear Dr. de Pokomandy:

We are writing to confirm that the study titled "*Canadian HIV Women's Sexual & Reproductive Health Cohort Study (CHIWOS), a Canadian Observational Cohort (CANOC) Affiliated Study.*" was submitted for all institutional reviews required by McGill University Health Centre policy.

The Genetics/Population Research/Investigator Initiated Studies (GEN) Research Ethics Board (REB) has notified us that ethical approval to conduct your study has been provided.

Please refer to the MUHC Study Code **11-102-GEN** in all future correspondence relating to this study.

Enclosed you will find a fully executed original contract for your files (OCC# 2011-182).

Important Note: You are required to advise the MUHC once the study has been initiated. Please complete the Study Status Report through the *eReviews* system to indicate the date the study became active. Instructions for accessing and using the *eReviews* system are available on the RI MUHC portal.

On behalf of the MUHC, we wish you every success with the conduct of the research.

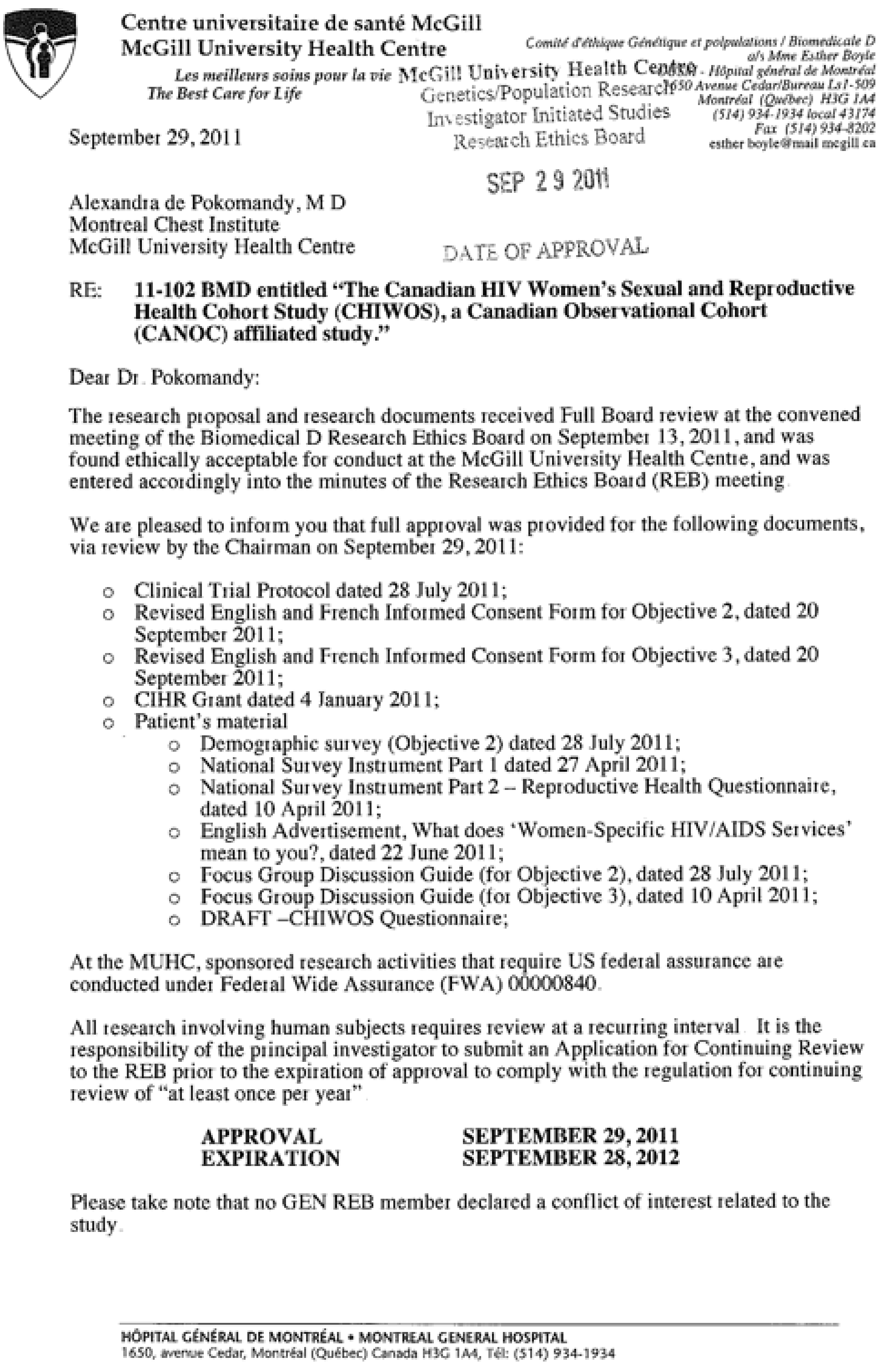
Sincerely,

Lamarche for:

Miguel Burnier, MD, PhD
Associate Director for Clinical Research
The Research Institute of the McGill University Health Centre

Enclosure(s)

cc: REB Study File
RI MUHC Study File
Contract Study File



Centre universitaire de santé McGill
McGill University Health Centre
Les meilleurs soins pour la vie
The Best Care for Life

Comité d'éthique Génétique et polpulations / Biomedicale D
a/s Mme Esther Boyle
CUSM - Hôpital général de Montréal
1650 Avenue Cedar/Bureau Ls1-509
Montréal (Québec) H3G 1A4
(514) 934-1934 local 43174
Fax (514) 934-8202
esther boyle@mail mcgill ca

McGill University Health Centre
Genetics/Population Research
Investigator Initiated Studies
Research Ethics Board
SEP 29 2011
DATE OF APPROVAL

September 29, 2011

Alexandra de Pokomandy, M D
Montreal Chest Institute
McGill University Health Centre

RE: **11-102 BMD entitled "The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), a Canadian Observational Cohort (CANOC) affiliated study."**

Dear Dr. Pokomandy:

The research proposal and research documents received Full Board review at the convened meeting of the Biomedical D Research Ethics Board on September 13, 2011, and was found ethically acceptable for conduct at the McGill University Health Centre, and was entered accordingly into the minutes of the Research Ethics Board (REB) meeting.

We are pleased to inform you that full approval was provided for the following documents, via review by the Chairman on September 29, 2011:

- Clinical Trial Protocol dated 28 July 2011;
- Revised English and French Informed Consent Form for Objective 2, dated 20 September 2011;
- Revised English and French Informed Consent Form for Objective 3, dated 20 September 2011;
- CIHR Grant dated 4 January 2011;
- Patient's material
    - Demographic survey (Objective 2) dated 28 July 2011;
    - National Survey Instrument Part 1 dated 27 April 2011;
    - National Survey Instrument Part 2 – Reproductive Health Questionnaire, dated 10 April 2011;
    - English Advertisement, What does 'Women-Specific HIV/AIDS Services' mean to you?, dated 22 June 2011;
    - Focus Group Discussion Guide (for Objective 2), dated 28 July 2011;
    - Focus Group Discussion Guide (for Objective 3), dated 10 April 2011;
    - DRAFT –CHIWOS Questionnaire;

At the MUHC, sponsored research activities that require US federal assurance are conducted under Federal Wide Assurance (FWA) 00000840.

All research involving human subjects requires review at a recurring interval. It is the responsibility of the principal investigator to submit an Application for Continuing Review to the REB prior to the expiration of approval to comply with the regulation for continuing review of "at least once per year".

APPROVAL	**SEPTEMBER 29, 2011**
EXPIRATION	**SEPTEMBER 28, 2012**

Please take note that no GEN REB member declared a conflict of interest related to the study.

HÔPITAL GÉNÉRAL DE MONTRÉAL • MONTREAL GENERAL HOSPITAL
1650, avenue Cedar, Montréal (Québec) Canada H3G 1A4, Tél: (514) 934-1934

Fuzzy Cognitive Mapping study ethics approval

UBC Behavioural Research Ethics Board

Certificate of Ethical Approval for Harmonized Minimal Risk Behavioural Study

The University of British Columbia
Behavioural Research Ethics Board
#102, 6190 Agronomy Road
Vancouver, BC V6T 1Z3

Also reviewed and approved by:

- **Simon Fraser University**

Principal Investigator:	Primary Appointment:	Board of Record REB Number: Board of Record:	UBC REB Number:
Angela Kaida	UBC/Medicine, Faculty of/Medicine, Department of	UBC Behavioural Research Ethics Board	H20-03264

Study Title:
Exploring predictors of women’s overall satisfaction with their HIV care

Study Approved: November 16, 2020 **Expiry Date: November 16, 2021**

Research Team Members: N/A

Sponsoring Agencies: - Canadian Institutes of Health Research (CIHR) - "SPOR Evidence Alliance via Saint Michael's Hospital"

Documents included in this approval:

Document Name	Version	Date
Protocol:		
Fuzzy Cognitive Mapping Protocol Oct 2020	N/A	October 28, 2020
Consent Forms:		
Fuzzy Cognitive Mapping ICF English Nov 2020	N/A	November 6, 2020
Fuzzy Cognitive Mapping ICF French	N/A	November 6, 2020
Advertisements:		
Fuzzy Cognitive Mapping Recruitment Script - English	N/A	October 28, 2020
Fuzzy Cognitive Mapping Recruitment Script - FRENCH	N/A	October 28, 2020
Questionnaire, Questionnaire Cover Letter, Tests:		
Fuzzy Cognitive Mapping Focus Group Script - English	N/A	October 28, 2020
Fuzzy Cognitive Mapping Interview Guide French	N/A	September 10, 2020
Fuzzy Cognitive Mapping Interview Guide Sept 2020	N/A	September 10, 2020
Fuzzy Cognitive Mapping Focus Group Script - French	N/A	October 28, 2020
Other Documents:		
Fuzzy Cognitive Mapping Demographic Survey French	N/A	June 19, 2020
Fuzzy Cognitive Mapping Demographic Survey	N/A	June 19, 2020

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2020-09-21

Dr. Alexandra De Pokomandy
Infectious Diseases and Immunity in Global Health Program
c/o: Hansi Peiris
email: hansi.peiris@muhc.mcgill.ca

RE: Final REB Approval of a New Research Project
Exploring predictors of women's overall satisfaction with their HIV care
(CHIWOS Substudy FCM / 2021-6824)

MUHC REB Co-Chair for the CTGQ panel: Me Marie Hirtle

Dear Dr. De Pokomandy,

Thank you for submitting your responses and corrections for the research project indicated above, as requested by the McGill University Health Centre (MUHC) Research Ethics Board (REB).

The MUHC REB, more precisely its Cells, Tissues, Genetics & Qualitative (CTGQ) research panel provided conditional approval for the research project after a delegated review provided by its member(s).

On 2020-09-21, a delegated review of your responses and corrections was provided by member(s) of the MUHC REB. The research project was found to meet scientific and ethical standards for conduct at the MUHC.

The following documents were approved or acknowledged by the MUHC REB:

- Initial Submission Form (F11NIR-60353)
- REB Conditions & PI Responses Form(s) (F20-60656 F20-64309)
- Consent form
    - (ICF_FR_Fuzzy Cognitive Mapping_21Sep2020_REBapproved.docx) [Date: 2020-09-21]
    - (ICF_ENG_Fuzzy Cognitive Mapping_21Sep2020_REBapproved.doc) [Date: 2020-09-21]
- Invitation letter
    - (FCM CHIWOS_Invitation Letter_10Sep2020_REBapproved.docx) [Date: 2020-09-10]
    - (FCM CHIWOS_FR_Invitation Letter_10Sep2020_REBapproved.docx) [Date: 2020-09-10]
- Interview Guide
    - (FCM Interview Guide_10Sep2020_REBapproved.docx) [Date: 2020-09-10]
    - (FCM Interview Guide_FR_10Sep2020_REBapproved.docx) [Date: 2020-09-10]
- Research Protocol
    - (Fuzzy Cognitive Mapping_MUHC Protocol_10Sep2020_REBapproved.docx) [Date: 2020-09-10]

This will be reported to the MUHC REB and will be entered accordingly into the minutes of the next CTGQ meeting. Please be advised that you may only initiate the study after all required reviews and decisions are received and documented and you have received the MUHC authorization letter.

The approval of the research project is valid until 2021-09-21.

Appendix B: Fuzzy Cognitive Mapping study materials

Participant invitation email

We are inviting you to take part in a research study because you participated in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS).

A PhD student and CHIWOS investigator from McGill University are interested in learning about your experiences accessing reproductive and HIV healthcare as a woman living with HIV. The main purpose of this study is to better understand your opinion about the healthcare you receive and how women, like yourself, living with HIV prioritize their reproductive healthcare among other aspects of their HIV care. This is something that is largely unknown in HIV research and healthcare.

If you agree to take part, your participation will include a 1-hour one-on-one confidential interview over video chat with the PhD student and a Peer Research Associate (a woman living with HIV who has completed training for this project). In the four months following your interview, we will reach out again to invite you to a 2-hour group discussion with 4-5 other women living with HIV, also over video chat, to share the early results of the study and hear what you have to say about the findings.

The researcher and the institution have received funding from the CIHR Strategy for Patient-Oriented Research Evidence Alliance to conduct this research project. For costs and inconveniences you experience during this study and to honour your expertise, you will receive compensation in the amount of $25 for the interview and $25 for the group discussion.

Would you like me to pass on your contact information (name and phone number or email) to the PhD student so that she can contact you?

Research Team Members:
Principle Investigator: Dr. Alexandra de Pokomandy, Associate Professor, McGill University Health Centre (Faculty supervisor)
Co-Investigators/Collaborators:
Lashanda Skerritt, PhD Candidate, Department of Family Medicine, McGill University
Dr. Angela Kaida, Associate Professor, Simon Fraser University, Canada Research Chair Tier II in Global Perspectives in HIV and Sexual and Reproductive Health
Édénia Savoie, Peer Research Associate, McGill University Health Centre
Dr. Nadia O'Brien, Post-Doctoral Fellow, Centre de recherche du Centre hospitalier de l'Université de Montréal (CR-CHUM)
Dr. Isabelle Boucoiran, Centre Hospitalier Universitaire Sainte-Justine, Université de Montréal
Dr. Mona Loutfy, Women's College Research Institute
Dr. Danielle Rouleau, Centre de Recherche de Centre Hospitalier de l'Université de Montreal (CR-CHUM)

Centre universitaire de santé McGill
McGill University Health Centre

INFORMATION AND CONSENT FORM

Research Study Title:	Exploring predictors of women’s overall satisfaction with their HIV care
Sponsor /Researcher responsible for the research study:	Dr. Alexandra de Pokomandy, Associate Professor, MUHC (Faculty supervisor)
Protocol Number:	2021-6824
Co-Investigator(s)/sites:	Lashanda Skerritt, PhD Candidate, Department of Family Medicine, Faculty of Medicine, McGill University (lashanda.skerritt@mail.mcgill.ca) Dr. Angela Kaida, Associate Professor, Simon Fraser University, Canada Research Chair Tier II in Global Perspectives in HIV and Sexual and Reproductive Health, (kangela@sfu.ca)
Collaborators:	Édénia Savoie, Peer Research Associate, MUHC Margarite Sánchez, Peer Research Associate, Simon Fraser University, Viva Women Dr. Nadia O’Brien, Post-Doctoral Fellow, Centre de recherche du Centre hospitalier de l’Université de Montréal (CRCHUM) (obrien.nadia@gmail.com) Dr. Isabelle Boucoiran, Centre Hospitalier Universitaire Sainte-Justine, Université de Montréal (isabelle@boucoiran.fr) Dr. Mona Loutfy, Women’s College Research Institute (mona.loutfy@wchospital.ca) Dr. Danielle Rouleau, Centre de Recherche de Centre Hospitalier de l’Université de Montreal (CRCHUM) (danielle.rouleau@umontreal.ca)
Funder:	CIHR Strategy for Patient-Oriented Research Evidence Alliance

INTRODUCTION

We are inviting you to take part in this research study because you are a woman living with HIV, at least 18 years of age, living in BC or Quebec. Before you agree to take part in this study and sign this information and consent form, please take the time to read, understand and carefully examine the following information. You may also want to discuss this study with your family doctor, a family member or a close friend. Please ask Lashanda Skerritt or any members of the research team any questions you may have about this study. Please also ask about any parts of this consent form you do not understand.

BACKGROUND

Women's experiences with reproductive and HIV healthcare are largely unknown. This study will ask you about your experiences accessing reproductive and HIV healthcare as a woman. This study is being undertaken as part of Lashanda Skerritt's PhD research. We will ask you for your verbal consent to participate in this study. The consent process will occur over Zoom, a secure videoconferencing platform.

PURPOSE OF THE STUDY

The main purpose of this study is to better understand how women living with HIV prioritize their reproductive healthcare among other aspects of their HIV care. This study also aims to understand how women living with HIV define 'satisfying HIV care' and the factors associated with receiving satisfying HIV care.

DESCRIPTION OF THE RESEARCH PROCEDURES

If you agree to take part in this study, your participation will include one 1-hour one-on-one interview over video chat and one 2-hour group discussion with up to 5 other women living with HIV, also over video chat. The group discussion will be held through a secure, free, and easy to use online meeting platform called Zoom. The interview and group discussion will be scheduled at a time and date that is convenient for you.

At the beginning of the interview, you will first be asked to complete a short confidential demographic questionnaire. The questionnaire will include questions on your age, gender identity, race/ethnicity, sexual orientation, relationship status, level of education, household income, year of HIV diagnosis, menopause status, contraceptive use, pregnancies since HIV diagnosis, and your desire to become pregnant in the future. This information will help the research team better understand the perspectives represented in the study.

Then, as part of your interview, a guided activity called Fuzzy Cognitive Mapping will be co-led by a Peer Research Associate (a woman living with HIV who has completed research training for this project) and a PhD student. During the activity, you will be asked to describe what satisfying HIV care means to you.

You will then be asked to identify factors that you associate with satisfying HIV care. The facilitators will draw these factors on a map in real-time and ask you to identify the connections between the factors. You will then be asked to rate the importance of each connection. At the end of the interview, you will have the opportunity to review and make changes to the map. Once you feel that the map reflects your knowledge of the subject, the individual mapping session will be complete.

After your interview, the research team will combine the Fuzzy Cognitive Maps of all the study participants to create one map. Within four months of completing your individual map, you will then be invited to participate in a group discussion, where we will present the combined map and ask you whether the map still reflects your ideas and understand of satisfying HIV care. You will have the opportunity to comment and discuss how the group map and factors and connections contributed by other women reflect or do not reflect your own knowledge and experiences. Your feedback will be used to make changes to the final map.

The time needed to participate in this study includes one 1-hour one-on-one interview over video chat (plus more time to first go through the consent process to participate in the study) and one 2-hour group discussion, also over video chat, for a total participation duration of approximately 3 hours.

PARTICIPANT’S RESPONSIBILITIES

Given the group format of the discussion, you will be asked to keep in confidence information and comments that could potentially identify any of the other participants.

BENEFITS ASSOCIATED WITH THE RESEARCH STUDY

There is no direct benefit to you for participating in this research. All participants will receive a copy of their personal Fuzzy Cognitive Map and the map combining the ideas and understanding of all participants. Additionally, we hope that the study results will contribute to the advancement of scientific knowledge in the study field and improved healthcare delivery for women living with HIV.

RISKS ASSOCIATED WITH THE RESEARCH STUDY

Due to the nature of group discussions, it is impossible to guarantee complete confidentiality as other members of the group will be aware of your identity. However, all participants are instructed to keep what is said during the session confidential, as mentioned in the “Participant’s Responsibilities” section. You may also choose not to participate in the group discussion and to review the group map in a one-on-one session with the facilitators instead.

Confidentiality cannot be absolutely guaranteed with the use of the videoconferencing platform Zoom.

To protect your privacy and confidentiality, we will be taking the following steps to make sure the platform is as secure as possible: 1) 24 hours before your interview and group discussion, we will send you a unique zoom link and password. Only those authorized to join the video chat will have access to the link and password. For your individual interview that includes you, the Peer Research Associate and the PhD student. For your group discussion that includes you, up to 5 other women living with HIV, the Peer Research Associate and the PhD student. 2) Once the video chat has begun, the PhD student will be able to control who enters the video chat. Those not listed above will not be able to enter.

If you find that particular questions or discussion make you uncomfortable, you can refuse to respond and/or choose to stop participating in the study altogether at any time. You do not have to give any reason for refusing to answer a question or for stopping to participate.

VOLUNTARY PARTICIPATION AND THE RIGHT TO WITHDRAW

Your participation in this study is completely voluntary. You may refuse to participate. You may also withdraw from the project at any time, without giving any reason, by informing a member of the study team. Your decision not to participate in the study, or to withdraw from it, will have no impact on the quality of care and services to which you are otherwise entitled. You will be informed in a timely manner if any information becomes available that may impact your willingness to continue participating in this study.

The researcher or the Research Ethics Board may put an end to your participation without your consent. This may happen if new findings or information indicate that participation is no longer in your best interest or if there are administrative reasons to terminate the project.

If you withdraw or are withdrawn from the study, you may also request that the data already collected about you be removed from the study. If you request that your data be removed, it will be destroyed.

CONFIDENTIALITY, DATA STORAGE AND SECURITY

During your participation in this study, the researcher and her team will collect and record information about you. They will only collect information necessary for the study from the questionnaire, the interview and the discussion. The interview and discussion will be audio recorded. All audio-recordings will be transcribed (your words will be written down) in a de-identified fashion (i.e. your name or other identifying details will not appear in the transcripts). The audio-recordings will then be destroyed (permanently deleted from all devises and servers). With your permission, anonymous quotations may be used in publications and presentations.

All information collected for the study will be kept strictly confidential. The only exceptions are if you share that you are going to physically harm yourself or someone else. This information may be shared with the Principal Investigator of the study, Alexandra de Pokomandy, Family Physician and HIV clinician, who will re-contact you to connect you with mental health or primary care services. To protect your personal identity, all information shared will be identified by a unique study ID. Your name or other personal information will not appear on study documents or in any publications or reports produced by the study. Although we will ask all participants in your focus group to maintain confidentiality, we cannot guarantee they will do so.

Only authorized research personnel will have access to all study materials over the course of the study. The information you share will not be shared with any disability support program, immigration authorities, the police, or the Canadian Revenue Agency. However, records identifying you may be inspected in the presence of the Principle Investigator by representatives of the McGill University Health Centre or the Research Ethics Board to monitor the research and ensure it is being done ethically. All of these individuals and organizations adhere to policies on confidentiality

Electronic study documents will be stored on the hospital server and will be password protected. As per ethical standards, the study data will be stored for 7 years by the researcher responsible for the study. After 7 years, the study documents will be permanently deleted from all devices and servers.

FUNDING OF THE RESEARCH PROJECT

The researcher and the institution have received funding from CIHR Strategy for Patient-Oriented Research Evidence Alliance to conduct this research project.

CONFLICT OF INTERESTS

The researchers have no conflict of interest to declare.

COMPENSATION

For costs and inconveniences you experience during this study (costs incurred to participate in the interview and group discussion) and to honour your expertise, you will receive compensation via e-transfer in the amount of $25 for the interview and $50 for the group discussion. If you withdraw before study completion, you will receive an amount proportional to your participation.

SHARING STUDY RESULTS

Results from this study will be presented at conferences and published in journals. We will also make the study findings available on the CHIWOS website (www.CHIWOS.ca)

SHOULD YOU SUFFER ANY HARM

By agreeing to participate in this research project, you are not waiving any of your legal rights nor discharging the researcher, the sponsor or the institution, of their civil and professional responsibilities.

CONTACT INFORMATION

If you have questions or if you have a problem you think may be related to your participation in this research study, or if you would like to withdraw, you may communicate with the researcher or with someone on the research team at the following number:
The main investigator/ study doctor Dr. Alexandra de Pokomandy at 514-843-2090 Alexandra.depokomandy@mcgill.ca, or Lashanda Skerritt (PhD student) at lashanda.skerritt@mail.mcgill.ca.

For any question concerning your rights as a research participant taking part in this study, or if you have comments, or wish to file a complaint, you may communicate with:

The Patient Ombudsman of the McGill University Health Centre at the following phone number: 514-934-1934, ext. 35655.

OVERVIEW OF ETHICAL ASPECTS OF THE RESEARCH

The McGill University Health Centre Research Ethics Board reviewed this research and is responsible for monitoring the study.

All members of the research team have read the Truth and Reconciliation Commission of Canada Report and will be applying the principles from the report in our research approach. An Indigenous Elder and our research team members have experience working with Indigenous women living with HIV and are available for consultation and guidance, if Indigenous study participants need support.

Appendix B

Research Study Title:	Exploring predictors of women's overall satisfaction with their HIV care.

SIGNATURES

I have reviewed the information and consent form. Both the research study and the information and consent form were explained to me. My questions were answered, and I was given sufficient time to make a decision. After reflection, I consent to participate in this research study in accordance with the conditions stated above.

1) I accept that my participation in the study be:

   Audio-recorded only ☐
   Video-recorded ☐
   Transcribed ☐

2) I authorize a member of the research study to contact me to check the transcript of what I said.

   Yes ☐ No ☐

3) I authorize the use of anonymous quotes in study publications and presentations.

   Yes ☐ No ☐

4) I wish to receive a copy of the study results by email.

   Yes ☐ No ☐ If yes, please provide contact information: ___________________________

5) I authorize a member of the research study to contact me in the future to ask if I am interested in participating in other research.

   Yes ☐ No ☐ If yes, please provide contact information: ___________________________

Appendix B

VERBAL INFORMED CONSENT OF PARTICIPANT

☐ Yes, complete below.

☐ Not required.

Study Title: Exploring predictors of women's overall satisfaction with their HIV care.

SIGNATURES

VERBAL CONSENT OF THE PARTICIPANT

I have reviewed the information and consent form. Both the research study and the information and consent form were explained to me. My questions were answered, and I was given sufficient time to make a decision. After reflection, I verbally consent to participate in this research study in accordance with the conditions stated above. A copy of this signed and dated informed consent form will be provided to me and will also be scanned and placed in my hospital medical chart.

Name of Participant: ____

Verbal Consent from participant obtained on: ________________________

Date (dd/mmm/yyyy)

☐ The consent form was read to the participant in its entirety. The person(s) signing below attest(s) that the study as set out in this form was accurately explained to the participant, and any questions have been answered.

____

Printed Name of Person
Conducting the Consent Discussion

_____________________________________ _________________________

Signature of Person Conducting
the Consent Discussion

Date (dd/mmm/yyyy)

____

Study Role

Appendix B

Demographic survey

1. **What is your age? _______**

2. **How long have you been living with HIV? ____________________________**

3. **With respect to your <u>gender</u>, how do you currently identify?**

Select all that apply.

- ☐ <u>Trans Woman (Male to Female)</u>

Woman

☐ Woman
☐ <u>Trans Woman (Male to Female)</u>
☐ Two-spirited
☐ <u>Intersex</u>
☐ Gender Queer
☐ Other, please specify: _________
☐ Prefer not to answer

4. **What do you consider to be your racial and/or ethnic background?**

Select all that apply.

☐ Aboriginal person living in Canada (e.g., First Nations, Métis, and Inuit)
☐ Indigenous Person from a country outside of Canada
☐ Black African (e.g., Nigerian, Somali)
☐ Black Caribbean (e.g., Haitian)
☐ Black Other (e.g., Black Canadian)
☐ Caucasian/White
☐ Chinese or Taiwanese
☐ Filipino
☐ Japanese
☐ Korean
☐ Latin American (e.g., Chilean, Costa Rican, Mexican)
☐ South Asian (e.g., Indian, Bangladeshi, Pakistani, Punjabi, and Sri Lankan)
☐ Southeast Asian (e.g.,Cambodian, Laotian, Malaysian, Vietnamese)
☐ Arab (e.g., Egyptian, Kuwaiti, and Libyan)
☐ West Asian (e.g. Iraqi, Isreali, Lebanese, Afghani, Iranian)
☐ Central Asian (e.g., Kazakhstan, Krgyzstan, Tajikistan, Turkmenistan)
☐ Multiple races / Multiracial / "Mixed"
☐ Other, please specify: __________________________
☐ Prefer not to answer

5. **Are you perceived or treated as a person of colour?**

☐ Yes
☐ No
☐ Prefer not to answer

6. **With respect to your sexual orientation*, how do you currently identify?**

Select all that apply.

☐ Heterosexual / Straight
☐ Lesbian
☐ Gay
☐ Queer
☐ Bisexual
☐ Two-spirited
☐ Questioning
☐ Asexual
☐ Other, please specify:
☐ Prefer not to answer

7. **What is your current legal relationship status?**

Select one.

☐ Legally married
☐ Common-law
☐ In a relationship but not legally married or common-law
☐ Single
☐ Separated / Divorced
☐ Widowed
☐ Other, please specify:
☐ Prefer not to answer

8. **What is your current legal status in Canada?**

Select one.

☐ Canadian citizen
☐ Landed Immigrant/Permanent Resident
☐ Refugee
☐ Other, please specify:
☐ Prefer not to answer

9. **What is the highest level of formal education you have completed?**

Select one.
☐ No formal education
☐ Elementary / Grade school
☐ High school / Secondary
☐ GED (General Education Diploma)

☐ Trade or Technical training
☐ CEGEP / College
☐ <u>Undergraduate university</u>
☐ <u>Post-graduate education</u>
☐ Other, please specify:
☐ Prefer not to answer

***10.* How much does your household make in a year, before taxes *(i.e., <u>household gross yearly income</u>)*?**

Select one.

☐ Less than $20,000
☐ $20,000 to $40,000
☐ More than $40,000
☐ Prefer not to answer

11. Since being diagnosed with HIV, have you ever been pregnant? This includes all pregnancies, whether the outcome was a live birth, miscarriage, stillbirth, termination of pregnancy (abortion), or an ectopic/tubal pregnancy.

Select one.

☐ Yes
☐ No
☐ Prefer not to answer

12. How would you describe your current menstrual status as it relates to menopause?

Select one.

☐ Premenopausal
☐ Perimenopausal
☐ Postmenopausal
☐ Don’t know
☐ Prefer not to answer

13. Do you intend to become pregnant in the future?

Select one.

☐ Yes
☐ No
☐ Don’t know
☐ Prefer not to answer

14. If yes, when in the future do you intend to become pregnant?

Select one.

☐ I’d like to get pregnant now
☐ Not now, but within 1 year

☐ In 1 to 2 years from now
☐ In 3 to 4 years from now
☐ More than 4 years from now
☐ Don't know
☐ Prefer not to answer

15. In the past six months, have you used any form of contraception, safer sex method, or any other means to prevent pregnancy or to regulate your periods?

Select one.

☐ Yes
☐ No
☐ Prefer not to answer

Appendix B

Interview guide

Q1: We want to know what you think about the care you got or are getting.
- Was it OK? Was it the right care for you?
- What could have made it better?
- Is it the right care for other women like yourself?
- What changes could be made to make it better?

Q2: What does satisfaction with HIV care mean to you?

The facilitator places the term "satisfaction with HIV care" and its definition in the centre of the map.

Q3: What factors do you believe positively or negatively influence satisfaction with HIV care?

The facilitator creates a list of factors identified by the participant and adds each factor to the map. The facilitator reviews the list with the participant, organizing factors with similar meanings near each other on the map. The facilitator may ask participants to further define and/or eliminate redundant factors

Factors that influence satisfaction with HIV care

1.	
2.	
3.	
4.	
5.	
6.	
7.	
…	

Q4: For each factor, one at a time, identify all of the causal relationships (a factor that is the cause of another factor) with the other factors.

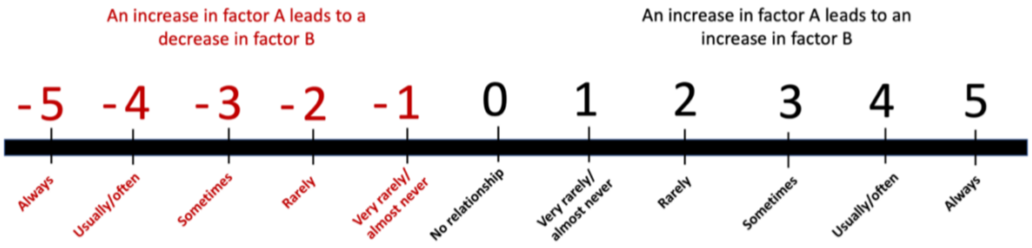
The facilitator draws an arrow on the map representing each causal relationship.

e.g. x represents a causal relationship from row to column. Factor 1 causes Factor 2.

Factor	1.	2.	3.	4.	5.	6.	7.	…
1.		x						
2.								
3.								
4.								
5.								
6.								
7.								
…								

Appendix B

Q5: Assign a weight between -5 and 5 indicating how strong the relationship is.



A 5 means that this factor *always* causes the other factor. A 4 means that this factor *usually/often* causes the other factor. A 3 means that this factor *sometimes* causes the other factor. A 2 means that this factor *rarely* causes the other factor. A 1 means that this factor *very rarely/almost never* causes the other factor. Positive relationships mean that an increase in one factor causes an increase in the other factor. Negative relationships mean that an increase in one factor causes a decrease in the other factor.

The facilitator adds the number and sign to the corresponding arrows on the map.

e.g. Replace x with a number between -5 and 5 representing the strength of the causal relationship from row to column. Factor 1 usually/often causes Factor 2.

Factor	1.	2.	3.	4.	5.	6.	7.	…
1.		4						
2.								
3.								
4.								
5.								
6.								
7.								
…								

Q6: Is there anything you would like to change in the final map?

Based on participant's response, the facilitator may add, remove, or clarify any factors or relationships on the map. Once the participant feels the map reflects their knowledge of the subject, the mapping session is complete.

Appendix B

Member-checking group discussion guide

A research team member presents the aggregate Fuzzy Cognitive Map, the most important factors that emerged from the interviews and the preliminary conclusions derived from the map.

Q1. What are your impressions of the factors and conclusions from the map? Do they reflect what you think are the most important factors in women feeling satisfied with their HIV care?

Q2. Why do you think these factors and their relationships are so important to women living with HIV? *[can discuss specific factors where clarification/ discussion would be helpful in interpreting the results].*

Q3. Is there anything that you would change in the map? Why or why not?