ON THE MARGINS OF CARE: WOMEN AND HIV IN ATLANTIC CANADA

WOMEN AND HIV CARE IN NEW BRUNSWICK AND NOVA SCOTIA, CANADA

By

PRISCILLA MEDEIROS, B.A., M.A.

A Thesis

Submitted to the School of Graduate Studies in Partial Fulfillment of the Requirements

for the Degree

Doctor of Philosophy

McMaster University DOCTOR OF PHILOSOPHY (2019), Hamilton, Ontario

(Anthropology)

TITLE: Women and HIV Care in New Brunswick and Nova Scotia, Canada

AUTHOR: Priscilla Medeiros, M.A. (University of New Brunswick)

SUPERVISORS: Dr. D. Ann Herring and Dr. Wayne Warry

NUMBER OF PAGES: 211

Dedication

This thesis is dedicated to the women living with HIV and community organizations involved in this study. Thank you for sharing your knowledge and lived experiences with me.

Abstract

This study explores the barriers to care women face living with HIV in New Brunswick and Nova Scotia, and also the health and support systems they navigate to improve their wellbeing. Women living with HIV are invisible within the epidemic and often to community sector employees, especially in the Maritime Provinces where men account for the largest number of diagnoses in Canada; this is a central theme in the data.

The thesis is rooted in applied medical anthropology and uses qualitative and quantitative methods to capture the changing health priorities of women living with HIV as they navigate the health care systems after diagnosis. This information was used to create maps that show the availability of services in relation to women's needs, including affordable housing, food security, accessible transportation, and reducing HIV stigma. I examine the efficiency of HIV women's referral network in both provinces, and the way forward for organizations to meet their long-term health needs, such as widening of outreach activities and improving gendered care.

The main findings of this study reveal that the barriers to care women face are not easily overcome by AIDS service organizations. Current support initiatives are no longer relevant to their lives because they are tailored mainly to men, but women increasingly value the referral activities of organizations. Among the most important contributions of this thesis is the envisioning of a women-centered care model that meets their health needs and acknowledges their diverse reality of their experiences.

Acknowledgements

This thesis would not have been possible without the time, support, and dedication of many people who were involved in this research project over the past five years.

I would like to thank my supervisors, Dr. D. Ann Herring and Dr. Wayne Warry for their continued support and encouragement during this project. Your confidence in my research helped me bring my voice out onto the page. I would like to give a special thanks to Dr. Dorothy Pawluch for her time and careful attention to detail.

It would have been impossible to create New Brunswick and Nova Scotia health maps using GIS without the assistance of Siobhan Hanratty, data and maps librarian at the University of New Brunswick, and Jay Brodeur, GIS and maps manager at McMaster University. Your guidance along the way was vital during this phase of my project.

I am also deeply grateful to Dr. Duncan Webster, Internist, Infectious Disease Physician and Medical Microbiologist at the Saint John Regional Hospital, for helping me to obtain additional ethics clearance from the New Brunswick Horizon Health Network Research Ethics Board.

I would like to thank my amazing family for their love, support, and constant encouragement throughout this journey. I also wish to thank my boyfriend Scott for always making sure I got up from my desk chair to take a break.

Finally, my PhD project would not have been possible without the research funding offered by the Department of Anthropology and School of Graduate Studies at McMaster University, and the Canadian Institutes of Health Research.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

ACAP   AIDS Community Action Program

AIDS   Acquired Immune Deficiency Syndrome

CBR   Community-Based Research

CHIWOS   Canadian HIV Women's Sexual and Reproductive Health Cohort Study

CMA   Critical Medical Anthropology

GIS   Geographic Information Systems

GRID   Gay Related Immune Deficiency Disease

HCV   Hepatitis C Virus

HIV   Human Immunodeficiency Virus

HON   Healing Our Nations

MOSH   Mobile Outreach Street Health

MSM   Men Having Sex with Men

STBBIs   Sexually Transmitted Blood-Borne Infections

Declaration of Academic Achievement

I declare that the content in this document has been completed by myself, Priscilla Medeiros, with contributions from Dr. D. Ann Herring, Dr. Wayne Warry, and Dr. Dorothy Pawluch at all stages of the project.

Chapter 1 Introduction

I was inspired to return to the Maritime Provinces as a PhD Candidate, after completing my Master's degree at the University of New Brunswick in 2012, to continue my work on women's health after a series of conversations with community sector employees about the changing landscape of HIV care. My PhD project builds on connections made during my MA research with AIDS New Brunswick, AIDS Saint John, and AIDS/SIDA Moncton, to create a multi-site project in New Brunswick and Nova Scotia, to better understand the barriers-to-care women with HIV face while navigating the care continuum to improve their wellbeing.

The circumstances confronting women diagnosed with HIV today cannot be separated from the history of the disease itself. When AIDS first emerged in the 1980s, discrimination and homophobia fueled ideas that the disease was a "gay plague" or gay related immune deficiency disease (GRID). At the time, gay men were thought to be the primary transmitters of the disease because they accounted for the highest rate of HIV diagnoses in North America (Allen, 1994). The common misconception that HIV only affected men having sex with men (MSM) rendered women invisible in the epidemic and in most settings (Bourassa & Bulman 2005; Wiley & Allen, 2009). In 1982, distorted media depictions of AIDS as a disease of gay men expanded to include other so-called risk groups (hemophiliacs, heroin addicts, and Haitians), also known as the 4-H, and failed to identify other diverse populations affected by AIDS, including women. The stigma and confusion around AIDS seemed to shift as the incidence of new diagnoses grew in subpopulations like heterosexual males, women, and children (Bourassa &

Bulman, 2005; Mainline Needle Exchange, 2012; Wiley & Allen, 2009).

Women nevertheless were neither diagnosed with AIDS nor enrolled in clinical studies in the 1980s because gynecological conditions or menstrual dysfunction were not common illnesses associated with it; yet, the first woman diagnosed with what would later be called AIDS was reported in the United States in 1981 (Bourassa & Bulman, 2005). The invisibility of women across all populations is not only traced to the portrayal by Centers for Disease Control and Prevention of the unusual immune syndrome as a gay man's disease, but also to their defining of four other groups at highest risk for HIV infection (homosexual, Haitians, hemophiliacs, and heroin users) in the early 1980s (Allen, 1994).

Even today, the health of women living with HIV is excluded from medical research, which speaks to their larger marginalization and invisibility in the epidemic. A main rationale for this thesis project is not only to address the absence of women in the literature in the face of rising rates of infection among this group in Canada, but also to explore the larger social and structural contexts that continue to marginalize women affected by this disease. This thesis is envisioned as a study of a chronic condition that prevails among women living with HIV, but is neglected in the current care landscape. The focus of the project is on HIV-positive women living in New Brunswick and Nova Scotia who account for 15% and 12% of all HIV test reports in the two provinces, respectively (New Brunswick, 2016; Nova Scotia Department of Health and Wellness, 2016; Public Health Agency of Canada, 2015a).

Federal Policies and Practices in Canada

The government of Canada introduced the National AIDS Strategy in 1990, more than a decade after the first case of AIDS was diagnosed in the country (Canadian Institutes of Health Research, 2008). Establishing a national strategy was important for developing educational initiatives and services to manage the spread of HIV infection. An increase in annual funding from $37.3 million to $42.2 million was successful in broadening the response to HIV, particularly by involving people living with and vulnerable to HIV/AIDS in decision-making and research. Yet, programs in place were still insufficient for reducing and managing the rising rates of HIV because they were tailored to men who accounted for the highest prevalence rates of infection nationally (Government of Canada, 2004).

The AIDS Community Action Program (ACAP) was established under the National AIDS Strategy and later incorporated into the Canadian Strategy on HIV/AIDS. ACAP is a federal funding stream that supports local community-based agencies across Canada to provide outreach and support services to people living with or vulnerable to HIV and AIDS (Kirkland et al., 2006; Public Health Agency of Canada, 2014a). ACAP funding, for example, helped community-based agencies in 2015 to offer 3,300 workshops and presentations across Canada on issues, such as safer sex and drug use practices and basic facts about HIV transmission (Treasury Board of Canada Secretariat, 2015). ACAP funding is important to community-based agencies for addressing the barriers-to-care for people living HIV, which include affordable housing, food insecurity, transportation, and stigma; it is insufficient however to offset the increased costs

associated with the enhancement of support initiatives like counselling, testing, and education outreach. Funding issues are an ongoing challenge for AIDS service organizations that want to strengthen their capacity of service delivery.

The Canadian Strategy on HIV/AIDS was launched in 1998 in an effort to better address the health and social challenges associated with HIV/AIDS by increasing collaboration among public health, community, and policy sectors (Government of Canada, 2004). The Canadian strategy was successful in mobilizing client centered-services and provisions for people living with and vulnerable to HIV, and took into account the long-term health needs of men and women. Agencies, nevertheless, continued to work in traditional silos of HIV service delivery because federal funding remained relatively constant and did not support gendered and tailored approaches to care.

The Federal Initiative to Address HIV/AIDS was introduced in 2005 to build on previous government initiatives and has become a key element in responding to the pandemic, specifically through funding to increase access to testing, care, treatment, and programs and services. The initiative provides provinces lacking an HIV/AIDS strategy, including New Brunswick and Newfoundland, direction in developing more relevant HIV prevention, care, treatment, and support programs. The provinces have been able to follow these directions closely, under the leadership and strategic direction of their boards. A core strategic pillar of the Canadian strategy is to increase efforts with other local community-based agencies to assess community needs and improve resources to meet the health priorities of people living with HIV. This is a principle all AIDS service organizations continue to follow in the face of an uncertain future.

The level of funding for all HIV and AIDS initiatives doubled in 2008-2009 from $42.2 million to $84.4 million (Canadian Institutes of Health Research, 2008). The increase in federal funding was essential for AIDS service organizations to hire new staff members to manage on-site social support interventions, including food program, emergency fund, and clothing bank services that people living with HIV have come to rely on, and enhance their capacity and outreach to rural regions. Yet, the federal funding received by organizations in New Brunswick and Nova Scotia continues to be insufficient to meet the immediate and long-term demands of persons living with HIV (CBC News, 2018; Easton, 2016).

The Federal Initiative is a partnership between the Public Health Agency of Canada, Health Canada, the Canadian Institutes of Health Research, and Correctional Services Canada to foster sharing knowledge and expertise to prevent the spread of HIV. Agencies share the funding as follows: the Public Health Agency of Canada ($51.9 million); Health Canada ($5.7 million); Canadian Institutes of Health Research ($22.6 million), and; Correctional Services Canada ($4.2 million) (Kirkland et al., 2006).

A new five-year initiative, *Leading Together: Canada Takes Action on HIV/AIDS*, emerged from the federal strategy in 2005. Leading Together, similar to the Canadian Strategy on HIV/AIDS, joins community members, researchers, and policy makers in partnership to increase awareness of HIV and AIDS, reduce social inequities that place at a greater risk for HIV infection, and strengthen prevention efforts (Kirkland et al., 2006). The renewal of *Leading Together* (2013) was an effort to continue coordinated work with all partners to address the rising rates of HIV infection in Canada and to prepare for the

new integrated funding expectations of the Community Action Fund, which began on

April 1, 2017. All of the AIDS service organizations and community-based agencies that

participated in this PhD were successful in obtaining the Community Action Fund,

according to the Public Health Agency of Canada, by strengthening their partnerships

with other agencies province-wide to provide HIV, hepatitis C, and sexually transmitted

and blood-borne infections-specific education, outreach, housing, and addiction services

(Kirkland, Patten, Krahn, Peddle, & Gaspar, 2014). It is unclear what effect new federal

guidelines will have on the remaining programs upon which women living with HIV have

come to rely, but a focus of this study is to understand whether existing health and social

services are meeting their basic needs.

HIV and Women in Canada

An estimated 75,500 Canadians were living with HIV and AIDS at the end of

2014 (Public Health Agency of Canada, 2015a; Public Health Agency of Canada, 2015b).

The majority of all new infections, about 79.2%, are acquired through heterosexual

contact and 20.8% from injection drug use exposure (Nova Scotia Advisory Council on

the Status of Women, 2003; Public Health Agency of Canada, 2015b). The provinces of

Ontario, Quebec, Alberta, British Columbia, and Saskatchewan accounted for the highest

number of reported HIV cases in Canada. Ontario, Quebec, and British Columbia

recorded the highest proportion of positive test reports among women (Public Health

Agency of Canada, 2014b). Women are least represented in HIV test reports in the

provinces of New Brunswick and Nova Scotia because there are barriers to accessing

services in rural and remote areas (Public Health Agency of Canada, 2014b). This

dissertation research project thus probes the barriers to care for women in both provinces, but also outlines the care landscape they navigate to improve their overall quality of life.

The HIV diagnosis rate (per 100,000 population) in the Maritime Provinces is much lower than in other provinces and territories: the rate for New Brunswick is 0.4 and Nova Scotia/Prince Edward Island is 1.1 because of population density differences (Public Health Agency of Canada, 2015a). The national reporting of HIV incidences in Nova Scotia and Prince Edward Island are combined for the same reason. The incidence of HIV diagnoses and infections affects the total federal government funds AIDS service organizations and community-based agencies receive to provide education, care, and treatment programs.

Women accounted for 3% of all new HIV infections in Canada in the late 1980s (Archibald, 2009). Rates of HIV infections among women are steadily on the rise because of changes in diagnosis and reporting procedures, gender inequalities, and the biological vulnerability of women to HIV (Archibald, 2009; Gahagan, 2013). One in five people living with HIV/AIDS at the end of 2014 was female (Public Health Agency of Canada, 2015b). In fact, the Federal Initiative on HIV/AIDS recognizes that while HIV affects all groups, women are more vulnerable than others because of biological susceptibility and unequal gender relations that affect their ability to negotiate safer sex practices (Gahagan & Ricci, 2011). Yet, women are least represented in HIV test reports in the provinces of New Brunswick and Nova Scotia despite rising rates of HIV infection among this group (Arthur, Beausoleil, Guay, & Gahagan, 2013; Public Health Agency of Canada, 2012). Adopting women-specific health strategies has been important for meeting the needs of

women affected by HIV and slowing down the transmission among this population.

Recent studies by Carter et al. (2013), Baran et al. (2014), Carter et al. (2014), CHIWOS (2016), Loutfy et al. (2016), Kronfil et al. (2017), and Jaworsky et al. (2018) accordingly focus on the health of HIV-positive women and their barriers to care. Most research has centered on the challenges of proximity to care, a lack of gendered services for women, unstable housing, long travel distances to and from medical appointments, food insecurity, and stigma. Additional major barriers to health care include HIV-related experiences of sexism, racism, and classism (Baran et al., 2014; Carter et al., 2013; Carter et al., 2014; CHIWOS, 2016; Jaworsky et al., 2018), violence (Carter et al., 2013; Loutfy et al., 2016), and mental health and addiction issues (Carter et al., 2013; Jaworsky et al., 2018; Loutfy et al., 2016).

With the exception of the study by Loutfy et al. (2016), the research cited above took place in the provinces of Ontario, British Columbia, and Quebec because these provinces have the highest incidences of HIV in Canada; less work has been done on the situation in New Brunswick and Nova Scotia or in other provinces with lower incidence rates. The combination of a lower incidence rate of HIV in New Brunswick and Nova Scotia and fewer studies on women's health make it more difficult to determine whether women with HIV face similar barriers to those experienced by women living elsewhere in Canada. The dearth of studies in these provinces, moreover, means that most of the information that is available comes from the grey literature. The grey literature focuses on men, however, because they account for the highest proportion of positive HIV tests. This absence of research on HIV and AIDS in women in New Brunswick and Nova Scotia is

the main impetus behind the development of my PhD project.

Although there has been a shift towards recognizing women's risk for HIV, the pervasiveness of the belief that HIV is a disease of promiscuity and immoral behavior continues to permeate society and affects women's access to HIV care (Gahagan & Ricci, 2011). New HIV infections among women have increased since positive test reporting first began in 1985. The largest proportion of positive tests among women occurs between the ages of 15 to 29. Prenatal HIV screening in all Canadian provinces is routine and helps to prevent perinatal transmission (Archibald, 2009; Public Health Agency of Canada, 2014b). In spite of the availability of HIV screening and testing, women continue to be diagnosed later in their illness, which delays their access to care and services. It is also estimated that 21% of individuals are not aware of their HIV-positive status, which further signals that barriers to testing and diagnosis may still exist (Public Health Agency of Canada, 2015b).

The role of injection drug use in the transmission of HIV infection among women exceeded all other exposure categories until 2009. Heterosexual contact accounts for 59.7% of all cases and is the most frequently reported exposure category among women (Archibald & Halverson, 2013; Public Health Agency of Canada, 2012). Women are more vulnerable to HIV infection than men because of a variety of interconnected determinants of health, including gender (power relationships and inequalities), education, access to health services (affected by living in rural and remote areas), unemployment, substance use, migration and mobility, and fear of disclosure, among others (Archibald & Halverson, 2013; Bourassa & Bulman, 2005; Bulman, 2004;

Gahagan, 2013; Public Health Agency of Canada, 2012). These inequalities in health not only place women at a higher risk of acquiring infection, but also limit access to HIV/AIDS treatment, care, and support services, and reinforce isolation resulting from a positive diagnosis (Gahagan & Ricci, 2011). Until recently, women have been invisible in the medical system and absent from the HIV/AIDS research agenda, which has led to misdiagnosis, and delayed entry into HIV care and treatment (Nova Scotia Advisory Council on the Status of Women, 2003). The invisibility of women in the HIV epidemic has led to poor health outcomes and quality of life.

Research Questions

The goal of this PhD dissertation is to identify major challenges women living with HIV face in navigating health and social services in the existing referral network in New Brunswick and Nova Scotia. The following broad questions guided this research:

1) What are the barriers-to-care for women living with HIV in New Brunswick and Nova Scotia?

2) What roles do AIDS service organizations and other community-based agencies play in the lives of women living with HIV? Are the services and programs they have created meeting the diverse needs of the women living with HIV? Are there any essential services missing to improve the quality of care for women living with HIV?

This thesis draws on an applied medical anthropology and health policy orientation to examine the experiences of women living with HIV and healthcare

providers.

A Focus on Applied Medical Anthropology

This research is rooted in applied medical anthropology. Applied medical anthropology is an essential orientation in the study of social suffering and serves as a framework for constructing and linking pertinent research questions, methodological procedures, and theory (Rylko-Bauer, Singer, & Van Milligen, 2006). These three inter-related areas of research guide applied analysis, to one degree or another. The term applied medical anthropology is, "…used by anthropologists to describe their professional activities in programs that have primary goal changes in human behaviour believed to ameliorate contemporary social, economic and technical problems, rather than the development of social and cultural theory" (Foster 1969 as cited in Van Willigen, 2002, p. 9). Policy research is a by-product of applied medical anthropology research and is not new to ethnographic engagement for anthropologists; anthropologists have been directly involved with policy research since the mid-1970s (Rylko-Bauer et al., 2006; Van Willigen, 2002). The value of using an applied perspective to influence change in public health policy lies in its ability to acknowledge the role of cultural systems of value in health, explore the place of holism within the study of health policy, and engage in a qualitative specific methods (e.g., participant observation and interviews) in an arena that is dominated by quantitative forms of research in the social sciences (Campbell, 2010).

The applied medical anthropology and health policy orientation furthermore provides a general framework to collaborate directly with communities (i.e., women living with HIV and community sector employees in New Brunswick and Nova Scotia) to

achieve community-directed change while integrating theory as an advocacy tool,

bringing into view the long-standing structural inequities that threaten women's quality of

life after diagnosis. Critical medical anthropology (CMA) and structural violence are the

two guiding conceptual frameworks under the applied medical anthropology perspective.

These frameworks are used to explore the experiences of women living with HIV who are

navigating health and social services in New Brunswick and Nova Scotia, and how their

experiences speak to a widening gap in the HIV care continuum.

Taking a Critical Medical Anthropology and Structural Violence Approach

Critical medical anthropology (CMA) became part of the discipline's active

school of thought in the 1980s; critical theory transcends its theoretical roots in the study

of social determinants of health, and experiences of health and illness (Brown & Closser,

2016; Witeska-Mlynarczyk, 2015). CMA, sometimes called the political economy of

health, continues to be primarily concerned with the social origins and consequences of

disease from the sufferer's perspective to better understand human health issues (Baer,

Singer, & Susser, 2003; Singer & Baer, 1995; Willey & Allen, 2009). Accompanying the

establishment of CMA was medical anthropologists increasing interest in the exploration

of the lived experience of suffering and the ways in which individuals embody structural

inequalities and the uneven distribution of social power (Campbell, 2011; Singer & Baer,

1995).

Medical anthropologists commonly use the CMA framework to analyze the

implications of political and economic forces "…that pattern human relationships, shape

social behaviours, condition collective experiences, re-order local ecologies, and generate

cultural meanings" (Singer & Baer, 1995, p. 65). This critical approach to illness in medical anthropology is distinct from the biomedical study of disease not simply because of its concern with the effect of social inequality on people's health, but more importantly its challenge of larger social structures with the goal of producing social change through qualitative methods (Baer, Singer, & Susser, 2003; Singer, 2001). The role of CMA in the study of illness, arguably, is to add socio-cultural depth and practices to a body of written works dominated by the quantitative nature of medical and epidemiological research that excludes the voices of people living with HIV, and wider health and social issues affecting the population under study (Ramin, 2007).

This is the case for the majority of current work on the topic of women's health and HIV. For example, Blaisa et al. (2015), Carter et al. (2016), Carter et al. (2018b), Johnson et al. (2015), Kronfil et al. (2017), Loutfy et al. (2016), Palmer et al. (2018), Pellowski (2013), all use univariate and multivariate regression models (i.e., barriers to care scale) to look more closely at the cause and effect relationships of women's experiences because interviewing, transcribing, and analyzing qualitative data are time consuming. Such studies may help find new ways to help women overcome their difficulties in accessing care, but Farmer (2003, p. 31) suggests "the experience of suffering…is not effectively conveyed by statistics or graphs." Following Singer and Baer, I see the sufferer experience as "a social product, one that is constructed and reconstructed in the action arena between socially constituted categories of meaning and the political-economic forces that shape the contexts of daily life" (Singer & Baer, 1995, p. 101). I believe a mixed methods approach is more revealing of women's lived

experiences because the inclusion of their voices better explains the affect of social

inequalities in their lives, rather then leaving interpretations and ascribed meanings to the

researcher.

The relationship of people to their environment in all its complexity is inseparable

in CMA (Singer, 1995). This point of view makes it possible to examine health structures

on a micro and macro level, "from the consciousness of the patient, to community

organization, regional political economy, and international corporate power" (Singer &

Baer, 1995, p. 63). The macro level, for example, draws attention to the role of the state

in health policy and health care decision-making, and its affect on the existing structure of

society. The term *state* implies an authoritative hierarchy that makes political economic

decisions on the behalf of its citizens. The micro-level is also central to the CMA

approach and is interested in the experiences of individuals, largely how those

experiences are shaped by society as a whole (Singer & Baer, 1995). This approach most

importantly has the ability to inform public health policy that is focused on the underlying

macro-level causes of poor health, and serves as the foundation for framing this thesis.

A second theoretical perspective and method of inquiry used in this study is

structural violence, which similarly focuses on the forces that constrain agency and create

social suffering. It was introduced in the 1960s by sociologist Johan Vincent Galtung as a

socioeconomic analysis tool that emphasizes social concern for fundamental rights and

needs of individuals in society; this approach complements the micro-level analysis of

CMA to understand individual experiences of health and a main reason it was chosen as a

theoretical lens to analyze the narratives of women (Farmer, Nizeye, Stulac, & Keshavjee,

2006; Sinha, Gupta, Sing, & Srivastava, 2017). Structural violence is a term in anthropology most clearly articulated in the work of Paul Farmer, introduced in his book "Pathologies of Power: Health, Human Rights, and the New War on the Poor" (2003). The term refers to the level of violence that is exerted systematically and indirectly by a certain social order, and prevents individuals from meeting their basic needs. Farmer and colleagues (2006, p. 1686) point to structural violence as "normalized by stable institutions and regular experience. Because they seem so ordinary in our ways of understanding the world, they appear almost invisible." Structural violence renders visible the realities of poverty, sickness, hunger, social exclusion, and the history and political economy of oppression that harm people's health (Farmer, 2004).

In doing so, the concept broadens the level of analysis in understanding how historical processes and the political economy adversely affect global-local health inequalities (Rylko-Bauer & Farmer, 2016). Structural violence as a framework also moves beyond identifying health disparities to examine the power relations that structure and sustain them (Rylko-Bauer & Farmer, 2016). Medical anthropologists maintain that the structural violence lens views health disparities as more than the consequences of individual decisions and actions, but rather as the products of systemic biases, exclusions, and social injustices in society (Rylko-Bauer & Farmer, 2016; Singer & Baer, 2007). While the outcomes of structural violence are experienced individually, the social suffering it produces is of interest to medical anthropologists because it exposes the connections between personal and societal problems (Rylko-Bauer & Farmer, 2016). The concept of structural violence also moves beyond science's positivist concern with cause

and effect towards a more holistic analysis of existing health inequalities and underlying social determinants of health towards through ethnographic inquiry (Farmer, 2015).

Using the complementary perspectives of CMA and structural violence under the umbrella of applied medical anthropology, in this thesis I explore how inequalities in the distribution of health and social services, and care, affect women living with HIV in the provinces of New Brunswick and Nova Scotia. The goal of this research is to identify how the quality and scope of women's health can be improved using ethnographic research methods. I show how adverse health outcomes resulting from barriers to accessing health services and a lack of women-centered care have contributed to the invisibility of the AIDS pandemic in New Brunswick and Nova Scotia, and continuing discriminatory attitudes towards women living with HIV. I situate the narratives of women living with HIV and service providers within the wider experiences of living with HIV in Canada in an effort to understand and respond to issues of health in communities with a growing incidence of HIV infection. CMA and structural violence are interconnected domains of inquiry in medical anthropology, which enhance our understanding of social issues associated with HIV.

The two theoretical approaches to examine the social dimensions of health and illness under the umbrella of an applied orientation reveal gaps in the care continuum for women living with HIV in New Brunswick and Nova Scotia. Scheper-Hughes's (1990, p. 196) perspective on illness in society and applied medical anthropology signals that "our work should be at the margins, questioning premises, and subjecting epistemologies that represent powerful, political interests to oppositional thinking." Previously published

research on HIV in women in New Brunswick and Nova Scotia mainly focus on the systems perspective[1] (Archibald & Halverson, 2013; Arthur et al., 2013; Gahagan & Ricci, 2011; Kirkland et al., 2006; McWilliam, 2002), grounded theory[2] (Colman, 2003; Gahagan, 2013; Gahagan & Proctor-Simms, 2013; Hayward & Colman, 2003; Medeiros, 2012; Medeiros, 2017; Nicol & Butler, 2005; Olivier & Stanciu, 1999), and feminist critique[3] (Bourassa & Bulman, 2005; Bulman, 2004; Bulman, 2005; Jane, 1994; Nova Scotia Advisory Council, 2003).

Although these studies were useful for shaping research questions about women living with HIV and for identifying underlying themes and structures in the data, this dissertation project undertakes a different reading of women's health in New Brunswick and Nova Scotia. It pays attention to the voices of women to bring visibility to their lived experiences and differs from the studies listed above by concentrating on embodiment, social suffering, and individual agency (Baer, Singer, & Susser, 2003). Although the research by Bulman (2004), Kirkland et al. (2006), and McWilliam (2002) combined historical, epidemiological, qualitative data, and a community-based approach, to the best of my knowledge, I am the only anthropologist studying HIV and women's health in New Brunswick and Nova Scotia.

The analytical framework of this thesis attends to the overlapping health and

---

[1] A systematic framework used to conceptualize a problem situation as a result of inequality, marginalization, and oppression.
[2] A set of rigorous methodological techniques used to identify the emergence of conceptual categories in the data.
[3] It uses the principles feminist theory and social justice to critique the forms that marginalization takes in the society.

social problems that are simultaneously experienced by women living with HIV. The use of multiple theoretical perspectives and methods of inquiry from anthropology is important for breaking down the silos of different disciplines that have dominated contemporary HIV research in these provinces, including medicine, nursing, and gender and health studies. This thesis is the first to combine political and economic perspectives with anthropology and history to further the understanding of service delivery for women living with HIV in New Brunswick and Nova Scotia. This approach aims to render visible the linkages between poverty, violence, and suffering, a common goal in applied medical anthropology studies.

Overview of Chapters

This thesis is organized into six chapters. Chapter 2 *HIV in New Brunswick and Nova Scotia* describes the existing service provisions for people living with HIV in New Brunswick and Nova Scotia, and discusses the similarities and differences in their HIV care continua.

Chapter 3 *Materials and Methods* outlines the process through which I collected data to achieve the guided research questions. I detail the quantitative and qualitative methods used to learn more about women's experiences living with HIV, from ethical considerations, to the collection of data before and after entering the field, to data analysis.

Chapter 4 *Barriers-to-Care for Women Living with HIV* is the first of two chapters presenting the results and discussion of the data analysis. This chapter focuses on describing the barriers-to-care women face in both provinces.

Chapter 5 *A Community of Care* further investigates the role of AIDS service organizations and other community-based agencies in the lives of women living with HIV after diagnosis and whether support services meet their basic needs.

Chapter 6 *Conclusion* summarizes the significant findings of this study, makes some general observations about the ways forward for community-based HIV agencies in New Brunswick and Nova Scotia to meet new federal funding guidelines, and considers the need for future research.

Chapter 2 HIV in New Brunswick and Nova Scotia

In this chapter, I provide an overview of the history of HIV/AIDS in New Brunswick and Nova Scotia. I then describe the existing service provisions for people living with HIV in both provinces, largely by discussing similarities and differences in harm reduction strategies, delivery of outreach services, and access to treatment in both provinces.

The number of people living with HIV is steadily rising in New Brunswick and Nova Scotia. Table 2.1 presents the total number of HIV and AIDS cases reported for persons in New Brunswick and Nova Scotia, as of 2016. It shows that there are twice as many people living with HIV in Nova Scotia (n=1200) than New Brunswick (n=632). Women in both provinces are less likely than men to get tested for HIV and to access treatment because of stigma and discrimination (Public Health Agency of Canada, 2012). For example, women in New Brunswick account for only 15% of all positive HIV test reports (New Brunswick, 2016; Public Health Agency of Canada, 2015a). Because of the small annual HIV numbers, the data for Prince Edward Island and Nova Scotia have been pooled since 2012 (Public Health Agency of Canada, 2012). Among all HIV diagnoses in Nova Scotia and Prince Edward Island, women represent 12% of all cases.

Men having sex with men (MSM) account for the greatest proportion of positive HIV test reports among adults in New Brunswick and Nova Scotia, which influences the direction of support systems involved in HIV caregiving. Similar trends appear in the national data where MSM continue to be the population most affected by HIV in Canada; accounting for 53% all people living with the disease in the country (CATIE, 2017b).

Table 2.1: Number of all HIV and AIDS reported cases for all ages in New Brunswick and Nova Scotia, 1985-2016 (New Brunswick, 2016; Nova Scotia Department of Health and Wellness, 2016; Public Health Agency of Canada, 2015a).[4]

	1985-2008	2009	2010	2011	2012	2013	2014	2015	2016	Total
New Brunswick										
HIV+	396	1	8	10	4	5	3	9	7	443
AIDS	175	2	1	1	2	1	2	1	4	189
Nova Scotia										
HIV+	722	13	15	15	18	16	10	17	16	842
AIDS	338	2	5	4	3	0	2	3	1	358

Women in both provinces are at a high risk for acquiring HIV, hepatitis C (HCV), and other sexually transmitted and blood-borne infections (STBBIs) due to high levels of unprotected sexual intercourse and the increased incidence of drug use, particularly opiates (e.g., heroin, codeine, and oxycodone) and crack. Most HIV diagnoses in women are attributed to heterosexual contact and this exposure category is the fastest growing in both provinces (Colman, 2000). Figure 2.1 shows the proportion of HIV and AIDS cases among men and women in New Brunswick and Nova Scotia since reporting began in Canada in 1985. The figure reveals the gender imbalance in the prevalence of HIV in the two provinces, with men accounting for 84% and 88% respectively of HIV and AIDS cases in New Brunswick, and for 86% and 91% respectively of HIV and AIDS cases in Nova Scotia. This gender imbalance is in keeping with the overall Canadian picture (CATIE, 2017a).

The higher incidence of HIV infections among all men and continuing misperception that HIV is a "gay disease" not only affects the programmatic and resource

---

[4] The reporting of HIV incidence in Nova Scotia and Prince Edward Island to the Public Health Agency of Canada was combined in 2012.

allocation decisions made by the federal-provincial governments, but also keeps women

invisible in the epidemic. This has a profound impact on women's vulnerability to HIV

and other STBBIs with less attention paid to HIV prevention intervention among women.

Figure 2.1: Proportion of reported HIV and AIDS cases by gender in New Brunswick and Nova Scotia, 1985-2016 (New Brunswick, 2016; Nova Scotia Department of Health and Wellness, 2016; Public Health Agency of Canada, 2015a).
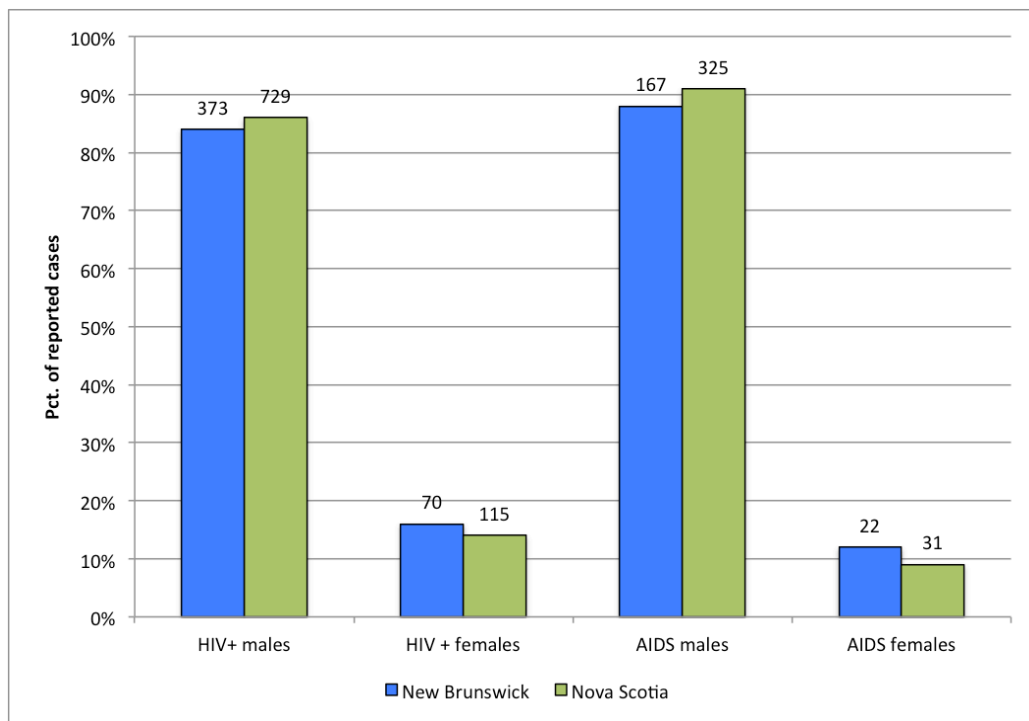
New HIV infections among women in Canada, especially those in New

Brunswick and Nova Scotia, are attributed to factors such as low literacy, unprotected

sex, and needle sharing. The Maritime Centre of Excellence for Women's Health reports

that 1 in 5 women in Atlantic Canada are more likely to live in conditions of poverty than

men (Colman, 2000). Until 2018, Canada did not have an official poverty line, but single-

parent families, mostly women, are the most impoverished. For example, nearly 70% of

female-led single parent families live below the low-income cut-offs at which families

can afford necessities like food, shelter, and clothing (Colman, 2000; Sharif, Dar, & Amartunga, 2000). There is a relationship between HIV and poverty. Yet, the specific impact of poverty on female-headed households where women are living with HIV has received little attention.

Nearly 46% of the total population of New Brunswick and Nova Scotia is rural (Kirkland et al., 2014). The number of people living with HIV in these regions is unknown. Rural, in this case, refers to "smallness, isolation…strong community feelings, [and] conservative and traditional values" (Bulman, 2005, p. 478). This statement remains relevant to the topic at hand and in combination with the Statistics Canada explanation of 'rural' serves as the definition in this study. Statistics Canada (2015c) defines rural as "all territory lying outside populations centres". There is little data on the spread of HIV in rural areas and the experiences of people living with HIV in these regions. There is, however, evidence that people with or at risk for HIV who live in rural communities face complex challenges similar to those faced by persons living in urban centers, including poverty, transportation issues, religious conservatism, and a lack of services (Bulman, 2005; Kirkland et al., 2014; McWilliam, 2002). For example, infectious disease specialists in New Brunswick are located in only two urban centers; people seeking medical care in the province must travel to Moncton or Saint John. The availability of healthcare, or lack thereof, in the province contributes to a delay in diagnosis and treatment of persons living with HIV.

Navigating provincial prescription drug plans and accessing up-to-date information about treatment options are other major factors affecting access to the HIV

care continuum (Kirkland et al., 2014). Although attempts have been made to improve the quality of care for persons living with HIV and other STBBIs in rural areas, including by AIDS service organizations and other community-based agencies, funding support for these new initiatives is often lacking (McWilliam, 2002). Services and programs in rural areas are short term and ad hoc to address challenges, needs, and resources within these communities. Kirkland et al. (2014) suggest that community-based organizations that assist people living with or at risk of HIV have a very large catchment area of about five to seven hours drive time.

The idea that '*HIV acquisition is something that only happens to other people*' places rural residents at a higher risk for the disease. This perception may be reinforced by conservative values that increase stigma, isolation, and the lack of HIV programs and services in rural areas (Medeiros, 2012). Status disclosure is a notable problem for women in rural areas, in contrast to disclosure by men, due to misconceptions that only promiscuous, careless, and unhygienic people contract HIV (Medeiros, 2012). There are new recommendations to improve the knowledge, attitude, and health of people in New Brunswick and Nova Scotia, including early diagnosis and treatment of sexually transmitted and blood-borne infections, more widespread anonymous testing, and outreach education to raise awareness about disease prevention and spread (Kirkland, Marshall, & AIRN Research Team, 2008). These strategies have been developed as part of the efforts made by New Brunswick and Nova Scotia to enhance services to meet the new federal funding guidelines, and also address the changing needs of people living with HIV, HCV, and other STBBIs (Gahagan & Ricci, 2011).

The following section presents the distribution of HIV prevalence, and program and service delivery, in the provinces of New Brunswick and Nova Scotia. This information not only reveals the diverse efforts of community-based organizations to enhance the delivery of social services to people living with HIV and bridge the gaps therein, but also the similarities and differences of the care continuum by province.

New Brunswick

As of 2016, a total of 632 people were living with HIV and AIDS in New Brunswick (Table 2.1), and the majority of cases were identified among injection drug users and men having sex with men (New Brunswick, 2016; Public Health Agency of Canada, 2015a). Since 1998, free anonymous HIV testing services have been available in the province to all people regardless of age (Gahagan & Proctor-Simms, 2013). Anonymous testing means a person does not need to provide their name or contact information, but instead an identifier is attached to the test and results. The data presented in Table 2.1 does not reflect all of the people who have tested positive for HIV and AIDS in the province. HIV testing is more readily available at AIDS service organizations, such as AIDS New Brunswick, and this creates a new and difficult challenge for reporting, owing to data privacy issues (Gahagan & Proctor-Simms, 2013). A closer look at Figure 2.1 also reveals a 6:1 ratio for male to female HIV and AIDS prevalence in the province, higher than the 4:1 male-female ratio in Canada (CATIE, 2017a).

Province-wide assessments produced by the three AIDS service organizations (AIDS New Brunswick, AIDS Saint John, and AIDS/SIDA Moncton) underscore the needs and experiences of women living with HIV. Olivier and Stanciu's (1999)

community report on the impact of the changing epidemic in New Brunswick identified

the systemic social and health problems of people living with HIV. Nearly half of the

participants in the project, for example, recorded travelling an estimated 150 kilometers to

see an infectious disease specialist, which presents a major barrier to accessing care and

treatment (Olivier & Stanciu, 1999). The lack of housing stability was another significant

finding from the assessment. Twenty percent of persons living with HIV/AIDS described

inadequate housing and home conditions, and dissatisfaction with their current living

situation as reasons for poor access to social service agencies, heighted stigma, and self-

isolation (Olivier & Stanciu, 1999). Results from the report supported the efforts of AIDS

service organizations to improve the availability of an emergency response fund to offset

costs associated with HIV/AIDS, and enhance relations with local farmers and food

producers to better the nutrition of people with this disease. AIDS/SIDA Moncton also

now provides access to subsidized housing units through cooperation with housing and

homelessness serving agencies.

Six years later, a second community assessment coordinated by Nicol and Butler

(2005) explored the experiences of stigma, discrimination, care, and support of people

living with HIV/AIDS in New Brunswick. Concerns about transportation and expense

issues, and the health of people living with HIV/AIDS were similar to those noted in the

1999 report and remain key social problems that AIDS service organizations try to

address. The high cost of travel to health and social services is a significant barrier for

people to access HIV care and treatment. Of the twenty-three participants in Nicol and

Butler's (2005) study, 30% lived in rural areas due to the lower cost of living. A total of

61% lived in Fredericton and traveled 1.5 to 4 hours round-trip to Moncton or Saint John to see an infectious disease specialist. An estimated 30% of participants traveled 5 to 20 minutes by vehicle to access HIV care (Nicol & Butler, 2005). This community report not only suggests that there is a high prevalence of people living with HIV in rural regions of New Brunswick, but also that the majority of the population travels long distances to access medical treatment. It identifies an ongoing gap in the care continuum from the perspective of people living with HIV in the province, largely in the diagnosis, treatment, and management of the disease.

That same year (2005), Bourassa and Bulman produced a community report assessing the quality of life among women living with HIV and AIDS in New Brunswick, with an emphasis on providing better access to health information and resources. A total of 93 women, aged 18 years or older, at risk of HIV infection took part in the study. Most of the women indicated they preferred to get health information about HIV/AIDS from (in descending order): infectious disease specialist, doctor, nurse, sexual health center, hospital or clinic, and AIDS service organization (Bourassa & Bulman, 2005). Factors such as privacy, trust, disclosure, and stigma affect how and where people access health information, such as in-person or a 1-800 support number. Of those participants, 10% reported difficulty accessing health information due to feelings of shame and embarrassment about what they required to meet their specific needs (Bourassa & Bulman, 2005). Medical professionals are also the first point of contact for individuals and the preferred source for information on treatment and disease progression after their HIV diagnosis, largely because of their medical training.

All three community reports focus on the changing needs and experiences of women living with HIV in New Brunswick. They consistently reveal the challenges women face when accessing care in the province, including transportation problems to and from medical appointments, housing instability, financial insecurity, and stigma. These barriers-to-care are the result of long-standing structural inequities in the province that can be traced to the federal investment mandate for funding AIDS service organizations and other agencies to enhance programs for populations that account for the highest proportion of those living with HIV, mainly MSM and injection drug users. This systemic flaw in health care provision remains unaddressed in New Brunswick. Instead, efforts are being made to bridge gaps in the care continuum that mostly consist of improvements in harm reduction strategies, needle exchange outreach services, and access to treatment.

Harm Reduction Strategies

AIDS service organizations, including AIDS New Brunswick, AIDS Saint John, and AIDS/SIDA Moncton, play an important role in the delivery of harm reduction, education, and support initiatives in the province, largely through school-based and community services. There are a number of challenges facing AIDS service organizations in New Brunswick aiming to provide support to persons living with and affected by HIV. These include the lack of an HIV/AIDS strategy, a total of only eight infectious disease specialists centered in the cities of Moncton and Saint John, provincial clinics that no longer provide sexual health testing to people between the ages of 20 and 24, and rising rates of chlamydia and syphilis. Sexually transmitted infection rates have been on the rise

in the province since 2007, especially among young adults aged 15 to 24. In 2014, women accounted for 73% of all recorded chlamydia cases in the province (CBC News New Brunswick, 2014). AIDS service organizations play an important role in normalizing HIV testing and access to care, treatment, and support after diagnosis. The condom distribution program at AIDS New Brunswick, for example, distributes between 20 to 30 thousand condoms each year through front line and outreach services (AIDS New Brunswick, 2017).

AIDS New Brunswick also began offering free biweekly testing for sexually transmitted infections, including chlamydia, gonorrhea, hepatitis, syphilis, and HIV, in an attempt to increase testing and reduce time to treatment after the province ceased sexual health screening for young adults in 2011 (CBC News New Brunswick, 2014). Testing for sexually transmitted infections as part of this new initiative through AIDS New Brunswick is made possible through partnerships with the University of New Brunswick's Faculty of Nursing and the Public Health Agency of Canada. The sexual health clinic at AIDS New Brunswick began in 2015, after my fieldwork was completed.

Further, instead of a provincial initiative to address HIV and AIDS, a New Brunswick hepatitis C management strategy was produced in 2014 to reduce the spread of communicable diseases in the province (New Brunswick HCV Advisory Board, 2014). This strategy enhances the expansion of harm reduction services, specifically screening, referral, assessment, and treatment in New Brunswick, through community partnerships and sharing resources. A priority of the plan is to reduce wait times for access to substance abuse treatment programs to within acceptable limits (Province of New

Brunswick, 2013). Blood screening for HIV infection, HCV, and other communicable diseases is extremely low among certain groups within New Brunswick, including homeless and insecurely housed persons, intravenous drug users, sex workers, persons released from incarceration, ethnic minority populations, and First Nations people (New Brunswick HCV Advisory Board, 2014). Expanding the capacity of sexually transmitted and blood-borne infection screening services and needle exchange programs is an important initiative to prevent, manage, and control communicable disease, but also further masks what is happening with HIV/AIDS and, more particularly, HIV/AIDS in women.

Needle Exchange Programs

New Brunswick began funding needle distribution services in the province through AIDS service organizations in 2008. The contract specified that the provincial government would provide funding of $50,000 per year for education, and condom and needle supplies distribution (New Brunswick Department of Health, 2010). Needle distribution services in the province, prior to 2008, were solely funded through the Public Health Agency of Canada. Yet, two of the AIDS service organizations were receiving support in the form of needles at the time. Needle exchange programs remain to be managed and delivered by all three AIDS service organizations, and are an increasingly important frontline service to people living with HIV and HCV infection (New Brunswick Department of Health, 2010).

Since then, there has been a significant expansion of harm reduction services in Fredericton, Saint John, and Moncton (Appendix I). Appendix I illustrates the number of

needles distributed to injection drug users through all three AIDS service organizations in

the province in an attempt to reduce the spread of HIV and HCV infection. Funding for

needle distribution services in New Brunswick is from the Department of Health and

Wellness, but sustaining these programs has become increasingly challenging due to

increased demand from users. To better reach their clients, in 2012 AIDS New Brunswick

expanded its needle service distribution program to the city of Miramichi (two hours

north of Fredericton) where reported HCV infections were on the rise. In the initial year

of operation for the Miramichi Needle Exchange program, an estimated 188 service users

accessed clean drug equipment 286 times, and these numbers have increased significantly

over the years (AIDS New Brunswick, 2013). The Miramichi Needle Exchange

Program's distribution of condoms, drug equipment, and total number of users accessing

the services continues to grow. In fact, AIDS New Brunswick (2013) reports a 15%

increase in syringes distributed and the number of times services were accessed. Harm

reduction services, providing sterile needles, syringes, and establishing appropriate

disposal protocols, are essential prevention programs to reduce transmission among

injection drug users, an exposure category for new HIV infections on the rise in the

province.

Access to Necessary Medications

The total cost of health care in New Brunswick is $3.46 billion annually; the

largest health spending categories, including human resources and professional fees,

health care facility infrastructure, and medical equipment (New Brunswick Health

Council, 2016). The Canadian Institute for Health Information (2017) in fact estimates

that each province and territory spends more than 60% of its total health spending on these expenditures. Although 30% of the cumulative health system's expenditure is spent on providing primary health services and other community services, the annual average cost of health services used by people living with HIV in the province is unknown because it accounts for a small portion of the overall health care use. Hypertension (27%) and arthritis (17.4%) cases respectively account for the highest chronic health conditions and drug copay assistance programs in the province (New Brunswick Health Council, 2016).

The province's health spending however is $6,643 per person (Canadian Institute for Health Information, 2017). Kingston-Riechers (2011) suggests that the direct lifetime treatment cost of HIV infection (i.e., antiretroviral therapy, hospital care, and home care) in Canada is $250,000 per person. This cost will increase with disease progression or decrease with health stability. The treatment value is assumed to be relatively the same for people living with HIV in both New Brunswick and Nova Scotia. The cost of treatment is a challenge in have-not provinces. The New Brunswick prescription plan for people living with HIV, Plan U, helps to offset the costs associated with drug treatment. The plan requires individuals living with HIV to pay 20% of the cost associated with prescriptions to a maximum of $20, and an annual registration of $50 to access the drug coverage plan (Government of New Brunswick, 2017).

The New Brunswick Prescription Drug Plan subsidizes drug coverage for 105,000 residents, including low-income seniors, organ transplant recipients, and people living with HIV (Government of New Brunswick, 2012). For individuals uninsured with New

Brunswick Medicare, such as homeless and insecurely housed persons, the Government of New Brunswick is developing a new drug plan to subsidize treatment costs based on annual income. Approximately 20-30% of people living in New Brunswick do not have drug coverage; it is unknown how many of these people are living with HIV, HCV or other STBBIs (Government of New Brunswick, 2012). The new drug plan ensures that all uninsured people in the province have access to treatment; to be eligible for Plan U, individuals must be registered with New Brunswick Medicare. The availability of a drug assistance program in the province and the federal government's control of treatment costs ensures women's access to antiretroviral drugs to treat HIV infection. The average annual cost of HIV treatment for persons in New Brunswick is unknown; however, low copayments in the face of rising prices for existing antiretroviral drugs results in further financial insecurity for women based on my observations in the field.

Nova Scotia

A total of 2,000 people live with HIV and AIDS in Nova Scotia and Prince Edward Island, and the majority of cases are identified among injection drug users and men having sex with men (Public Health Agency of Canada, 2015a). The reader will recall that the Public Health Agency of Canada combined the data for Prince Edward Island and Nova Scotia in 2012 due to the small number of cases in Prince Edward Island reported annually. For simplicity from hereon, references to "Nova Scotia" will include Prince Edward Island.

The data on HIV incidence for Nova Scotia reflects the number of reported cases in the provinces. Free HIV screening is available in two different ways: nominally (since

1985) or non-nominally (since 1991) and anonymously (since 1994) (Gahagan & Proctor-Simms, 2013). HIV testing is readily available through the Halifax Sexual Health Centre, the AIDS Coalition of Cape Breton, and at three sites in Cape Breton (Gahagan & Proctor-Simms, 2013). A closer look at Figure 2.1 also reveals a 7:1 ratio for male to female HIV and AIDS prevalence in the province; the incidence of HIV incidence among MSM is almost double the national average. Men who have sex with men for 88% of all HIV and AIDS cases in the province (in Figure 2.1), but this is no longer the most common exposure category for men. As is the case for New Brunswick, injection drug use and heterosexual contact are now the leading contributors to new HIV infections among gay and bisexual men (Nova Scotia Health and Wellness, 2012).

The first province-wide assessment of the health of women living with and affected by HIV in Nova Scotia was produced in 1994. The most striking finding from this one-year study is that women reported greater worry about being infected with HIV and stigma than men. Women with HIV, and their experiences with the infection, were apparently invisible within the epidemic, especially in the Maritime Provinces (Allen, 1994). Allen's (1994) study discussed how physicians did not consider women to be at risk for HIV infection. This attitude reflected the lack of understanding of women's vulnerability to HIV infection and consequently, a large proportion of women were not tested for HIV until much later in the disease progression (Allen, 1994). Many available HIV resources and materials in the 1990s were designed for men in response to the much higher proportion of gay and bisexual men living with HIV. AIDS service organizations made an effort to bridge the gap in the care continuum by providing women with

information about HIV and AIDS, including how to navigate care, treatment, and support services for this underserviced population because this knowledge for HIV positive women was lacking (Allen, 1994). The development of HIV and AIDS resources by AIDS service organizations was a starting point for addressing women's unique care needs that larger agencies, including the Canadian AIDS Society and the Canadian AIDS Treatment Information Exchange, produce for national distribution.

Researchers, government agencies, and private foundations have produced a great deal of literature on HIV/AIDS and hepatitis C in Nova Scotia, but little information is written on the experiences and needs of HIV-positive women living in rural and urban areas. Susan McWilliam's (2002) MA thesis is one of the earliest studies of the care, treatment, and support needs of women living with HIV and AIDS in Nova Scotia. Ten women were involved in the project. Nearly all of the participants were living in poverty with one or more dependents and felt that their ability to access health and support services was affected by the lack of integration of HIV care with sexual and reproductive health care, and inexpensive or free childcare to attend medical appointments. Other barriers affecting access to care among women living with HIV included the high costs associated with transportation to medical appointments and the limited hours of operation for support services (McWilliam, 2002). The results of this study suggest that women are excluded from much of the HIV service landscape and they expressed feelings of being pushed to the margins of care, where spaces are male-centered. Although efforts by AIDS service organizations and other community-based agencies are being made to create women's health workshops and programs, there is a lack of financial support for new

initiatives in this area due to the relatively small number of HIV-positive women in the province (McWilliam, 2002). AIDS service organizations and other community-based agencies providing care, treatment, and support services to all persons living with HIV have traditionally provided generic materials that do not meet the complex needs and preferences of different populations. Structural changes to AIDS service organizations, which began on April 1, 2017 to meet the new funding criteria of the Public Health Agency of Canada, will create an even further gap in gender-specific services. The changing Public Health Agency of Canada funding structure combines support for HIV and HCV programs. The new integrated approach to treatment and prevention of STBBIs could increase access to care and improve health outcomes for the population. Shifting away from services specific to the needs of people living with HIV/AIDS is not only central concern for AIDS service organizations, but its affect to further limit women's access to care and increase their invisibility in the epidemic (Rogers, 2013). Enhancing harm reduction is one way AIDS service organizations are attempting to keep people living with HIV at the forefront of the agencies' programs and initiatives.

Harm Reduction Strategies

Harm reduction activities in Nova Scotia focus on hepatitis C rather than HIV or other STBBIs because the prevalence of HCV is two times higher than the national rate and is on the rise (Nova Scotia, 2015; Silva, 2016). A total of 5,000 people are living with HCV and the number of reported cases in Nova Scotia is on the rise and is highest among men between the ages of 25 to 39 (CBC News Nova Scotia, 2013b; Nova Scotia Health and Wellness, 2014). Hepatitis C infection, in fact, is ten times more prevalent than

HIV/AIDS and a growing health care issue in New Brunswick and Nova Scotia (CBC News Nova Scotia, 2013b). There are growing efforts by AIDS service organizations and other community-based agencies in the province, including the Ally Centre of Cape Breton, Northern Healthy Connections Society, Healing our Nations, Direction 180, and Mainline Needle Exchange, to enhance the reach of HIV and hepatitis testing and care to rural communities.

Mobile outreach street health is a harm reduction service unique to Nova Scotia in the Maritime Provinces. A mobile outreach service involves the delivery of primary care services to underserved populations, in this case the Halifax and surrounding areas by Mainline Needle Exchange, Direction 180 Bailey Bus, and the mobile outreach street health (MOSH) unit. All of these mobile services are located along Gottingen Street, Halifax. The 180 Bailey Bus, the service's formal name, is a mobile service that provides methadone treatment to four sites, including Halifax, Dartmouth, Fairview, and Spryfield (Direction 180, 2017). Mainline Needle Exchange and MOSH have integrated the delivery of harm reduction services three times a week in the Halifax area.

Figure 2.2 shows the major stops along the route used by both organizations to provide harm reduction services to the community. The demand for mobile services is rising. MOSH, for instance, will often visit 270 people a month in the Halifax regional municipality area (Hill, 2011). Mobile outreach efforts in the urban-rural fringe are important to prevent and control the spread of HIV in the province by providing free condoms or resources to persons who not have access to health or social programs. Point-of-care testing and counseling in mobile units in community and outreach locations is the

next initiative for agencies to undertake in curbing its transmission in Nova Scotia. It has

proven to be an effective outreach tool for at-risk groups in the provinces of British

Columbia, Alberta, Saskatchewan, Manitoba, Ontario, and Quebec. Rapid testing is not

available in the Atlantic Provinces or in the Territories (Broeckaert & Challacombe,

2015).

Figure 2.2: Street outreach locations for Mainline Needle Exchange and MOSH mobile
services.[5] Created by P. Medeiros© using ArcGIS 10.2.
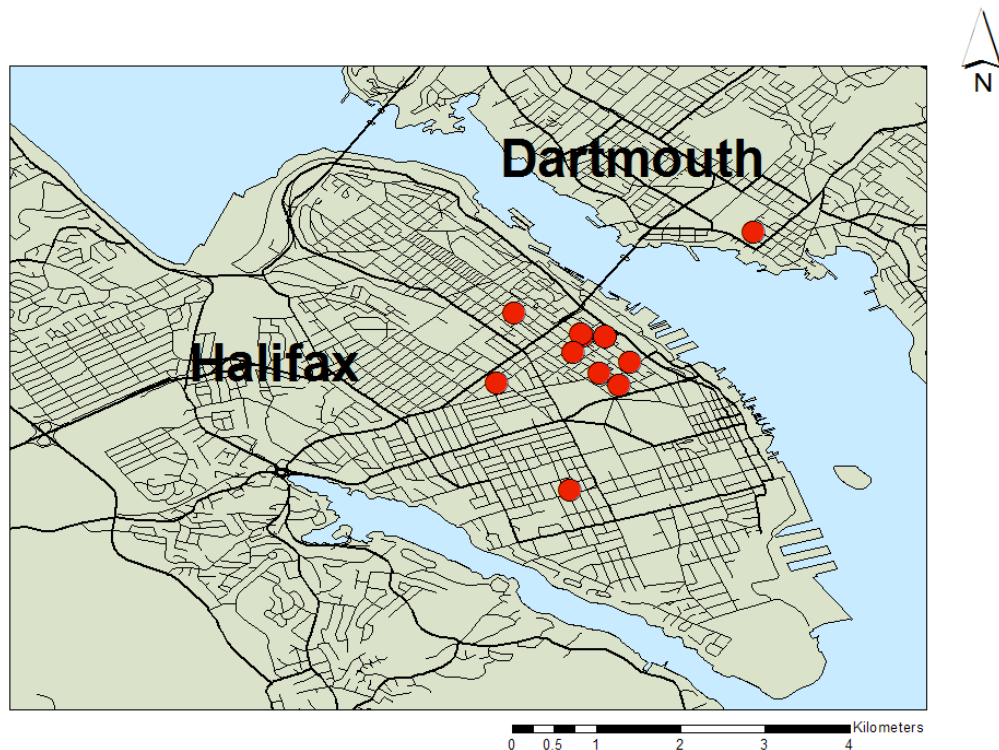
All of the mobile outreach services in Nova Scotia are located in Halifax and

provide medical support to people living with and affected by HIV, including harm

---

[5] Information gathered from Mobile Outreach Street Health (2017). See webpage
http://moshhalifax.ca/where-to-find-us/ for a complete list of checkpoints along the route.

reduction supplies (e.g., condoms, swabs, cookers, Vitamin C), wound care, addiction-related support, health education, and community referral support. A priority of mobile services is to target youth between the ages of 20 to 29 who account for a quarter of all positive HIV tests in the province (Hill, 2011). Rotating schedules around work areas in the Halifax regional municipality and some surrounding communities are important for reaching underserved and marginalized key populations living with HIV, HCV or other STBBIs.

The Nova Scotia Strategy on HIV was released in 2003 to enhance the provincial response, delivery, and uptake of HIV care and treatment (Provincial HIV/AIDS Strategy Steering Committee, 2003). An up-to-date provincial strategy was produced by the Nova Scotia Advisory Commission on AIDS in 2005 to address stigma and discrimination issues, especially within the context of gender, as well as detail the impact of HIV infection on the province (Kirkland et al., 2008). The involvement of people living with and affected by HIV was key to developing an evidence-informed advocacy strategy to reduce the number of people who become infected with HIV, increase access to care and treatment, and improve health outcomes (Provincial HIV/AIDS Strategy Steering Committee, 2003). Each element of the HIV care continuum in Nova Scotia is important for reducing HIV transmission; however, shared decision-making with caregivers is one of the unique guiding principles in the strategy, and a critical feature of patient-centered communication and care. Other principles that underpin the provincial AIDS strategy include the delivery of better coordinated and integrated care in the community, strengthening of community-based hospice and palliative care, and the larger initiative to

identify gaps in HIV service delivery from the perspective of people living with HIV (Nova Scotia Advisory Commission on AIDS, 2013a).

The Nova Scotia continuum of care is more efficient than New Brunswick's, largely because of its aim of progressive change. AIDS service organizations in New Brunswick have come to rely on the Nova Scotia Strategy on HIV to develop new programs in their communities because New Brunswick does not have a formal strategy of its own to direct HIV prevention, treatment, and care initiatives. Community-based organizations that provide health and social services to people living with HIV in New Brunswick rely on the core principles of the Nova Scotia Strategy on HIV to improve access to prevention, testing, treatment, and support services. It remains to be determined whether the guiding principles of the Nova Scotia Strategy on HIV are still relevant for AIDS service organizations in the context of the expansion of the federal mandate to enhance programs and services for people living with HIV and other STBBIs. A review of HIV in both provincial policies is needed to align with the new national guidelines released by the Public Health Agency of Canada, including increased availability of sterile syringes, drug paraphernalia, condoms, and other resources through needle exchange programs for people living with or affected by HIV and HCV.

Needle Exchange Programs

The Government of Nova Scotia funds all needle exchange and distribution of other safer injection equipment services. The demand for harm reduction programs is on the rise in the province (Nova Scotia Advisory Commission on AIDS, 2016). Other safer injection supplies include glass stems, metal pipe screens, crack pipes, street cookers,

matches, and alcohol swabs. Core funding from the province to support harm reduction programs provided by community-based organizations has remained unchanged in the past six years (CBC News Nova Scotia, 2013a). Needle distribution programs across the province saw an increase of about 42% in demand for needles and other drug equipment (Chiu, 2016). For example, Mainline Needle Exchange distributes on average 10,000 to 30,000 sterile needles each day (Chiu, 2016). Kirkland (2008, p. 36) suggests that "80% of the needle exchange program clients are HCV+, about 8% HIV+, and about 5-8% are co-infected [in the province]."

Community-based organizations, including Mainline Needle Exchange, the Northern Healthy Connections Society, and the Ally Centre of Cape Breton, all provide integral direct frontline services in prevention, education, care, and support for persons living with and affected by STBBIs. The provincial government is committing more than $1 million in funding to three community-based harm reduction organizations in response to growing opioid drug crisis in the province. Mainline Needle Exchange ($247,000) and the Northern Healthy Connections Society ($160,000) will receive additional funds to support enhancing harm reduction efforts (Previl, 2017). Because the distances they need to travel is a main barrier-to-care for persons living in the province, Mainline Needle Exchange will use the funds to expand its central mobile outreach program to rural areas to seven days a week. Appendix J reveals the number of needles distributed to injection drug users by Mainline Needle Exchange and the Northern Healthy Connections Society, a main frontline care service accessed by people living with HIV in the province. Needle distribution data for the Ally Centre of Cape Breton was not made available; however, a

total of 433,284 needles were distributed in the year-end of 2014 (Melissa, personal communication, January 21, 2015).

Mainline Needle Exchange is the main needle and syringe distribution program in the Halifax area and surrounding communities. A needs assessment produced by Mainline Needle Exchange in 2002 not only expresses the need to continue supporting current and former drug users through harm reduction strategies, but also to expand needle and syringe distribution programs via mobile outreach to other regions, including Truro, New Glascow, Kentville, Lunenburg, Bridgewater, and Yarmouth. These particular regions of the province have higher rates of needle sharing compared with that in other areas of the province like the Halifax area (Mainline Needle Exchange, 2002). The study reveals two major findings associated with injection drug use and its connection to the spread of HIV and HCV infection: 1) access or lack thereof to needle exchange programs influences the behaviors of persons to share needles with others, and 2) traveling to Halifax for care and treatment places persons from rural regions at an elevated risk for exposure to urban drug behavior (Mainline Needle Exchange, 2002). Increasing access to needle distribution services in the urban-rural fringe is important because injection drugs are the second leading cause of HIV infection in Canada. Nova Scotia has the highest prevalence of injection drug use in Atlantic Canada (Adamson, 2013). Appendices I and J reveal that the distribution of injecting equipment and other supplies are greater in Nova Scotia. The higher distribution of resources (e.g., information, condoms, and needle supplies) in the province relates to the population size differences in the two provinces and the increasing efforts of organizations to bring underserved populations in rural regions.

Access to Necessary Medications

The total cost of health care in Nova Scotia is $10.5 billion annually; $6.2 million in new health spending funds in 2017 was in an effort to increase mental health resources, social assistant monies, and the reach of harm reduction programs in the province (Doucette & Tutton, 2017). It is unknown how much of provincial monies fund the treatment of HIV and AIDS, but the province's overall health spending is $6,996 per person; a total of $353 more is spent to improve overall health in Nova Scotia than New Brunswick (Canadian Institute for Health Information, 2017; Kephart et al., 2016). Although every effort is being made by the Government of Nova Scotia to train new doctors to practice medicine in rural areas and to enhance home care and support services, persons living with and vulnerable to HIV infection continue to face complex barriers to access care ("2014 Budget Highlights", 2014; McLeod, 2013).

High prescription drug costs are a concern for people living with HIV and can affect treatment adherence; however, the Nova Scotia Department of Health and Wellness has a formulary and Pharmacare program to offset the costs associated with HIV treatment. The provincial prescription plan requires that an individual pay a $10.42 dispensing fee for a three-month supply of medications (Nova Scotia Advisory Commission on AIDS, 2013b). Although basic and special needs allowances are also available to offset costs associated with treatment, placing HIV medications on a specialty tier by insurance companies makes it a challenge for people living with HIV to access some HIV drugs, vitamin supplements, and alternative therapies prescribed by their doctors. Because of the high cost of antiretroviral therapy, some are opting for

lower-cost drugs and others are experiencing periods of poor adherence while waiting for alternative treatment plans (Nova Scotia Advisory Commission on AIDS, 2006). Pharmacare programs include persons who are homeless or low-income earners to make sure all groups have access to care and treatment; eligibility for Pharmacare programs requires that an individual be registered with a health plan or evaluated based on their individual circumstances (Nova Scotia Advisory Commission on AIDS, 2006).

The federal, provincial, and territorial governments of Canada are responsible for administering their prescription drug benefit program. Each offers varying levels of coverage, eligibility criteria, enrolment processes, and copayments. While drug formularies for New Brunswick and Nova Scotia are similar, there are items of which are not covered, including those dealing with the side effects of medication, and vitamin supplements ("Access and coverage", 2017; Marshall, 2006). Increasing formulary access to all antiretroviral treatments and retaining a low dispensing fee like Nova Scotia ensure that treatment is more access to those living with this disease.

Summary

This chapter examines the existing landscape of health and support services for women living with HIV in New Brunswick and Nova Scotia to understand the delivery of harm reduction, education, and outreach services. This review of the literature points to the increased efficiency and effectiveness of health service delivery in Nova Scotia compared to New Brunswick. The reader will recall that Nova Scotia provides more funding for harm reduction and community outreach efforts (i.e., mobile and needle

distribution programs) to better service the diverse needs of people living with HIV and AIDS.

Most of the information on HIV and AIDS in both provinces comes from the grey literature, which underlines the need for this study to learn more about the diverse health needs of women. The grey literature focuses heavily on the topic of harm reduction (i.e., needle exchange programs) because it is the only direct service these organizations provide to the community and requires the most government funding to enhance its capacity and outreach to rural regions.

This focus on harm reduction and community outreach, which is increasing in the face of a changing mandate, masks the life stories of women and their experiences with HIV and AIDS. The shifting response from "HIV in Canada" towards "hepatitis C and other STBBIs" has also meant fewer publications emphasize first-hand accounts of experiences and feelings of people living with HIV. As a case in point, my 2012 MA dissertation is the most recent study on women's lived experience with HIV/AIDS in New Brunswick.

The abundance of information on harm reduction strategies, needle exchange outreach services, and access to treatment tends to highlight injection drug use as the main risk category for HIV infection in New Brunswick and Nova Scotia, making other exposure groups, like women, invisible in the epidemic.

The following chapter describes the methods employed in this study to collect data in New Brunswick and Nova Scotia.

Chapter 3 Materials and Methods

In this chapter, I describe the process and mixed methods through which I collected data for my analysis of women's experiences, needs, and complexities of accessing health and social services in New Brunswick and Nova Scotia. I also describe the challenges faced while conducting nine months of fieldwork in the two provinces.

A Community-based Research Study Design

It has been common practice to involve people living with and affected by HIV in health research in Canada since the signing of the UNAIDS Greater Involvement of People Living with HIV declaration in 1994 (Chung & Lounsbury, 2006). A total of 192 countries are now part of the declaration which includes a commitment to "support a greater involvement of people living with HIV at all…levels…and to…stimulate the creation of supportive political, legal and social environments (UNAIDS, 2007, p.1). Community-based research (CBR) refers to collaboration between scholars conducting research, and community members living with and affected by HIV, to address structural inequities, social, health and cultural disparities (Schensul, 2010). The role of this methodological framework is to develop relationships with community informants and to verify key findings with community members (Harris, 2006). Researchers, however, define the community to be involved in a study and determine their level and method of involvement (Harris, 2006). Respect and humility, diplomacy (efforts to maintain relationships in the field), and flexibility (working closely with the community to design and change elements of the study) are key interpersonal skills that assist researchers to strengthen community ties and engagement in the field (Hatala et al., 2017).

The decision about the extent to which women and community-based agencies would participate in this dissertation research was made early in the planning process. All key community informants in this study had the opportunity to review and modify my thesis proposal, including predefined research questions, during a live webinar I hosted on April 9, 2014. The CBR orientation was important for designing a project relevant to the lives of women living with HIV in New Brunswick and Nova Scotia, but also for adhering to the framework used in all other HIV research studies in Canada (Archibald & Halverson, 2013; Arthur, Beausoleil, Guay, & Gahagan, 2013; Bulman, 2004; Gahagan, 2013).

Before Going to the Field

The live webinar I hosted on April 9, 2014 was also my first initiative to recruit community-based agencies to participate in my study. The 12 participants in the webinar included researchers, health care workers, community workers, educators, people living with HIV, and employees of community-based organizations, all of whom are members of the Atlantic Research Interdisciplinary Research Network. In attendance were key community stakeholders, including AIDS New Brunswick, AIDS Saint John, AIDS/SIDA Moncton, Hepatitis Nova Scotia, and the Nova Scotia Advisory Commission on AIDS. I presented a 15-minute presentation focused on the roles and responsibilities of participating community-based agencies, research goals and methods, and when and how my doctoral study would be conducted. They all agreed to support my study. Meeting minutes were sent to others who could not attend (Appendix A).

The second step in the recruitment process involved working closely with

community-based HIV organizations to identify where women living with HIV were

accessing health and social services, including clinics, health care centers, food banks,

and transition housing centers. Interviews with the women who participated in this study

confirmed this list and added several other locations. Table 3.1 lists all 43 of the

organizations that posted recruitment information about my study and where I conducted

interviews. It was clear from the outset that these community organizations would yield

rich insights into the experiences of women living with HIV and accessing care,

treatment, and support services.

Table 3.1: Community-based organizations assisting in the recruitment process.

Organization	City
New Brunswick	
AIDS New Brunswick	Fredericton
Women in Transition House	Fredericton
Community Health Clinic	Fredericton
Grace House for Women	Fredericton
Gignoo Transition House	Fredericton
Fredericton Sexual Assault Crisis Centre	Fredericton
AIDS/SIDA Moncton	Moncton
Crossroads for Women	Moncton
AIDS Saint John	Saint John
Sophia Recovery Centre	Saint John
Sexual Health Clinic	Saint John
Hestia House	Saint John
Coverdale Centre for Women	Saint John
Charlotte County Hospital Methadone Treatment Program	St. Stephen
Campobello Health Centre Methadone Treatment Program	Welshpool
Nova Scotia	
Antigonish Women's Resource Centre	Antigonish
South Shore Transition House	Bridgewater
Healing Our Nations	Dartmouth
Elizabeth Fry Society of Mainline Nova Scotia	Dartmouth
Mainline Needle Exchange	Halifax

Direction 180	Halifax
Mobile Outreach Street Health	Halifax
Nova Scotia Advisory Commission on AIDS	Halifax
North End Community Health Centre	Halifax
Halifax Sexual Health Centre	Halifax
Avalon Sexual Assault Centre	Halifax
Manna for Health	Halifax
Adsum for Women and Children	Halifax
Bryony House	Halifax
Mi'kmaw Native Friendship Centre	Halifax
Feed Nova Scotia	Halifax
Chrysalis House Association	Kentville
Ally Centre of Cape Breton	Sydney
Every Woman's Centre	Sydney
Cape Breton Centre for Sexual Health	Sydney
Cape Breton Regional Library	Sydney
Cape Breton Transition House Association	Sydney
Well Women's Clinic	Sydney
Marguerite Centre	Timberlea
Northern Healthy Connections Society	Truro
Colchester Sexual Assault Centre	Truro
Third Place Transition House	Truro
Juniper House	Yarmouth

Despite the support and assistance of these organizations, it was difficult to recruit women for this study. The circumstances of their lives, such as poor health, time constraints, concerns about HIV status disclosure, and stigma, inaccessibility to childcare and transportation, coupled with distrust of the researcher, meant that many women were reluctant to participate. I agreed to a 10-minute radio interview by CBC News PEI on November 5, 2014, broadcast on 96.1 FM (http://www.cbc.ca/news/canada/prince-edward-island/aids-researcher-seeks-p-e-i-women-1.2824231). This interview gave me a chance to talk about the research design, aims, and the gaps in service delivery

approaches to HIV testing and treatment in the Maritime Provinces. Key community informants and friends shared the digital radio recording across Canada through Twitter and Facebook.

The radio interview was an effective way to promote my research and resulted in the participation of three women living with HIV from the city of Halifax. The recruitment challenges in this study were addressed by acknowledging the sensitive nature of the research topic, maintaining a flexible interview schedule, facilitating interviews in the offices of the community-based organizations, and assigning pseudonyms to ensure the confidentiality of women's identity. Raising awareness to the fact that women living with HIV in New Brunswick and Nova Scotia have received little attention in the literature resulted in the recruitment of another seven women for this study. All three efforts – the webinar, posting recruitment materials at community organizations, and the CBC interview – attracted 49 community sector employees to the study, largely because the use of pseudonyms concealed their identities and reassured them about discussing underlying problems in the organization and gaps in the HIV care continuum. A multi-pronged, adaptive approach was necessary in the recruitment process to overcome the challenges of the low incidence of HIV among women in New Brunswick and Nova Scotia, and the vast geographical region encompassed of the two provinces.

Ethical Considerations

The study was given clearance by McMaster University's Research Ethics Board on May 9, 2014. Before beginning the project, I was aware it would be difficult to recruit

participants in New Brunswick. I was fortunate that Dr. Duncan Webster, from the Saint John Regional Hospital, agreed to serve as the staff member signee on the ethics application to the New Brunswick Horizon Health Network Research Ethics Board, which then allowed me to gain permission to post recruitment materials in municipal health clinics (Appendix B and C). With his support, the Horizon Health Network waived the $2,500 application fee (Appendix D), which was well beyond my budget. In Nova Scotia, identification and recruitment of participants was not difficult because of the overwhelming support of AIDS service organizations and community-based organizations.

Two changes were made to the project after ethics clearance had been obtained from McMaster University, including additional clearance from the Health Research Ethics Authority in Newfoundland, and offering $10 gift cards to Tim Horton's or the Atlantic Superstore as compensation to participants. The gift card amendment was made as a result of recommendations from AIDS New Brunswick. I withdrew my application for Newfoundland and Labrador Research Ethics Review Board after completing the province's eight-module research ethics tutorial (Appendix E). This setback occurred because the AIDS Committee of Newfoundland and Labrador explained they could no longer be involved in my research because they had committed all their time to a larger study in the province.

In the Field

My multi-sited ethnographic fieldwork, carried out in seven cities during nine months from June 2014 to March 2015, was conducted in the offices of AIDS service

organizations and community-based organizations, including AIDS New Brunswick, AIDS Saint John, AIDS/SIDA Moncton, Northern AIDS Connection Society (renamed Northern Healthy Connections Society), AIDS Coalition of Cape Breton (renamed Ally Centre of Cape Breton), Healing Our Nations, Direction 180, and Mainline Needle Exchange. Locating my research efforts in these organizations allowed me to learn about each organization's everyday activities and to inform participants about this study (Figure 3.1). I spent three months collecting data in New Brunswick, two months in Prince Edward Island, and four months in Nova Scotia. I travelled from one organization to another either by renting a vehicle or taking the Maritime Bus. My mode of transportation was dependent on the weather. I made the decision to exclude the Prince Edward Island data from the study at the end of my fieldwork period. This decision was necessary because of extremely low incidence rates of HIV and my failure to recruit women from the province.

To maintain rapport with community-based organizations and their members, I attended a series of meetings and live webinars to discuss integration as a way of delivering better continuity of care, reducing the duplication and gaps in programs and services, lowering stigma related to HIV infections and its associated behaviors (e.g., homosexuality and substance abuse), and focusing on providing care for people who are co-infected with both HIV and HCV (L. Smylie, personal communication, November 5, 2014; Paquette, 2014). The goal of these meetings was to increase the capacity of outreach services and to address the initial challenges of integration for service providers (Arthur et al., 2013). For example, one of the larger meetings with community members,

researchers, and AIDS service organizations from Atlantic Canada was held at Dalhousie

University in November 2014. All of the community-based agencies involved in my

project were present except AIDS New Brunswick. The meeting touched upon issues

surrounding the impact of HIV and its treatment on daily life.

Figure 3.1: Research site locations in New Brunswick and Nova Scotia.[6] Created by P.
Medeiros© using ArcGIS 10.2.
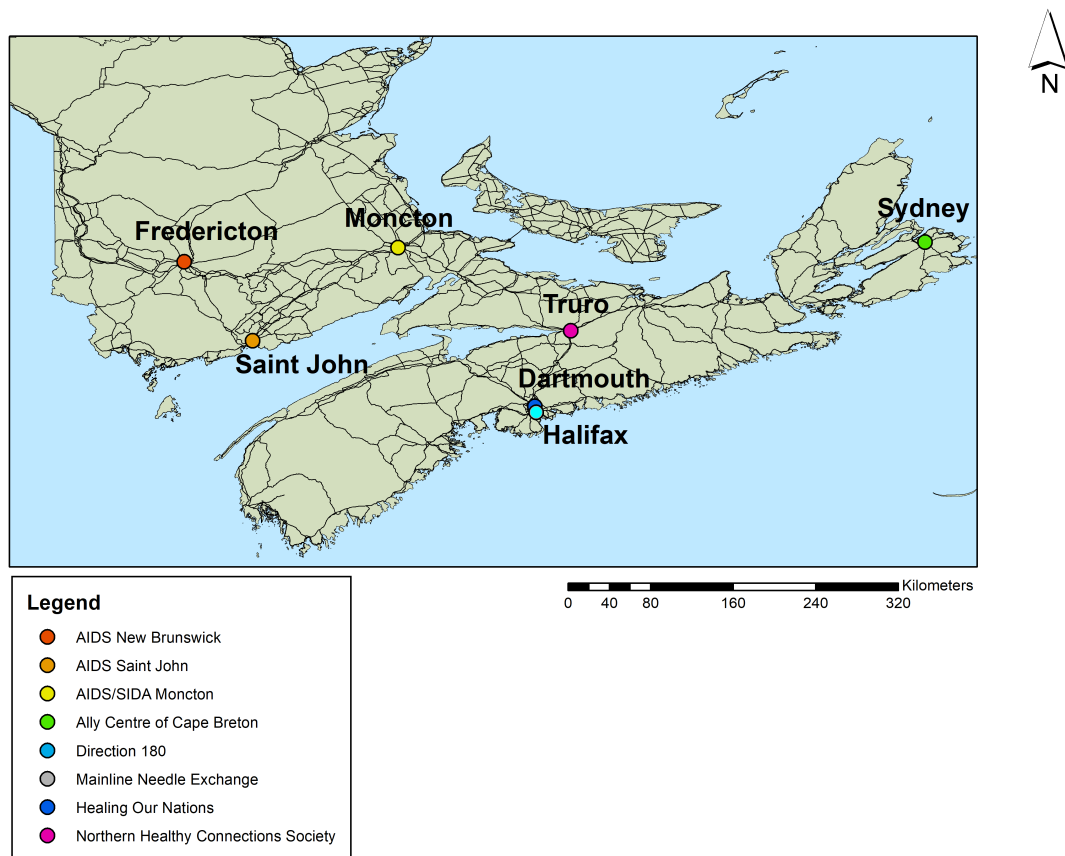
It also centered on the changing funding structure for core programs, such as volunteer

services, administration, and support positions. Conversing with attendees during coffee

---

[6] In my original design for the study, I planned to include the AIDS Coalition of Nova
Scotia, Halifax, and the AIDS Committee of Newfoundland and Labrador, St. John's.
Unfortunately, neither agency had time to participate in the study.

breaks, sharing in small group discussions and activities, and attending the AIDS

awareness flag-raising event in downtown Halifax allowed me to stay in communication

with all the far-flung groups taking part in this project and to update members on my

progress (Figure 3.2).

Figure 3.2: Annual flag raising ceremony in Halifax, Nova Scotia. Photograph by P. Medeiros, November 2014.

To help me recruit women living with HIV for this study, community-based

organizations agreed to display my recruitment posters, and to make my brochures and

information cards available in their waiting areas (Figure 3.3). I provided recruitment

material on my first visit to each organization. I was also fortunate that community

agencies agreed to send recruitment emails on my behalf to female clients over the age of

18 who were living with HIV.

Figure 3.3: A recruitment poster in the waiting room of Direction 180, Nova Scotia. Photograph by P. Medeiros, December 2014.
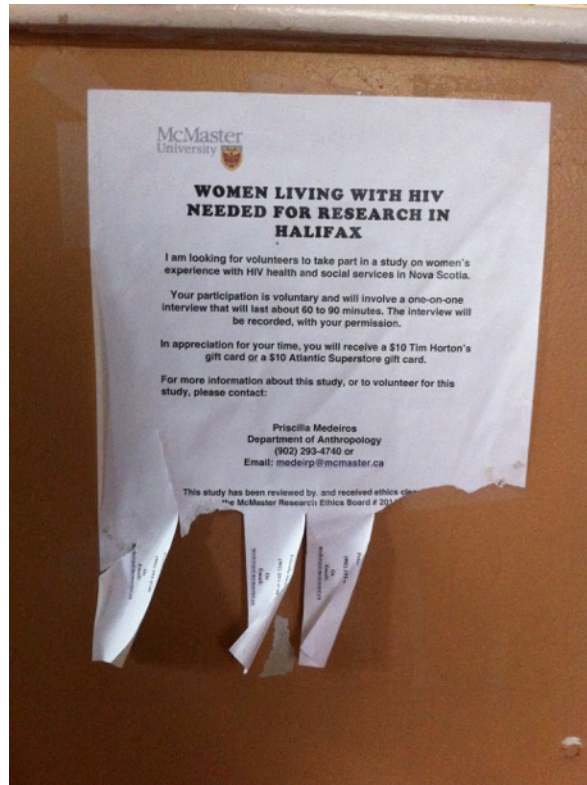
Data Collection Methods

My research was facilitated by previous relationships I had established with a number of community-based organizations during my Master's degree, and new relationships I was able to forge with community members and researchers as a result of the webinar I hosted. The first phase of data collection involved visiting each of the community-based agencies and collecting demographic data that allowed me to better understand the persons being served, community ties, and to observe the interactions between employees and women living with HIV. These data were hand-recorded and transformed into field notes. Participant observation and semi-structured interviews were

used to facilitate the study (Appendix F and G).

On days that I was not observing in the field or conducting interviews, I was at the University of New Brunswick, Dalhousie University, or the Nova Scotia Archives collecting literature on HIV in New Brunswick and Nova Scotia produced by researchers, government agencies, and private foundations. One of the first steps I undertook upon my arrival in New Brunswick was to register for a Council of Atlantic University Libraries card, which gave me borrowing privileges at all libraries. The *eduroam* network provided access to electronic resources at all the universities, including the Canadian newspaper index, Eureka, Dalspace, and the Novanet catalogue.

Participant Observation

To deepen my connections to participants in this study, I took part in the everyday activities of a variety of community-based organizations. I volunteered to answer the telephone, assemble educational materials on substance use and safer sex practices, distributed hypodermic needles and associated paraphernalia, filled condom displays, assisted with the needle pick-up program, and collected needle disposal kits or sharps containers from clients for safe disposal (Figure 3.4). I volunteered for eight organizations while in the field, including AIDS New Brunswick, AIDS Saint John, AIDS/SIDA Moncton, Ally Centre of Cape Breton, Northern Healthy Connections Society, Healing Our Nations, Direction 180, and Mainline Needle Exchange.

Each day began with the Executive Director pairing me with an employee so that I could learn about different tasks and functions in the organization. Task rotation gave me a chance to observe, take notes, and collect other forms of data while working within the

organization. This volunteer work gave me the chance to meet women living with HIV in the early stages of my research and to introduce the project to them. As a result, I was able to conduct informal interviews all the time on topics ranging from treatment and caregiving to more casual conversations about related issues. I established rapport more easily with women because of the informal time spent in the offices of community organizations that provide women with daily support and essential direct services, such as access to HIV testing and counseling. I kept a notepad with me at all times to record the details of my participation in the everyday activities of the organizations. I spent two hours each day writing up my field jottings into field notes.

Figure 3.4: Needle exchange and condom distribution desk at AIDS Saint John, New Brunswick. Photograph by P. Medeiros, July 2014.

Initially, clients were uneasy about my presence in community-based organizations.

Although community members did not express it directly, some people understandably had concerns about my ability to keep their identities anonymous. This reaction is illustrated by a situation that arose as part of my work as a regular volunteer with the on call Mainline Needle Exchange team in the Spryfield area of Halifax. Mainline Needle Exchange jointly works with the Mobile Outreach Street Health unit twice a week to provide accessible primary health care services to people who are homeless or insecurely housed in Halifax and Dartmouth, often meeting people in spaces where there is a greater level of comfort. The mobile team provides a number of health and social services, including blood work, vein care, PAP tests, addiction-related support, and health education. On this particular night, I was working closely with a nurse practitioner and outreach worker. My job was to distribute supplies for safer drug injection, safer smoking (e.g., mouth pieces, push stick), and condoms. A woman called the mobile team to arrange an appointment within the hour to receive wound care for an abscess. When we arrived at her house, she asked me to leave and return to the mobile van after introductions by the nurse practitioner. She was worried about my role as a researcher on the mobile unit and did not want me to observe her care experience.

Reactions to my presence as a researcher were quite varied. The following summaries are taken from my field notes working with the Northern Healthy Connections Society, Healing Our Nations, Mainline Needle Exchange, and Direction 180 methadone clinic. The following vignettes bring into view my different experiences developing and maintaining relationships with participants in the field.

October 28, 2014

I spent the day at the Northern Healthy Connections Society editing the silent auction booklets for spelling and grammar in preparation for their annual fundraiser, greeting community members coming into the office for harm reduction services, and organizing the gift basket raffle with remaining donations. Volunteering in the office gave me a chance to learn more about the organization's history, introduce my project to community members, and arrange interviews with employees.

November 26, 2014

Today I spent two hours working with Healing Our Nations (HON) staff in their boardroom to assemble Aboriginal and First Nations health education resources for the organization's annual gathering on Sunday and future on-reserve workshops. The resource packages included a HON information brochure, four condoms, a condom carrier, an event schedule, and a list of anonymous HIV testing locations in Halifax and Dartmouth. Observing the activities of HON has given me a chance to build relationships with the community sector employees, learn more about the structure of the organization, and the delivery of their education programs to rural communities in the province.

November 30, 2014

Today I volunteered with the staff of HON at their annual gathering in Dartmouth. I was asked by the program manager to facilitate a trivia game to educate people on the basics of HIV prevention. Other activities at the event included jeopardy, foosball, and flash memory card games. The gathering also featured Aboriginal elders, speakers,

dancers, singers and drummers, and Aboriginal arts, crafts, and displays. Volunteering

gave me a chance to strengthen relationships and promote my study in the community.

December 10, 2014

I worked with two outreach street support workers from the Mainline Needle

Exchange mobile unit today from 1:30-7:00 p.m. I was tasked with handing out snacks

(e.g., carrot muffins and chocolate chip cookies) and tracking the distribution of supplies

to people to restock the van. The two-outreach workers gave out needles, syringes, swabs

and other injecting supplies, condoms, and lubricant. The outreach workers kindly

introduced me to each person accessing the street-outreach van services, a total of 25

people. Volunteering with the street-based outreach team resulted in the scheduling of an

interview with a woman the following day.

December 12, 2014

I was asked by the head case manager at Direction 180 to answer phones at the

front desk today, and manage the check-in process to ensure that patient information was

current and schedule the next opiate urine drug screen test for clients. Because the clinic

was busy, the head case manager added collecting urine samples to my duties for the day.

She explained that I was to collect a urine sample from each patient on the screening list

before his or her appointment. Working closely with the head case manager gave me a

chance to introduce my project to a number of women living with HIV in the community

and schedule an interview with one participant for Monday afternoon.

Interacting with study participants in their real-life environments, like the offices

of the organizations or through street outreach services, was important for me to learn

about the HIV care landscape in New Brunswick and Nova Scotia. This fully immersive approach was critical for building relationships with participants and was essential to the integrity of my project. Observing and participating in the day-to-day activities of each organization was a way of building trust during the fieldwork process and recruiting participants for interviews.

Semi-structured Interviews

I conducted 49 one-on-one interviews with community-based employees (n=39) and women living with HIV (n=10). Participants from AIDS service organizations and other community-based agencies came from: AIDS New Brunswick, AIDS Saint John, AIDS/SIDA Moncton, Ally Centre of Cape Breton, Northern Healthy Connections Society, Healing Our Nations, Direction 180, and Mainline Needle Exchange. Seventy-five percent of the organizations are located in urban areas because of their high population density and to create a stronger referral network among community-based agencies that provides health and social services to people living with and affected by HIV. Table 3.2 provides the total number of employees interviewed in this study from each organization.

Table 3.2: Total number of employees interviewed at each site.

Name of the Organization	City Name	Number of Employees	Site Location
New Brunswick			
AIDS New Brunswick	Fredericton	4	Urban
AIDS Saint John	Saint John	6	Urban
AIDS/SIDA Moncton	Moncton	4	Urban
Nova Scotia			
Mainline Needle Exchange	Halifax	5	Urban
Direction 180	Halifax	5	Urban
Northern Healthy Connections Society	Truro	2	Rural
The Ally Centre of Cape Breton	Sydney	7	Rural
Healing Our Nations	Dartmouth	6	Urban

Interviews were 90 to 120 minutes in length and took place at the offices of the organizations for the convenience of participants. Bustling waiting areas and pre-arranging to meet participants in a vacant room in the organization was helpful in protecting privacy and confidentiality. Alternative interviewing arrangements were made on two occasions. One woman in Dartmouth suffered a fractured femur and was unable to travel to the methadone clinic. The interview was held at her home instead. In a second case, a snowstorm in Halifax caused highway travel delays making it difficult to drive to Kentville, a one and a half hour drive from Halifax. The participant and I rescheduled an

over-the-phone interview at the last minute.

I provided in-depth responses to participants' questions and concerns during the informed consent process. Participants were asked a series of questions about the benefits of a women-centered approach to HIV care, their involvement and access to health and social services in the community, navigating the social service and referral system, and the future of HIV treatment and care (Appendices F and G). Some questions were expanded for clarification. Participants were compensated with a Halifax transit ticket, $10 Tim Horton's gift card or $10 Atlantic Superstore gift card.

All of the interviews were digitally recorded with the consent of participants to ensure accuracy of the transcribed data. Audio files and transcribed interviews were stored in an encrypted file folder on my desktop computer. The hardcopy of consent forms and other confidential forms were locked in a filing cabinet in my office. I listened to each recorded interview at least once before jotting analytical notes in my field journal. It took me 6-8 hours to transcribe each recording. Careful note taking, recording, and rereading of field notes were helpful in identifying important themes and trends before analyzing the data.

Interviewing the Employees of Organizations

The positions of employees interviewed for this study ranged from the executive director, prevention programs manager, support programs manager, education programs manager, peer support, outreach nurse, to case manager. Table 3.3 reveals the diverse composition of the employees of AIDS service organizations and community-based

organizations taking part in this study. Pseudonyms were assigned to community sector

employees to protect their identity.

Table 3.3: Demographic characteristics for employees interviewed.

Variable	Number	Percentage (%)
Age Range (in years)		
25-29	6	15
30-39	12	31
40-49	15	39
50-59	6	15
60+	0	0
Gender		
Male	12	31
Female	27	69
Number of Service Years		
1-6	23	59
7-12	6	15
13-18	4	10
19-24	3	8
25+	3	8
Highest Education Level		
Master's degree	1	2
Bachelor's degree	10	26
College certificate or diploma	17	44
High school diploma or equivalency certificate	10	26
No certificate, diploma or degree	1	2

More than 69% of the AIDS service organization and community-based agency

employees involved in this study are women; most of them hold leadership positions in

the organizations. For example, six out of the eight executive directors for the

participating AIDS service organizations and community-based agencies are women. All

of the executive directors emphasize that despite gender equality practices in hiring, their

organization display less gender diversity in its leadership structure. This finding is

typical of the non-profit and voluntary sectors in New Brunswick and Nova Scotia where 87% of employees are women (Community Sector Council of Nova Scotia 2016; New Brunswick Advisory Council, 2007). Perhaps a striking feature of the demographic profile of participants is the high attrition of employees that occurs within one to six years of working within the non-profit labour force. Most individuals leave the community sector because of a lack of clarity in job expectations, poorly defined career paths, and income disparity (Cordeaux, 2017; New Brunswick Advisory Council, 2007). Yet, young workers are essential to the long-term sustainability of the sector and now entering the community labour marker with higher levels of education, and the soft skills that organizations have come to expect from new hires.

In addition, 26% (10 out of 39) of the community sector employees involved in this study are living with HIV, HCV or both viruses. Their experiences with physical health problems related to their diagnosis and difficulties accessing selected care are similar to those of their clients. The shared experience of illness affects the way they work with their clients, largely regarding the inclusion of subpopulations in program development and decision-making.

Employees at all levels of the participating organizations were interviewed in this study. They provided a good sampling of the many different perspectives in the community sector on the gaps in delivery of HIV care and treatment in New Brunswick and Nova Scotia. A bias toward representatives from Ally Centre of Cape Breton, Healing Our Nations, and AIDS Saint John resulted from the large size of the organizations needed to deliver social services in these places. While the involvement of

the AIDS Coalition of Nova Scotia was not possible, I would have liked to interview the

AIDS service organization to fully investigate the challenges faced by women living with

HIV in Nova Scotia. They were the only AIDS service organization to decline to

participate in my project.

Interviewing Women Living with HIV

Women living with HIV comprised a second group of participants in this study.

Table 3.4 shows the demographic composition of the participants in this study.

Pseudonyms are used to protect their identity. All but one woman (Lois) lived in urban

settings. The decision to live or move to urban areas was spurred by the desire to improve

access to care and enhance their quality of life. While the incidence rates of HIV infection

in the remote communities of New Brunswick and Nova Scotia are unknown, employees

of the AIDS service organizations suggest it is reasonable to infer from population data

that the number of persons living with HIV in rural regions is less than in urban areas.

Table 3.4: Socio-demographic characteristics of the women living with HIV in this study.

Participant Pseudonym	Age	Number of Years Living HIV+	Marital Status	Family Characteristics	Household Characteristics	Labour Force Status	Yearly Income ($CAD)	Location
New Brunswick								
Ruth	41	17	Married	Couple - 2 children	Owner	Employed	20,000	Fredericton
Nancy	52	18	Widowed	Lone parent – 1 child	Renter	Unemployed	6,000	Saint John
Doris	38	11	Divorced	Lone parent – 1 child	Renter	Employed	30,000	Moncton
Nova Scotia								
Marion	51	10	Widowed	Lone-parent family - 1 child	Renter	Unemployed	9,000	Dartmouth
Lois	48	6	Single	One person household	Renter	Unemployed	9,600	Kentville
Mary	40	8	Single	One person household	Shelter	Unemployed	10,800	Halifax
Edna	55	13	Single	One person household	Renter	Unemployed	6,000	Dartmouth
Jane	39	10	Single	Lone parent – 2 children	Renter	Unemployed	10,800	Halifax
Phyllis	75	29	Divorced	One person household	Renter	Retired	16,800	Halifax
Beatrice	44	17	Married	Couple – 1 child	Owner	Employed	NR[7]	Halifax

[7] "NR" stands for 'not recorded'.

Two participants (Nancy and Doris) had been involved in my Master's research. All the women face hurdles in managing their disease and other chronic conditions, but were in good health at the time of the study. Two women (Marion and Jane) are the only participants currently living with HIV and HCV.

Table 3.4 also reveals that six out of 10 women rely on social assistance income to meet their most basic needs, such as housing, food, and transportation, and they continue to live below the poverty line in Canada. Nancy's and Edna's reported income is after rental and utility deductions. The same six women are also receiving monthly rental assistance from the governments of New Brunswick and Nova Scotia. They are spending more than 30% of their annual income on housing because housing is less affordable, regardless of where you live in New Brunswick (Bourassa & Provencher, 2004). Ruth, Doris, Beatrice, and Phyllis are employed and have formal university educations. They continue to work with proper care and treatment. The other women living with HIV remain unemployed and receive social assistance after diagnosis because of ill health related to disease progression, fear of the effects of disclosure, and the difficulties of entering the labour market at older ages. I did not collect information on level of educational attainment. Economic instability is a serious concern for the women in this study because it is the primary driver of challenges they face relating to travel to and from care services, treatment costs, housing and food insecurity, and the fear of employment.

The participants in this study may not represent the broader population of women living with HIV in rural areas of New Brunswick or Nova Scotia, but the collection of narratives from employees of organizations and women living with HIV delivers new

insights into the HIV care continuum. I would have liked to expand the geographical reach of my study to more rural communities in both provinces as a way to increase the number of participants, but time and budgetary constraints made this unfeasible and was beyond the scope of this project.

To better understand the diversity of women's experiences in New Brunswick and Nova Scotia beyond Table 3.4, their life stories of being diagnosed and living with HIV are sketched here.

RUTH

Ruth was diagnosed with HIV at the age of 34 while living in Montreal. Her first husband died of AIDS in the 1990s and she was diagnosed HIV positive two years later. Watching her husband's worsening condition was emotionally devastating for Ruth, in addition to her bereavement in the loss of her spouse. Ruth remarried an HIV negative man in the late 2000s and immediately began trying to get pregnant. She made frequent visits to an infectious disease specialist in Toronto to access fertility services for HIV-positive women. Through in vitro fertilization, Ruth and her husband had two HIV negative children, now two and three-and-a-half years old. Being a military spouse not only meant frequent moves across Canada (now living in Fredericton), but also access to comprehensive health care and insurance to cover high costs associated with treatment. Ruth and her family had been living in Fredericton for less than a year when the interview for this study took place, and she is still learning about the social supports in place for HIV positive people in the community.

NANCY

Nancy contracted HIV during the 1980s tainted blood scandal. She learned that she had tested positive for the virus after a series of multiple surgeries to treat cancer. Nancy spiralled into a depression following her diagnosis and moved in with her parents while receiving HIV treatment and care. AIDS Saint John was the first organization Nancy visited after her diagnosis to learn more about the disease and support services in the community. She was introduced to a counselor to whom she attributes her access to support services to meet her basic needs. Nancy eventually joined the organization as a volunteer member to ensure that the voices of women living with, and at risk for, HIV were present; she served on the committee for three years. Nancy no longer volunteers, but provides transportation services to help people living with HIV reach medical and preventative care appointments who cannot afford the cost of a $2.75 bus ticket or monthly pass. She provides transportation services to people living with HIV for a small fee and meets with Donna from AIDS Saint John regularly for counseling.

DORIS

Doris was tested regularly for HIV antibodies as part of good sexual health practices until she got married. She never suspected that she would become infected with HIV in a monogamous marriage. Doris remembers feeling upset and angry after being diagnosed with HIV, and confronting her husband. She had no idea how she contracted the disease. Her husband was guilt-ridden about the news of her diagnosis and admitted a week later to infidelity in their marriage. He was reluctant to be tested and treated for HIV despite sharing an HIV negative child. Doris filed for divorce after learning about

her husband's infidelity and was granted sole custody of their two-year-old son. Doris received support from friends and family after disclosing her HIV status one month after starting treatment. She continues to work and often counsels other women in the province about her experiences with the disease.

MARION

Marion has been struggling with an opiate addiction to dilaudid and synthetic heroin for a large portion of her life. Her drug use fluctuated and sometimes dwindled to complete abstinence for weeks or even months at a time after her diagnosis. She relocated from New Brunswick to Nova Scotia in an attempt to escape her substance abuse problems and break free from addiction for good. Her move to Halifax was supposed to be a fresh start on life, but instead it was met with more severe consequences of addiction, violence, and homelessness. Marion contracted both HIV and HCV from sharing needles with a group of users she met in a local homeless shelter in her early forties. Marion's family abandoned her after learning about her HIV status. She has seen them since and is trying to build a strong family relationship. Methadone treatment has helped her stay away from drugs and take care of her family over the past four years. She regularly volunteers at a Halifax food and clothing charity as a way to give back to the community and help others who are struggling with drugs or alcohol relapse.

LOIS

Lois understood the risks related to HIV with reusing a needle or syringe and sharing other injection equipment, but admittedly found herself sharing needles one night. She never expected to contract the virus through sharing a needle once with a drug user

she considered a friend. After months of feeling ill, Lois went for an antibody-screening test where she found out she was HIV positive. Substance abuse was difficult for Lois to escape, but relocating eight months ago was the beginning step to recovery for her. A childhood friend welcomed Lois into his home to help her escape drug addiction and a bad family situation, while she sought treatment for both HIV and substance abuse in Halifax. Her diagnosis is now stable and she is on methadone treatment for her substance abuse.

MARY

Mary immediately gave her parents legal custody of her two children after her diagnosis with HIV to ensure they had a stable home environment, and to protect them from the effects of substance abuse and domestic violence. Her children continue to live with their grandparents in another province. She contracted the virus from a former partner while living in Halifax. Mary has not talked about her experiences living with HIV, treatment progression, or the continuing struggle with drug addiction to opioids since disclosing her HIV status to her family. She had been living in an emergency shelter for women in Halifax for two months at the time of this project, trying to leave an abusive situation while waiting for a permanent housing placement, which she did eventually receive. She hopes to visit her children when her opioid dependence and withdrawal has reduced.

EDNA

Edna, like Marion, contracted HIV and HCV at a local homeless shelter in Halifax. At first she was in denial that she was sero-positive and spiraled even more

deeply into substance abuse. Her addiction to dilaudid continued for many years and she described feeling unable to quit even after learning of her diagnosis. There were pitfalls and setbacks in her recovery, coupled with numerous drug relapses, but her reliance on social support services was helpful during her treatment and recovery process. She often traveled to Halifax by bus three times a month to access these services, largely when she feared relapsing or could not meet basic needs in her life. Edna has been in recovery from drug problems for three-and-a-half years. She now dedicates herself to sharing her story and conveying the importance of HIV awareness.

JANE

Jane has lived in Halifax for her entire life. In 2004 she was diagnosed with both HIV and HCV at the age of 29 while serving a prison sentence. She did not reveal the reasons why she was in prison. Jane does not know how she contracted HIV, but admits to spending most of her life as a sex worker and drug user. She started methadone treatment for her opioid dependence and HIV care while in prison, and continues to do so in Halifax. Her parents were given legal guardianship of her two children in order to provide for their care while Jane was in prison. The children still remain in the care of their grandparents today. Jane has been living in between two women's shelters since her release from prison in Halifax. She attributes her recovery from addiction to her reentry into the workforce. Jane now dedicates her time to counseling other women living with HIV.

PHYLLIS

Phyllis was diagnosed with HIV following a car accident. Like Nancy, she was

infected with the virus during the 1980s tainted blood scandal. Phyllis was undiagnosed for 14 years and did not know she was sero-positive until she was tested in 1999. She divorced her husband three years before her diagnosis and has joint custody of the two children. Disclosing her HIV status to family members was an emotional experience that was heightened by the fear of rejection by her children. Instead, she received support and acceptance of her diagnosis from family members and friends. Both of her children were her primary caregivers during the first one-and-a-half years after diagnosis while Phyllis was adjusting to side effects from the HIV treatment. She continued to work part-time until retirement in her early sixties. Phyllis started volunteering shortly thereafter to help other women living with HIV accept their new diagnosis. She no longer volunteers but continues to meet with women to discuss life after diagnosis.

BEATRICE

Beatrice was 27 years of age when she contracted the virus from a former partner. She was married for five years when she had an affair that lasted only a few months. She confided in her husband immediately about the affair and told him she was pregnant; a paternity test revealed that her husband was the father of the child. She was truly happy about this pregnancy and believed a child would strengthen the couple's commitment to each other. Beatrice learned about her HIV status through a series of standard tests for HIV during pregnancy. Both her husband and first child were HIV negative. Following pregnancy complications associated with her HIV status and recurrence of other infections, Beatrice miscarried her baby. She remembers feelings of sadness and grief after the miscarriage, and the support she received from friends and family members to

overcome the depressive disorder. She also started treatment for HIV soon after diagnosis and has adjusted well to the medications. Beatrice began volunteering after learning about her HIV status. She no longer volunteers, but continues to provide counseling services to newly diagnosed women.

Collecting narratives from community sector employees and women living with HIV is important for understanding women's lived experiences and how they navigate services. Given that access to health care is centered in metropolitan areas, it is understandable that most of this study was conducted in urban settings, with the exception of two organizations in Nova Scotia (Northern Healthy Connections Society and the Ally Centre of Cape Breton). Further, the shared experience of illness for 10 out of 39 community sector employees who are living with HIV, HCV or both viruses provided an opportunity for deepened analysis of the issues concerning barriers-to-care and the changing landscape of care in both provinces.

Data Analysis

I returned to McMaster University in March 2015 after completing my fieldwork in New Brunswick and Nova Scotia. An important part of my analysis involves combining geographic information systems (GIS) software with NVivo analysis to evaluate, interpret, and explain the complexities associated with accessing health and social services by women living with HIV. Both methods were used to sort information and examine relationships within the data. Data were stored in encrypted file folders on my computer desktop. I purchased a license for ArcGIS 10.2 from Patrick DeLuca, GIS Specialist in the Faculty of Science, McMaster University.

NVivo Software

Interviews and my literature search were coded using NVivo 11 for windows, which helped to facilitate content management. The process of NVivo analysis entailed an iterative process to explore the thematic links between the interviews of service providers and women living with HIV. I first organized the data according to underlying themes and structures. Open coding linked related items into cultural themes, hierarchies of relationships, and consistent relationships in the realm of service delivery. For example, all information related to the disenfranchisement or marginalization of the poor was coded as "Women's Poverty". A search for key works or phrases in interviews, field notes, and other data documents helped reveal important themes. Displaying results in a word tree also identified missing elements that needed further study. Next, the thematic categories were expanded to explain the network of social phenomena observed in the field. For example, the category "Women's Poverty" was subdivided into further classifications, such as housing issues, food insecurity, and stigma.

Geographic Information System Software

Geographic information systems (GIS) computer software has the capacity to manage, analyze, and display spatial or geographical data. GIS helped to visualize health and social service problems in New Brunswick and Nova Scotia using the locations of people and organizations under study. Creating maps that show the availability of services in relations to needs of people was an important component of my ethnographic research to better understand the challenges faced by women living with HIV who were attempting to access health and social services. I took a number of GIS e-courses through

McMaster University to prepare for this phase of the project, including: basics of the geodatabase model; creating, editing and managing geodatabases for ArcGIS desktop; the 15-minute map; creating a basic map in ArcMap, and; working with map typology.

Data for spatial analysis were collected over the nine months of fieldwork. My first task was to compile a list of local resources women were accessing to create a resource map of New Brunswick and Nova Scotia. Resource materials located in the offices of organizations about other agencies in the community were also helpful for expanding this list. Addresses were organized and entered into an Excel spreadsheet by province. I was fortunate that the organizations also agreed to provide me with a list of the first three digits of women's postal codes. Coordinates for the nearest Canada Post office were assigned to protect women's identity and to calculate access measures based on road travel times.

I created baseline maps with the guidance of Siobhan Hanratty, head GIS librarian at the University of New Brunswick, from June to August 2014. Shape file layers were gathered from the government webpages of New Brunswick and Nova Scotia for free. The baseline layers I downloaded for analysis include land cover, coastline, county lines, municipal boundaries, ferry segments, roads, and census tracts. Two of the topological shape files for New Brunswick, including the county and health regions maps, were outdated, requiring me to edit data in different coordinate systems before adding a new field to the attribute table.

Next, I uploaded the Excel spreadsheets to ArcGIS 10.2 to visualize where clusters of health and social services are located. I then calculated the distances between

service providers and the locations of women's homes using the measurement functions of Google My Maps. This was the only time I used Google My Maps to measure the exact distances between two or more points along up-to-date routes of navigation. This online platform possesses the same spatial query and viewing capability as GIS, but differs in its capacity to manage large disparate data types and methods of data representation. The simplicity and ease-of-use of Google My Maps versus GIS was useful in defining and measuring the distances women travel to access specialized care in New Brunswick and Nova Scotia.

GIS has been an important tool in archaeology since the 1990s, largely used to visualize sites in their context and settings (Aldenderfer & Maschner, 1996). It is a relatively new research method and analytic technique in medical anthropology, but is common practice in a wide variety of fields, including the natural, engineering, and medical sciences. The use of this geographic technique to identify gaps between programs, services, and community health needs for women living with HIV in New Brunswick and Nova Scotia is the first study of its kind in both provinces. The visual displays of health service utilization by women living with HIV presented in this study are an asset to service providers and policy makers in the building of new care facilities in underserviced communities.

Challenges and Inquiry

I faced many unexpected and inevitable challenges while conducting field research. For example, the June 2014 shooting of four RCMP officers in Moncton delayed my participant observation work in the AIDS/SIDA Moncton office by one week

at the request of the organization's executive director. This time was spent as a period of mourning in the community. In a second case, in July 2014 post-tropical storm Arthur left most of Fredericton without power for a week's time. Downed trees and power lines made it difficult to visit the study sites. For six days, I did not have air conditioning, lighting, or hot water. I walked to the Fredericton Convention Centre to charge my electronic devices and shower each morning. The emergency response center was opened in response to the widespread power outages.

Winter road and weather conditions were among the biggest challenges encountered during my research, especially given the distances involved in traveling from one study site to another. It took me, for example, four hours to drive to Sydney, Cape Breton from Halifax. Heavy snowfall and cold temperatures often delayed my departure from Halifax or led to the cancellation of my site visit entirely. I began traveling by Maritime Bus in the winter months because of the speed with which weather and road conditions changed. My apartment was also five minutes by foot to the Maritime Bus Halifax Terminal. Although it took significantly longer to travel by bus than by driving my own vehicle, I felt more comfortable and safer using public transportation. Interviews were rescheduled with participants who were unable to travel on their appointment dates due to extreme weather conditions.

My second challenge was recruiting women living with HIV for this study. Discrimination against people with HIV and the poor health of women living with HIV adversely affected participation. The mental and physical health of a woman was a significant influence on whether they volunteered to participate in the study. Community-

based organizations also considered the health status of a woman before introducing my study and providing my contact information. For example, one woman I had interviewed during my Master's research declined an interview in-person or over the phone because of her pain and nerve problems.

Another challenge was establishing trust with people in the community from my position as a researcher. Support from community-based organizations was the first step toward building trust. Building and maintaining trust through observing and participating in the daily lives of women was a way of establishing confidence with community members. Despite the time and effort I spent building relationships with community members, some women declined to participate in the study because they distrusted my intentions in the field. For example, I met a young woman on several occasions while volunteering and observing on the mobile outreach van in Dartmouth, Nova Scotia. After weeks of casual conversations about women's health and invisibility, the woman still declined an interview fearing the far-reaching consequences of disclosure even though I explained my methods to shield participants' identity, such as assigning pseudonyms to ensure confidentiality.

Summary

This chapter describes the qualitative and quantitative research methods used in this study, including data collection before and after entering the field. Relationships established with community-based HIV agencies during my Master's degree were vital in laying down the groundwork for this multi-site PhD project, especially in the face of low incidence rates of HIV in both provinces.

Chapter 4 Barriers-to-Care for Women Living with HIV

This chapter addresses the first question posed in this study: what are the barriers-to-care for women living with HIV in New Brunswick and Nova Scotia? I describe the barriers to care and access to support services outlined by women participating in this study as well as their perspectives on the impact these barriers have on their quality of life.

People living with HIV navigate a complex, sometimes contradictory, landscape of health and social services to manage their wellbeing. An array of social and health system barriers, including unfamiliarity with new care and support services, eligibility access issues, lack of care provider knowledge, precarious finances, and distrust of service systems are some of the challenges women living with HIV face when trying to access care and support services to meet their needs.

This is illustrated in the word cloud in Figure 4.1 created using NVivo 11, which is an analysis of the responses by participants to the following interview questions: What do you feel are some of the gaps in programming and services for women living with HIV? What are the key issues facing women living with HIV in your community? How do current services and programs available by AIDS service organizations and other community-based agencies meet the basic needs of women?

Figure 4.1: Word cloud of interview analysis using NVivo 11.

This word cloud analysis was a starting point for refining interpretations in the interviews that would otherwise be unclear or difficult to see in tabular format. Often the importance of keyword metadata is shown with font size or colour. A closer look at the smaller keywords and their associations to the textual comments in Figure 4.1 reveals a more nuanced description of women's experiences accessing care in both provinces, including the emergence of housing or home, food, money, access, and treatment as theme nodes in barriers-to-care.

The comments from HIV-positive women in this study and community sector employees on the topic of barriers-to-care were similar. This finding was not surprising given that 10 out of 39 of the community sector participants are living with HIV, HCV or both viruses, and face similar struggles to overcome significant problems around diagnosis, treatment, medication, and stigma. The frontline workers I interviewed

appreciate what it is like for the women to negotiate the systems they create because they too navigate the same services to meet their basic needs.

Barriers to Access Care for HIV-Positive Women

HIV-positive women living in the two provinces face a number of barriers to care. Affordable housing, food insecurity, and transportation issues to and from health and social services, strongly affect their overall health and were commonly identified by participants in this study. All of the women living with HIV in this study were members of low-income households (with total individual incomes of less than $900 a month), which is well below the basic need poverty line for a single person in Canada. The financial support women receive from the Canadian Pension Plan Disability Benefit, Employment Support and Income Support, part-time work, or retirement income is inadequate to address the needs of people living with lifelong episodic disabilities, such as HIV, and therefore forces them to rely on community-based programs to meet their most basic needs, such as housing, food, and transportation (Nova Scotia Advisory Commission on AIDS, 2014).

Affordable Housing

Affordable housing, or precarious housing, was the most common barrier-to-care reported by women with HIV and the community sector employees. Eight of the HIV-positive women in this study were homeless or living in unstable housing at some point in their lives, particularly after HIV diagnosis. Five of them relied on transitional support from community-based agencies during this time, largely to navigate housing access and support services in their community. None of the participants was willing to share their

experiences of accessing affordable housing because of past distress related to escaping an abusive relationship, or feelings that they might be jeopardizing their ability to access future housing services.

Housing stability and quality was important to these women for maintaining proper care and treatment, and was a particular priority for women with children. Stable housing for their families was increasingly important to Jane and Mary, who gave legal guardianship to their parents to protect their children from the effects of substance abuse and domestic violence. Both women struggle with opioid addiction and attribute their recovery to the social supports of Direction 180 and Mainline Needle Exchange, and having a stable place to live through the Affordable Housing Association of Nova Scotia or Housing Nova Scotia. Mary had sought housing support in Halifax not only to improve her quality of life, but also to escape a violent relationship with a former drug-involved man. She was relying on Direction 180 to assist her with navigating housing support services in the community and to access methadone treatment to overcome her drug addiction to opioids so as to obtain legal custody of her children. She lived in an emergency shelter for women in Halifax for two months while on a waitlist for a subsidized housing unit. Access to safe and affordable housing for women who are hard to house because of addiction or for women fleeing violent relationships is often a challenge due to discrimination by landlords. Mary now has permanent housing, her diagnosis is stable, and she is continuing her drug rehabilitation at Direction 180. Mary's experience is a good example of how support services offered by community-based organizations like Direction 180 are effective in overcoming challenges women face

associated with housing instability. Although life has certainly improved for both women, continuing opioid addiction and their inability to provide regular care for their children fuels negative stereotyping of these women as 'bad mothers'. Downe (2017) suggests that mother blaming in the context of HIV has long-term negative health effects for women looking to achieve wellbeing.

All of the women and community sector employees also reported that finding affordable housing in urban centers is difficult because of strict eligibility requirements and a lack of coordination across housing support systems. Histories of eviction or even an extremely low individual income are two main reasons for denying housing support in both provinces. Unstable, temporary or transitional housing was also thought to have far-reaching consequences on the health of women, including increased substance abuse and mental health problems. Obtaining permanent housing in the community is one of the first social supports organizations seek for clients at the time of treatment intake. 'Housing first' is a basic underlying principle for all of the community-based agencies to ensure continuity of care. Brenda, for example, has been working as a wellness coordinator. She was hired to enhance the organization's programming, but due to the relatively small size of the service organization she, like other employees, was responsible for a wide range of work tasks. Brenda assisted the executive director to find Doris permanent housing. Assessing Doris's housing and service needs revealed that the absence of a nearby bus stop at her current residence was posing a challenge to her travelling to medical appointments. Additional travel costs associated with taxi fares to and from her medical appointments was placing undue strain on Doris's monthly budget.

The executive director of the organization brought the issue to the attention of the NB Housing Association and Doris was relocated to a new housing unit that was a five-minute walk to the nearest bus stop to travel to the HIV clinic for her appointments. Assisting people living with HIV and HCV navigate housing support services has given community sector employees like Brenda insight into the systemic challenges women face in navigating the care continuum, including an extremely low individual income, lack of affordable housing, strict regulatory requirements for eligibility, and growing wait lists for housing.

> There's a real issue with affordable housing within our province [New Brunswick]… the average one bedroom apartment in Moncton is $590 [per month] and the average social assistance cheque is $580 [per month] so… our retirement plan our golden egg [for people living with HIV) is NB Housing. However, if someone has a debt with NB Housing then they can't re-apply…But, I try to work with people on that…so for instance, I will have somebody come in [to the office] and say we got evicted, I can't go to NB Housing because I owe a debt, the other option is a room, but rooms don't house families. [And they are] trying to evade social development and have their kids taken away [while] trying hard to find something within their means before winter hits. And I'm having a hard time to find them something [housing]. I also have a couple of people that have been black listed from NB Housing…but I don't blame them for evicting when the house is damaged. [Brenda, New Brunswick]

Low income poses a barrier for women to enter safe and affordable housing. With the exception of Ruth, Doris, Phyllis, and Beatrice, the other six women in this study receive monthly social assistance from the provincial government. The monthly income assistance payments they receive are higher than reported by Brenda because of other financial replacement programs they access to offset the costs associated with HIV care and supporting their dependent children. For example, the basic rate for social assistance in a single parent household with one child has risen to $887 per month in New

Brunswick (CBC News New Brunswick, 2013; New Brunswick, 2013). Even with a 7% increase in social assistance, and the availability of other income replacement programs in both provinces, women are still spending more than 30% of their annual income on housing (Bourassa & Provencher, 2004). Nancy and Edna, for example, are living on an annual net income of $6,000 after all utility and rent deductions. This is not nearly enough to compensate for their basic needs like food and transportation. They make payments on time to the housing associations to evade homelessness, poor health outcomes, and improve their quality of life, but this leaves them struggling to meet their basic needs. Nancy and Edna, instead, rely heavily on sources of emergency funding from community-based agencies and family members to bridge their resource gaps and prevent tenant black listing.

A shortage of safe and affordable housing in desirable areas near health and support services is a reality for women living with HIV and contributes to their poor health outcomes. Lori is the one of the longest serving community sector employees in this study. Valerie has been working as a community-based methadone clinic caseworker for 10 years. Both participants work closely with persons living with HIV, HCV, and other STBBIs. Their interviews not only speak to the housing needs of low-income women living with HIV in New Brunswick, but also to the inadequate conditions of some community housing units.

> Within the community housing is a big problem. The majority of the rooming houses of course are crawling with bed bugs even some of the non-profit housing has bed bug issues. That really bothers me. There's [also] not enough affordable housing around here and I think as the industries are closing, we're having more people move to the city in hopes of something better. Men are ending up at the TP [Metro Turning Point], the Salvation Army, the women in the women's shelters

[and] they're getting caught up in this drug scene. Hopelessness is definitely a part of what we're seeing with people [and housing] here. [Lori, New Brunswick]

There's not enough housing [here]. That's another thing that we also do is we refer [people] to Halifax Housing to get them into some housing, especially the homeless…[the problem is that] there are not enough decent [and] safe places for people to stay. [Valerie, Nova Scotia]

These observations highlight an important trend: a decline in the growth of industries, including forestry, fishing, mining, quarrying, and oil and gas, has resulted in increased population movement from rural to urban areas in both provinces (Statistics Canada, 2015a; Statistics Canada, 2015b). The decline of productivity and economic growth in New Brunswick and Nova Scotia is also linked to increases in diseases of poverty like HIV, and the need for improving the availability and quality of housing for everyone. The increase in people accessing affordable housing services in both provinces has prompted a rise in investment in this area and more partnerships with private landlords (Housing Nova Scotia, 2015; New Brunswick Housing Corporation, 2010).

Even though government contributions for social housing are rising there is not nearly enough supportive housing to meet the need. Lori and Valerie, along with other community-based employees, suggest that people living with HIV consistently fall through the cracks of the system as a consequence of structural-level barriers. Falling through the cracks may lead to the placement of some people in overcrowded community housing units and poor living conditions. Mary's experience with abysmal living (e.g., bed bugs, inadequate water, ventilation and electricity) while living with a former partner in a number of community housing units speaks to the appalling living conditions faced by low-income people. Conversations with clients and other community-based employees

in clinical settings revealed that the lack of affordable housing is not unique to these two provinces, but is a barrier-to-care for low-income persons across Canada.

Cynthia was part of early HIV grassroots organizing initiatives in New Brunswick. She has been serving as a community-based employee for 15 years. Her continuing work as a member of local community committees has been important for identifying health issues for people living with HIV and provides insights into the connections between poverty and housing needs of people living in New Brunswick.

> I think that for many years we tried to fix poverty and we were run ragged in organizations…10 years later we just had to say we just can't sustain it…We sit on the [a number of homeless steering committees] and have, well I have for the last 15 years…recognized that if people aren't securely housed, really nothing else matters. They're just so at risk and life is so precarious that if people aren't housed [their health outcomes may worsen]. We learned the hard way that you can't help somebody get stabilized on methadone if they don't have a place to live. It's that simple. You can't help somebody get their children back from foster care if they're not in stable housing. So I think that bigger issue really comes down to poverty. [Cynthia, New Brunswick]

Cynthia's comments on the problem of affordable housing in New Brunswick not only align with comments of other community sector employees, but also reveal the need for a more rigorous approach to address the issue of poverty by increasing the affordability and quality of housing. The poverty reduction strategy adopted in the two provinces in the late 2000s has a shared goal of alleviating the effects of poverty, particularly through housing, income and employment support, healthcare, and food security. The Housing First program is a core initiative in four other Canadian provinces (Ontario, Saskatchewan, British Columbia, and Newfoundland) to address the rising housing insecurity of persons with low incomes. The federal government has invested $7.2 million in New Brunswick and $59 million in Nova Scotia to expand and improve its

affordable housing system (Canada Without Poverty, 2016; Province of Nova Scotia, 2009). Like Lori, Valerie, and other community sector employees in this study, Cynthia agrees that the increase in federal funding for affordable housing is an effective way to tackle housing needs, poverty, and income insecurity as part of a holistic approach to the problem. For example, since 2003, more than 1,100 affordable housing units have been constructed or preserved across Nova Scotia (Province of Nova Scotia, 2009). New social housing units have also reduced the wait list by 10%, making it possible for community-based agencies in both provinces to help women like Mary, and other low-income persons access immediate safe and affordable housing (Housing Nova Scotia, 2015).

Even though their lives continue to be very difficult, all of the women with HIV in this study are now living in stable housing because of assistance from family or friends and because of effective referrals to housing support by community-based organizations. AIDS/SIDA Moncton advocates for and provides a unique social housing program for people living with HIV in partnership with NB Housing Association, the only affordable housing assistance program of its kind in Eastern Canada. The AIDS/SIDA Moncton housing program has been in operation for 20 years and expanded from two to five apartment units. Because of a lack of affordable housing options in urban regions, in close proximity to HIV care and treatment services, there is increasing demand for community-based organizations to address housing needs.

> I'm going to say [we started the housing program in] 1997-1998 and we have since expanded with more units. So we have [been able to house] several of our clients. I know of one couple that we have helped that are both HIV-positive [and] they've been in that unit I'm going to say 10 years...long term [renters]. We have another unit [where the family] has been 12 or 13 years. What I it did for them was that they only paid a third [of rent], so even if they don't get a lot of money, I mean I don't

know how you live on $500-$600 a month, but instead of putting it all towards housing, they now pay a third. This now leaves two-thirds of their income at least to buy food [for their families]….So that was huge once we were able to get them in subsidized units, where we often negotiated to have the heat and electricity included in the rent. [Lori, New Brunswick]

The AIDS/SIDA Moncton housing program partnership with NB Housing Association is a novel. This housing program model does not affect existing programs or their annual budget; instead, it requires establishing a strong relationship with housing association boards and requesting special priority status for clients, depending on their life circumstance (i.e., victim of family violence or the need to live closer to care services due to disease progression). The housing program model is also feasible for other community-base organizations because the full resource impact falls on the provincial housing association. AIDS/SIDA Moncton, for example, has never contributed funding to the development or preservation of community-housing units. Acquisition of long-term permanent housing for people living with HIV and expansion of the housing program to five apartment units has had no affect on the organization's budget. The housing program also meets the federal governments expanding mandate for AIDS service organizations to develop new integrated care programs in their communities. The interviews I conducted with both HIV-positive women and community sector employees further illustrate not only the immediate connections between housing and health, but also how broader inequalities such as poverty and food insecurities produce and exacerbate homelessness and housing instability.

Food Insecurity

Food insecurity is a significant concern for HIV-positive women because of its association with poverty and contribution to poor health outcomes. Participants in this study rely on food banks and local food programs to meet their basic needs. The availability or access to food is a growing problem for them because of rising food costs. Food security and good nutrition is increasingly important for HIV-positive women to manage the short- and long-term side effects of antiretroviral therapy on the body, including anaemia, diabetes or insulin resistance, heart disease, and osteopenia or osteoporosis. Some of the HIV-positive women in this study who are in more advanced stages of HIV infection were on a high caloric eating plan to prevent weight loss that often accompanies HIV treatment. A low income makes it difficult to afford the high quality diet they need to offset the effects of infection; consequently, some of the HIV-positive women rely on churches and food banks to meet their dietary needs and to feed their families.

Food banks and food programs in local churches and community centers are the most reliable sources of nutrition for HIV-positive women, but accessing these programs presents challenges. Four of the women living with HIV in this study face insecure access to food and regularly visit food assistance programs, once or twice a month. Nancy, for example, has been living with HIV for 18 years and since her diagnosis has been accessing social support services regularly from AIDS Saint John, such as counselling and their community food program. Her interview illustrates the painful emotions, especially shame and anger, women face when accessing food banks.

Look if you don't have your ID and your address, then you have to go. This is so stupid, this system; this is food that you're giving away. You need to have receipts and bills with your home address with [recent] dates on them, so they know that you're still living there. You have to have your Medicare card and then you go to a church to get a slip to bring to the food bank. Because [of course] poor people have all kinds of times to go running around to a church before they get to the food bank with their little cart and their six kids following them…I don't know why you can't just walk in and [get the food you need]. This is not your food! This was donated for you to give. I'm a poor woman whose hungry and just standing their wanting something to eat. Are you going to embarrass me in front of all the people that are sitting there? And are you going to say that you don't have your Medicare, so you can't have any food. Getting back home, I live 17 blocks away [just to] get them all that information with my six kids in the pouring rain and bring it all back to get food [is outrageous]. I just get too frustrated with this food bank because it doesn't make sense to me at all to walk to a church and then walk to a food bank to get discriminated. [Nancy, New Brunswick]

Nancy's interview brings to light the complex interrelated issues women and low-income families face while navigating food assistance programs, and the extent of confusion and stigma that accompanies accessing these services. Subsequent conversations with Nancy about her experiences with food insecurity not only revealed the deepening shame and embarrassment she felt from others knowing she is without food, but also the disrespectful treatment she has faced from staff or volunteers. Her comments show how emotional accessing food assistance programs can be and how these negative encounters often discourage needy people from returning.

Yet, a lack of community food assistance programs and a growing demand for food in both provinces limits the alternatives available to meet this basic need. Nancy's humiliating experiences navigating food banks was the main reason for her decision to volunteer at a community organization shortly after her diagnosis. Her goal was to connect with community sector employees to enhance the organization's commitment to

food security for its clients by increasing monthly food donations from local churches like soup, stews, fruit, and cookies, and create awareness of the challenges women face in accessing food assistance programs by sharing her own experiences with other members. She served on one local committee for three years, and during that time was able to secure regular food donations from a local church. Community food programs that operate out of AIDS service organizations not only improve food security for women like Nancy or other low-income persons, but also have become one of the most accessed support services. AIDS/SIDA Moncton, Ally Centre of Cape Breton, and Mainline Needle Exchange have partnered with food banks and local food programs to solicit and distribute food to people living with HIV. In an effort to address growing food insecurity, two local churches in Saint John, New Brunswick, deliver frozen meals and perishables to AIDS Saint John once a month for distribution to low-income people living with HIV; many food parcels are given to women and their families.

New Brunswick and Nova Scotia have the highest prevalence of food insecurity in the country. The level of food insecurity in New Brunswick is 15.6%; it is the second highest level of observed food insecurity despite being one of two provinces to receive both federal and provincial funding for food assistance (CBC News PEI, 2014; Martorell, 2017). The food insecurity rate is highest in Nova Scotia at 17.5% and continues to rise. Neither province has a provincial food security program as do British Columbia, Ontario, and Quebec, nor covers the costs associated the dietary needs of persons living with HIV (Martorell, 2017).

Like Nancy, several of the women in this study have served on a number of community committees. They not only understand the importance of good nutrition for people living with HIV, but also continue to work towards bridging the gaps in food insecurity in the face of structural barriers to food access and negative health consequences.

> Sometimes it's as simple as food. We have wonderful supporters in church organizations that were friends with who will supply us with food…that may sound very simple but it's very profound in somebody's life that has never asked for some help right [for them or their children]. [Donna, New Brunswick]

Two of the women in this study were responsible for the overall management and coordination of food program partnerships with local churches and community centers in Saint John in the mid-2000s. The local food program at AIDS Saint John, for instance, is the first of its kind in New Brunswick. As the demand for the program has increased, its capacity now reaches people living with HCV and other STBBIs in the hinterland. The development and success of the AIDS Saint John food assistance program inspired the Fresh for Less food program by AIDS/SIDA Moncton, a community program that brings together farmers and food producers to provide low-income persons with food.

Doris emphasized the importance of food programs for achieving a sense of stability in clients' lives and the need to use these services or risk losing them.

> Well the [food program] that I access now is called Fresh for Less and it's for all people with HIV. What it is- is that AIDS Moncton provides a basket [of food] at the end of the month full of fresh produce and stuff like that to encourage healthy eating. And at first, I was thinking I don't need that I'm good. The thing is, if you don't use it you lose it. [Doris, New Brunswick]

She is one of seven HIV-positive women in this study who continue to regularly obtain food from community-based organizations' food programs. Ruth, Phyllis, and

Beatrice do not access food banks or local food programs because they either live in a

dual-income household with a high median income, live in a region where food programs

are not available, or prefer that persons requiring this support to meet their basic needs

access this service instead of them. AIDS New Brunswick, for example, does not have an

established food program for its clients. They instead rely on food bank partnering

agencies and other local food programs to address hunger and promote food security to

the most vulnerable households and communities in the province. The organization's food

referral and resources network is inclusive of the two food banks in Fredericton, including

Greener Village and the Fredericton Food Bank, and has been effective in promoting and

alleviating food insecurity for its clients.

The Ally Centre of Cape Breton in Nova Scotia, on the other hand, has a food

pantry service that is stocked by the local food bank that is open during regular drop-in

hours. The program was created in 2007 to address the rising rates of food insecurity for

low-income persons living with HIV, HCV, and STBBIs in Sydney and the surrounding

area. The Ally Centre of Cape Breton also is the only AIDS service organization in this

study to have an on-site food program for its clients. Comments from employees reveal

that food and nutrition assistance for persons living with HIV is the most accessed service

program the agency provides to its clients. Mark's comments speak to the state of food

security and nutrition in Nova Scotia.

> We get donations [once a week] through Feed Nova Scotia…People call or walk in
> and provide their health care number [to access food]. A food truck comes once a
> week and we put out any produce or perishable food items that everyone has access
> to right away. That's the stuff that's really important when you're talking about
> feeding people…[it] is a basic human need, so it's really cool to be able to do that.
> And then the food bank itself has a lot of perishable food items like soups, Kraft

dinner, and cereal that goes a long way. There are a lot of people relying on that each month, especially if they don't have a place to go and they're accessing things like a shelter…There's definitely a variety [of food items we receive] and it depends on the week…you [may even] see a difference in volume of food, quantity of food, and quality of food. We see a lot of snacks, and not a lot of the healthier items [that a person with HIV would need]. For the most part, it's prepared and processed food. [Mark, Nova Scotia]

The presence of an on-site food program at the Ally Centre of Cape Breton has positioned the organization to improve food security and nutrition for persons living with HIV, HCV, and other STBBIs. Similar to the AIDS/SIDA Moncton housing program model, the Ally Centre of Cape Breton partnership with Feed Nova Scotia is a novel food initiative that other community-based agencies can create to address the increasing food security needs of people living with HIV. The integration of a food program into the offices of community-based organizations does not require that the agency apply for additional government funding or redirect funds from other program or projects. The provincial government, for example, provided funds to support the hiring of Mark to facilitate the organization's food program. The full resource impact falls on Feed Nova Scotia to regularly package and deliver food for distribution at the Ally Centre of Cape Breton. This type of initiative would not only require organizations to strengthen their relationships with local food programs to create on-site distribution food centers, but also obtain proper licensing and permits; nominal fees and costs are associated with the latter that fall outside of an organization's operating budget. Conversations with employees of the Ally Centre of Cape Breton shows that their one-stop model, including support groups and counselling, testing, education outreach, needle exchange, and food program, has helped to alleviate food insecurity for clients. The availability of a second direct service

on-site has improved food access to those who would otherwise not receive services due to stigma and discrimination.

It is rare for AIDS service organizations in Canada to have an on-site food program; food and nutrition programs are mainly operated by separate organizations, which perpetuates silo-based approaches to service delivery and funding. The absence of effective and affordable resources to improve the quality of life for persons living with HIV, HCV, and other STBBIs is the main reason why the Ally Centre of Cape Breton began its on-site food program. The program's increased capacity and accessibility of food to low-income persons are two important reasons for other agencies to support the integration of food programs into their offices to assist clients achieve food security.

The Manna for Health food program in Halifax, Nova Scotia, is a unique partnership among farmers, farmworkers, and retail food companies. It is dedicated to meeting the specific dietary needs of people living with HIV and the only food bank in Canada that specializes in helping persons living with HIV and other life threatening illnesses to meet their nutritional requirements while undergoing treatment. All five of the HIV-positive women living in Halifax access food services from Manna for Health and other community centers at least once a month.

Manna for Health is also near the other care, treatment, and support services HIV-positive women access in the city. Lois and Edna, for example, simultaneously struggled to afford food and household expenses, such as rent and utilities, even before their diagnoses with HIV. Their comments reveal the connections between food insecurity with barriers to HIV care and treatment.

I use Manna for Health. It's a food bank, but you have to be HIV-positive in order to go there. The food that you get there it's not like the normal food bank. They give you meat, Ensure (a dietary supplement), [and] anything that you need to get a proper diet…plus other groceries [you may need]. I use it every second Wednesday and I leave there with a lot of food. To access this food service], I had to get a letter from my counselor [at the AIDS service organization] acknowledging that I was HIV-positive and that is the way that you get in...But it is accessed by a lot of people. It's full every time that I go there. [Lois, Nova Scotia]

I have to go to food banks because if I didn't I couldn't afford [to meet my nutritional needs]. Rent is $575 [a month] and [income assistance] only give me $535 [a month], so that means $40 extra dollars that I have to give for rent and I [only] make $130 on my Canada pension, so [groceries] comes off of that check. And so I end up with $90 a month and that's not enough [to live]. How are you supposed to move on...I have [also] accessed Manna for Health? I used to go there when I lived in Dartmouth a few years back. They used to actually deliver [to me] because I was sick at the time [associated with my diagnosis with HIV]. I was in and out of the hospital and they used to deliver food to me [fruits, vegetables, and meats]…It was really helpful when they could deliver to me. [Edna, Nova Scotia]

Lois and Edna, whose stories and experiences are similar to those of other women in this study, rely heavily on the Manna for Health food program to achieve a quality diet that might not be available at traditional food banks. Weight loss, wasting, and malnutrition are common problems that people living with HIV face while undergoing treatment. Substance abuse, coupled with homelessness, is a reality for Lois, Edna, and three other participants in this study. These life circumstances heighten concerns about the side effects of HIV treatment and worries about the lack of sufficient nutrition and difficulties accessing care.

The expansion of food programs aimed specifically at people with HIV, such as Manna for Health food program, is a second solution for addressing food insecurity in both provinces. Similar to the Ally Centre of Cape Breton's on-site food program, the Manna for Health partnership with Feed Nova Scotia is a unique food initiative operated

solely by volunteers. Its placement in different regions of the two provinces, such as Fredericton, Saint John, Moncton, Sydney, and Truro, would bridge the gap in addressing nutrition requirements for people living with HIV. Replicating the Manna for Health food model would involve community organizations to strengthen their relationships with existing food banks, and locate meal programs in regions with high rates of HIV infection, involving further research to pinpoint these sites in both provinces. The cost associated with this initiative falls outside of the new funding guidelines for community organizations. It would be more feasible instead to establish partnerships directly with food banks, like the Ally Centre of Cape Breton and Feed Nova Scotia, and create an on-site meal program aimed specifically at HIV populations.

Clearly, there are multiple complex interrelated barriers-to-care women faced by HIV-positive women in this study. Access to a wider support system network (e.g., education outreach, housing, and addiction services) through community-based organizations was a way for some of them to stabilize their health and improve their overall quality of life. Edna's reliance on social support services like the AIDS Coalition of Nova Scotia and Manna for Health food bank was not only helpful during her treatment and recovery process, but helped her to overcome the desperate dependence on housing and food assistance. Lois and Edna continue to visit Manna for Health when they are in Halifax accessing care services.

Most of the women in this study have come to rely on services that combine food and education programs no longer offered by community-based organizations because of extremely limited funding and increased demand. Food vouchers for farm products were

regularly used. This service was important for offsetting the rising costs of food and

helping women meet their increased dietary needs while living with HIV. This is a unique

approach used in all three community-based organizations in New Brunswick and the

AIDS Coalition of Nova Scotia, and was intended to address one of the most significant

social problems facing HIV-positive women.

Nancy and Ruth, for instance, were regularly accessing food voucher programs

from AIDS service organizations to offset costs associated with special dietary

requirements and antiretroviral treatment. Comments from both women illustrate the

importance of the voucher program to bridge the gap in food security, voucher programs

that no longer exist because they do not meet new federal funding guidelines.

> I did enjoy having the market slips. I used to like picking out my own vegetables [at the market]. I would have never gone to the market [otherwise]. I don't think that I've been there since they took them away. [Market slips were $20.00] and you could pick anything in the market…There's milk [and] there was bread - it just depended on you [and what groceries you needed that week]. [Nancy, New Brunswick]

> It's a shame that they had to stop [the food program]. It really did help me. In the middle of the month, when I had no money, that couple of bucks would help me to get through the end of the month [with groceries]…Someone said that the St. Vincent de Paul does [provide food vouchers], but I haven't called them yet. [Ruth, Nova Scotia]

Follow-up conversations with community sector employees show that by no

means was the loss of the voucher program an easy decision to make and organizations

are aware of the impact it has on women struggling to provide adequate food for

themselves and their families. 'Doing more with less' in the face of new federal funding

guidelines and broader outreach and care initiatives are the main reasons for the loss of

food voucher programs in both provinces. The loss of federal funding did result in the

positive effect of strengthening community referral networks in both provinces, largely in social and community development, to meet the complex health priorities of women.

Transportation

The lack of transportation and the long distances necessary to travel for specialized care were the most commonly identified barriers for HIV-positive women in this study who live in the rural-urban fringe of New Brunswick and Nova Scotia. Although these women require less frequent HIV monitoring because of a stable viral load, they still have to travel to receive specialist care every four to six months. Conversations outside of the interviews with women living with HIV show that they struggle with a continual lack of basic transportation services, the high cost of bus fares, extreme weather conditions, and challenging roads to access community services in the urban areas, sometimes on a weekly basis.

Table 4.1 shows the distances women travel from their homes to seek health and social services in urban areas. The distances range from two to 104 kilometers and most must travel by bus and/or by foot.

Table 4.1: Distance women in this study travel to and from appointments.

Pseudonym	City	Distance travelled (KM)	Means of travel
Marion	Dartmouth	2	Bus and walking
Ruth	Fredericton	8	Bus and vehicle
Beatrice	Halifax	4	Bus and walking
Mary	Halifax	3	Bus and walking
Edna	Halifax	3	Walking
Phyllis	Halifax	3	Bus and walking
Jane	Halifax	5	Bus and walking
Lois	Kentville	104	Vehicle
Doris	Moncton	2	Bus
Nancy	Saint John	6	Vehicle

Lois is the only woman living with HIV in rural Nova Scotia. Her experience of traveling extremely long distances to access specialized care is not unique, but a barrier faced by many people living with HIV in the two provinces because of the location of care and support services in urban areas.

> I don't have the money to come in [to Halifax for my six-month treatment appointments] so, there's a doctor that I see in town [sometimes]…but they don't have any buses that run there either, so I'm kind of limited to where I can go and when I can get into Halifax [for my medical appointments] because it costs money. This is a poor province…I don't have the same resources here as I did in Saskatchewan… [I was just] thinking about moving back home [to be closer to my family after the HIV diagnosis]. [Lois, Nova Scotia]

Lois's experience with transportation-related barriers to care is a special case of a woman travelling a long distance from the urban-rural fringe. Her observations about the lack of care for women in rural communities due to reduced public transportation services, which creates a dependency on family members for accessing health services in urban areas, brings into view a growing barrier-to-care that is invisible in the New

Brunswick and Nova Scotia literature. These findings were corroborated by conversations with four other women in the offices of community-based organizations.

Conversations with community sector employees revealed that Lois's story about transportation-related barriers to care was shared with other HIV-positive women in the two provinces. Figures 4.2, 4.3 and 4.4 lay out the main highway routes women travel to access specialized HIV care in New Brunswick (Saint John and Moncton) and Nova Scotia (Halifax). Persons living with HIV in remote communities have limited access to specialized care, treatment, and support for their condition. The need for specialized HIV care, including the renewal of antiretroviral drugs every six months and treatment for adverse reactions to other underlying or acquired illness, are two main reasons given by community sector employees to explain why women leave their home communities and travel long distances to urban centers for services. Ruth, for example, traveled from Fredericton to the Saint John Regional Hospital HIV clinic every six months for renewal of her antiretroviral drugs (see Figure 4.2). Ruth owns a vehicle that she uses to travel to her medical appointments in Saint John. Women living in Fredericton or its surrounding rural communities had to travel long distance for medical appointments because at the time of this study there were no infectious disease specialists there. In 2017, an HIV clinic opened at the Fredericton Downtown Community Health Centre as a way to bridge the gap between community needs and access to specialized HIV care. The head infectious disease specialist at the Saint John Regional Hospital now travels to the Fredericton clinic once a week to deliver medical care to people living with HIV in an effort to reduce transportation-related barriers to care for clients.

Figure 4.2: Distance travelled from Fredericton to Saint John to access care services. Created using Google My Maps (https://www.google.com/mymaps/).
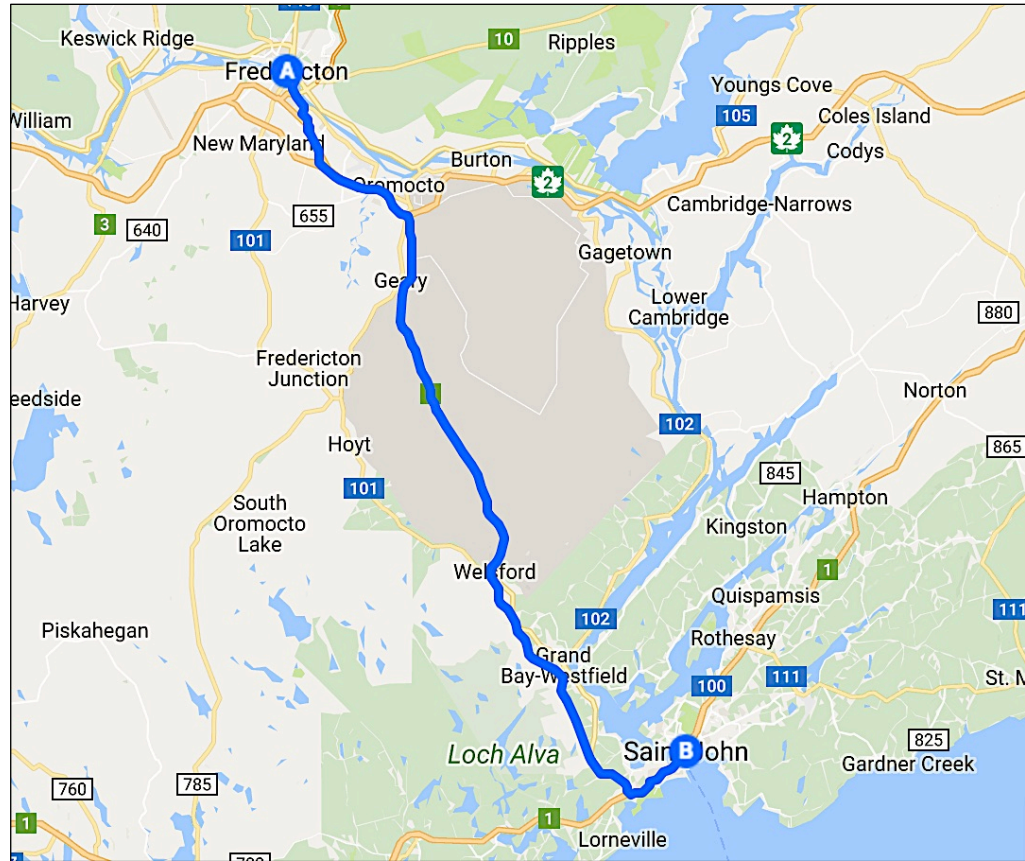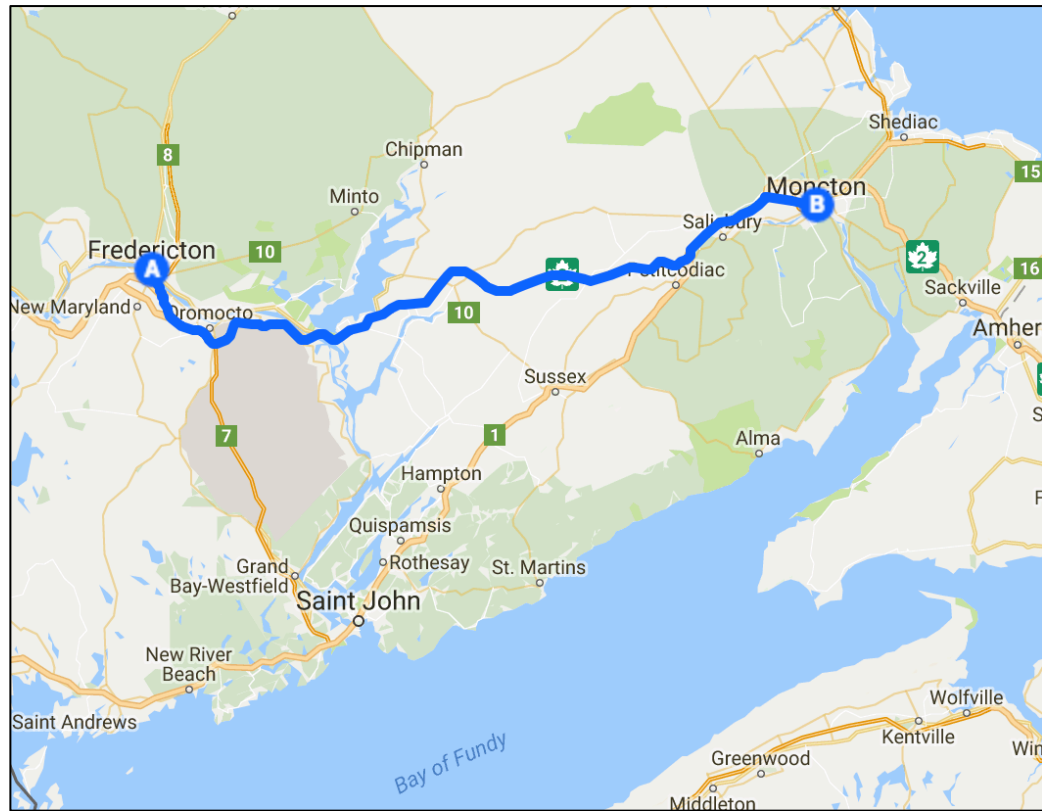

Distance: 116 kilometers   **Average Time**: 1.17 hours one-way

This infectious disease specialist also provides a unique service: free home-based care for people living with HIV in Fredericton, Saint John, and surrounding regions who are bed-ridden. This approach to care is not available in other parts of the province or in Nova Scotia, and would be difficult to replicate because of the vast geography of the provinces, most of which are rural, and the high health care costs associated with community home-based care in two 'have-not' provinces. Fewer women are thus

traveling long distances to their medical appointments because they now can access the

HIV clinic in Fredericton, unless they are seeking continuity of care from the infectious

disease specialist in Moncton (see Figure 4.3).

Figure 4.3: Distance travelled from Fredericton to Moncton to access care services.
Created using Google My Maps (https://www.google.com/mymaps/).
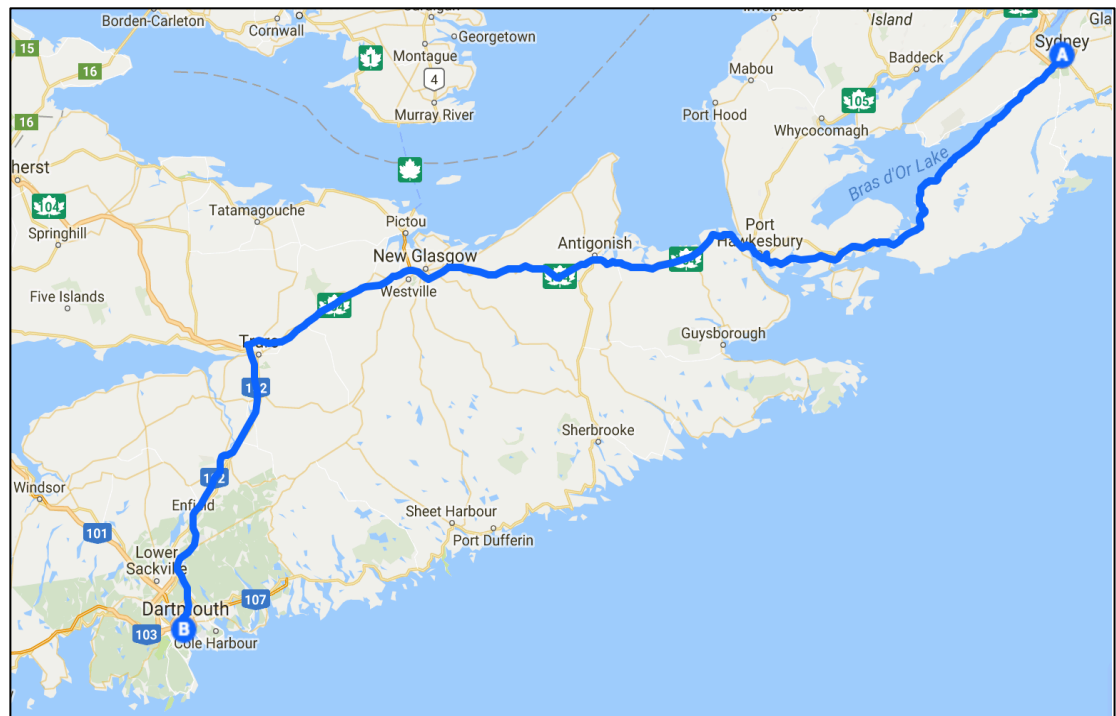

Distance: 176 kilometers   **Average Time**: 1.51 hours one-way

Doris relocated to a housing unit in a New Brunswick city because the absence of

a nearby bus stop at her former residence meant that she was traveling half an hour to

forty minutes one way on the route shown in Figure 4.3 for her medical appointments and

to access social supports. The cost of her taxi fare to and from medical appointments was exorbitant while she was receiving stabilizing treatment.

How many women living with HIV travel the distance from Fredericton or surrounding rural areas to Moncton? Community sector employees from New Brunswick are under the impression that fewer women are traveling to the Moncton Hospital HIV clinic for specialized care than to Saint John. This is because of the shorter average distance to access medical services and the availability of an infectious disease specialist at the Fredericton Downtown Community Health Centre. The longest distance traveled for HIV care is from Sydney to Halifax (see Figure 4.4).

Figure 4.4: Distance travelled from Sydney to Halifax to access care services. Created using Google My Maps (https://www.google.com/mymaps/).

Distance: 407 kilometers   **Average Time**: 4.25 hours one-way

I relied on discussions with community sector employees from the Ally Centre of Cape Breton and Northern AIDS Connections Society to understand the transportation-related barriers to care faced by women who lived on the North Shore of Nova Scotia. Interviews with the nine employees from these organizations suggest that the majority of HIV-positive women live in the urban-rural fringe around Halifax because of the lack of affordable transportation options in the North Shore region. More recently, the loss of the only infectious disease specialist in the area because of poor incentivizing practices in this underserved area of the province has worsened the situation (CBC News Nova Scotia, 2017; Dinshaw, 2017).

AIDS service organization employees identified the lack of affordable transportation in rural communities as the main barrier-to-care in rural Nova Scotia, and pointed out the need to implement a transportation assistance program and increase the frequency of public transportation. The comments of Gregory and Mark underscore the challenge of transportation barriers-to-care for women and other low-income people living in rural or remote communities when specialized HIV care is mainly located in Halifax.

> Transportation is a big issue, because in most rural communities in Nova Scotia, there are no bus services. [Although] Halifax does have a bus system, so you certainly can take the Maritime Bus [and] get a bus from Truro to Halifax, but you're usually dropped off [in an inconvenient place] and then you have to find transportation to the city to [access testing and treatment services]. So when you're dealing with unemployment [and] poverty or homelessness, and you don't have the money, [transportation to care services can be even more challenging]. [Gregory, Nova Scotia]

> Speaking from personal experience, there's nothing at home for you [in Sydney, Cape Breton]… services [are] only be offered in Halifax. Because a lot of the services in Nova Scotia are Halifax centered, you're forced with a decision. Do you

stay here, struggle, and try to get back and forth between appointments, especially if you're low income, and you can't afford to keep the travel up or do you move [closer to urban areas]? [Mark, Nova Scotia]

Both participants' comments reveal how complex the navigation to and from medical appointments in Halifax can be by public transportation. The poor service frequency of shuttle bus departure times makes it a challenge for women like Lois to travel to Halifax for treatment. According to interviews with community sector employees, there are women living with HIV who travel three hours one-way to access HIV care and treatment. To do so often requires overnight stays and arrangements for childcare. For example, a single round-trip shuttle bus from Sydney, Cape Breton, to Halifax departs once per day at 8:00am, arrives in the city at 3:00pm, and costs $121.97. Similar observations were made by AIDS service organizations in New Brunswick (Medeiros, 2012).

Employees of the three AIDS service organizations in New Brunswick similarly argued that most persons with HIV were permanently living in the urban-rural fringe of Fredericton, Moncton, and Saint John to be in closer proximity to medical and support services that are unavailable in rural regions of the province, and to be closer to family members who are jointly responsible for the care of their children. The number of people living with HIV in these regions is not known (Public Health Agency of Canada, 2013). Even though people living with HIV in rural and urban areas cope with different travel distances that affect their care, they remain connected by unstable or low incomes and ill health, which worsen the challenge of traveling any distance for specialized care.

Seven of the HIV-positive women in this study depend on unreliable forms of transportation, including public transit, or have to rely on others to travel to community health and social services, which further exacerbates the role of distance as a barrier-to-care. Nancy, for example, has been providing transportation to people living with HIV to social services, including local food and clothing banks, for 14 years. She met the HIV-positive people she now transports through local food and clothing banks. Learning about their difficulties getting to appointments and social service organizations was the main reason she started the transportation service aimed at assisting low-income persons living with HIV.

> I know where all the poor people go to get their stuff…I'm [drive] everybody to help them all out. If there's any program out there that I could find [that can help] other people like the community Christmas baskets, I will take them, especially those that are on social assistance and have many children…[and] I take them to local food [and clothing] banks [and soup kitchens]…that's what keeps me busy in my life. Helping out my less fortunate friends everywhere they need to go… because they have no way of getting to these places…$2.75 [to ride the Saint John metro bus] is a lot of money for some people… for somebody who doesn't have a lot of money [to begin with]…the monthly [bus] passes are also too expensive. I don't know anybody who would get one. [Nancy, New Brunswick]

Nancy asks the people she transports to pay a small fee to offset the increasing cost of fuel. Though her service is a noble gesture, it is not a long-term solution to poverty or to transportation-related barriers to care in the province.

The employees of AIDS Saint John acknowledge that there are transportation problems in Saint John, often leading to missed or rescheduled medical appointments, and support Nancy's efforts to bridge the gap between transportation and community health. They argue, however, that these transportation problems result from a larger systemic issue that requires government funding. Even though community-based organizations

have insufficient resources to address transportation-related barriers to care for every

client, in cases of emergency they continue to provide persons living with HIV with

transit tickets and monthly passes to assist them in travelling to their medical

appointments. It took Doris, for example, a long period of time after diagnosis to achieve

stable health. She relied heavily on the monthly bus pass provided by the local AIDS

service organization while adjusting to antiretroviral treatment.

> I had a rough few months [financially] and [the community-based HIV organization I access] knew about it…I had a lot of medical appointments, so I was given a bus pass. They still check in and ask if I need a bus pass this month and I say [that] I don't want to take advantage [of programs and services]… if I don't need it, I won't ask for it because [the organization is resource restricted] and they have to make stuff [meaning funds] last. I don't have a car [because of high insurance costs] so getting back and forth to the doctors is kind of tricky if I'm not [living or working] on a bus route…The bus route I'm on now takes 45 minutes to get to my doctor's appointment… actually about an hour to get there and back depending if you want to walk 10 minutes in one direction, so it takes about three hours out of my day to get to one appointment. [Doris, New Brunswick]

She is now in stable health and employed as a full-time worker, but continues to

face long travel times. She often requests time off work to attend medical appointments to

avoid explaining her whereabouts to her employer and to give her time to adjust to any

treatment changes. The high cost of public transit fares are a challenge shared by other

women, such as Marion. She is in recovery from an opiate addition that she has struggled

with for the greater part of her life and continues to rely on monthly bus passes from local

community-based organizations to access medical and support services in Halifax.

> No, I can't afford a bus pass. I have to put it [my money] towards my groceries, so I buy bus tickets [when I can to travel from Dartmouth to Halifax for medical appointments]. I know how many tickets it takes to get to [downtown] Halifax, so I set aside a number of tickets [each month] to go to different places [including the food bank, Manna for Health, and clothing banks] that I do go to in town…[I travel

> to Halifax] three or four times a month [for programs or services]. I have to go every three weeks for my methadone anyway to get a new prescription and do urine analysis. It's mandatory now [to continue my treatment]. [Marion, Nova Scotia]

Owing to her ill health, Marion travels to Halifax more frequently than other women in this study to access care services. She typically walks one hour to one-and-a-half hours each way to access services in Halifax when she is unable to secure a bus ticket or monthly pass from community-based organizations. The changing federal mandate and government funding for AIDS service organizations has resulted in the complete loss or decreased availability of transit bus passes for clients. Mainline Needle Exchange is the only community-based organization that continues to distribute single transit bus tickets to its clients on a case-by-case basis. The continuing availability of transit bus tickets for their clients is made possible through funding for the wellness navigator program by the provincial government.

To address the long term transportation-related issues persons living with HIV face, Mainline Needle Exchange in Halifax (in cooperation with the Mobile Outreach Street (MOSH) Health and Direction 180) uses mobile units to provide outreach and support services to persons isolated from health and human services or lack transportation in remote and rural communities. This is a one-of-a-kind care and treatment service distinguished from mobile outreach services elsewhere in Canada. The mobile unit delivers one-site care and community supports, including harm reduction supplies (e.g., condoms, swabs, cookers, Vitamin C), wound care, addiction-related support, health education, and community referral support.

Figure 4.5 shows the location of daily mobile outreach services in Halifax and Dartmouth. Mainline Needle Exchange and MOSH also provide mobile outreach services every two weeks to other parts of the province, including rural areas such as Truro, Amherst, Pictou County, and the Annapolis Valley. Employees from all three organization note that women access mobile services as often as men because of the convenience of increased access to health services after hours.

Mobile outreach units also provide an entry point to healthcare services for HIV-positive women. Teresa, for example, coordinates a methadone maintenance program. Teresa explained the management and organization of the Direction 180 mobile methadone program, which is the largest outreach service in the province.

> We specifically travel in order to meet clients…the mobile unit runs 365 days of the year [providing methadone treatment]. Right now we have 4 sites located all throughout the metropolitan area [of Halifax and Dartmouth]. The mobile unit was actually started [when the] metro transit had gone on strike a few years back, so a lot of our clients who take the metro transit system to get here every day for there methadone where unable to [do so]. So we launched an outreach [mobile] service to get people their methadone [with the support of the province]…the amount of people actually coming and accessing the treatment was amazing [and this is where the organization] got the idea to launch a mobile unit to broaden access and increase adherence to methadone treatment [in the community]…People accessing methadone treatment need to get up and they need to travel here using public transit systems every day, so having the mobile unit in communities of need has been important to adherence [during methadone stabilization]. [Teresa, Nova Scotia]

Four of the seven women living with HIV from Nova Scotia access methadone treatment from Direction 180 in the hope of achieving substance abuse recovery. They were among the 160 persons on the organization's wait list for admission to full treatment from the methadone clinic on Gottingen Street in Halifax. They travelled from their homes by foot every day to the closest service sites, including Halifax, Dartmouth,

Fairview, and Spryfield, to receive their medication. The provincial drug benefit program

covers costs associated with methadone maintenance treatment. They also accessed

outreach services from Mainline Needle Exchange and MOSH less frequently for health

education information, testing, and condoms.

Figure 4.5: Mobile care sites in Halifax and Dartmouth, Nova Scotia, to support people living with HIV and hepatitis C. Created by P. Medeiros© using ArcGIS 10.2.
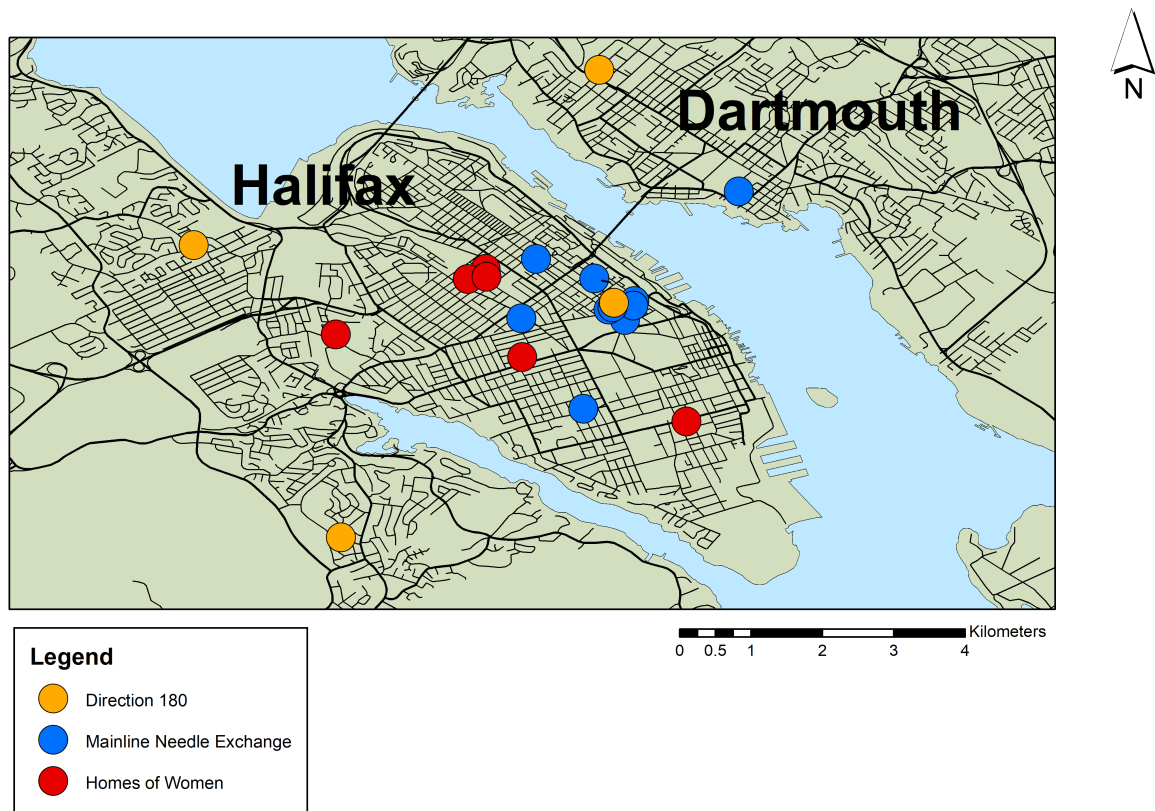
The emergence of different transportation services and availability of a mobile

outreach service helps HIV-positive women navigate the health care system. The

planning and investment in mobile outreach for rural or remote communities by

organizations like Direction 180 and Mainline Needle Exchange is a feasible approach for

addressing transportation-related barriers to care for people living with HIV, HCV, and other STBBIs. The new Direction 180 mobile methadone clinic, for example, did not require that the agency apply for additional government funding or redirect funds from other programs at its brick-and-mortar location. The full resource impact fell on private donors and the MAC Cosmetics AIDS Fund to cover the full $160,000 cost associated with the retrofitting of the bus (CBC News Nova Scotia, 2015).

I believe that expanding annual fundraising efforts and acquiring additional provincial government funding would help to increase the number of routes of mobile outreach programs to underserved rural or remote communities. AIDS service organizations in New Brunswick, for example, could use a similar mobile outreach approach to provide services to persons living with HIV, HCV, and other STBBIs in their own communities rather than requiring individuals to secure transportation to their fixed locations during standard business hours. Enhancing mobile outreach programs would not only promote the continuity of care for persons facing transportation-related barriers, but also improve their quality of life by providing services to communities that currently lack them. A main challenge for outreach services in rural areas, however, is the greater stigma associated with a positive HIV diagnosis.

Stigma

HIV-related stigma and discrimination are significant barriers to women's health and health-seeking behaviours. The consequences of HIV-related stigma are widespread, as shown in the narratives of women and community sector employees in this study. The effects of stigma include concealment of HIV-positive status, increased suffering, and

delay in seeking HIV testing and treatment. The internalization of HIV-related stigma and discrimination also causes isolation, self-blame, and feelings of fear and sadness. All ten women in this study were struggling to overcome stigma, regardless of their stage of HIV infection.

Employees of AIDS service organizations are aware of the impact of stigma, especially those who have been in a position to establish close relationships and a measure of trust with clients.

> [Stigma is a growing issue affecting women's access to care services]. Many people don't walk through our doors or if do come in for something, they're so worried that someone [from the community] will see them coming in here and think they have HIV [so people avoid the organization]…I also think that just our name alone doesn't help us much either. We are an AIDS organization, but we've expanded to do so many things that [people and the community can benefit from]. [Karen, New Brunswick]

> There are many [groups and] populations that are [invisible in the epidemic] and they choose to be underground because of the stigma that is attached to the HIV disease. So it's very hard to work with certain populations because they're so fearful [of the impacts of status disclosure]. They prefer the organization provide some sort of outreach service to them at a neutral location that would be safe for them rather than them come into the office. [Gregory, Nova Scotia]

These observations reveal how severely people living with HIV are stigmatized. HIV-related stigma can affect willingness to seek basic services, such as information on harm reduction and referrals to other appropriate community support services. The inclusion of the word AIDS in the name of the organization proved to be a major deterrent for persons living with HIV to access services because of fears associated with disclosing their HIV status. Two AIDS service organizations in this study changed their names because of the stigma associated with AIDS, coupled with the enhancement of services to meet the needs of people living with HIV, HCV, and other STBBIs. The

Northern AIDS Connection Society changed its name to the Northern Healthy Connections Society. The AIDS Coalition of Cape Breton also changed its name to the Ally Centre of Cape Breton. A more recent name change was made to AIDS Saint John in early 2018; its new name is Avenue B Harm Reduction. This name change took place shortly after my departure from the field. I assume these name changes will significantly improve clients' anonymity and increase the overall uptake of programs.

Barbara's observations about HIV-related stigma are drawn from her experience as a community service employee working closely with remote communities in Nova Scotia.

> We're still fighting that age-old stigma and discrimination within rural communities and I don't necessarily feel that it's only impacting rural communities – stigma and discrimination also exist in the cities… there's just a lot more offered and there's a lot more availability of services, and places to go where you can actually feel a part of your community in a city more so than in rural communities [to begin addressing HIV-related stigma]. [Barbara, Nova Scotia]

Her comments highlight the severe degree to which stigma and discrimination remain barriers for people living with HIV to seek out medical and social support services in their communities. She suggests that HIV-related stigma may be more pronounced in rural areas. For example, the Northern Healthy Connection Society's new hepatitis C education program was poorly received in Truro because persons in the community viewed the opioid crisis as a taboo topic. Discussions with community members during public meetings and organized events highlighted misconceptions and a lack of understanding about HCV, and its increasing incidence in the region. The meetings mostly provided a way for community feedback to be incorporated into the existing hepatitis C education program, and to reduce stigma related to living with HIV.

117

Community involvement in the development and delivery of anti-stigma initiatives is a common approach organizations are using not only to improve the content of their programs, but also to gain a thorough understanding of the community and its needs.

Stigma, and its associated internalization characterized by persistent negative thoughts about the act of disclosure, has damaging effects on the wellbeing and quality of life for HIV-positive women (Arthur et al., 2013). All of the women in this study found it particularly troubling to discuss with me issues of social stigma and its harmful impact on their lives, possibly because they distrusted my intentions as a researcher; instead, I relied on the comments of community sector employees to understand the influence of stigma on access to care services. Because the stigma attached to a positive HIV status is so pervasive, women like Mary often delay accessing local community resources that facilitate health care. She talked about being fearful of ostracism from the community or abandonment by family members after her diagnosis. These fears make Mary reluctant to disclose her positive HIV status to others, including medical and support workers. Counseling she received through the office of her infectious disease specialist in Halifax has helped her to disclose her status. Nevertheless, her worries about disclosure contributed to the poor uptake of services to meet her basic needs for food and shelter.

Summary

This chapter explores the barriers-to-care for women in New Brunswick and Nova Scotia through the experiences of women who are HIV-positive and employees of AIDS service organizations. Their stories not only illustrate the connections between poverty and barriers-to-care, but also underscore the broader inequities that affect their quality of

life and leave them struggling to meet their fundamental needs. Community-based AIDS organizations play an important role in harm reduction, education, and support services, but little is known about how the expansion of their mandate to enhance programs and services for people with other STBBIs will affect the health of HIV-positive women.

The next chapter describes the support services offered by community-based organizations to improve the quality of life of women living with HIV.

Chapter 5 A Community of Care

This chapter covers three questions addressed in this research: what roles do AIDS service organizations and other community-based agencies play in the lives of women living with HIV? Are the services and programs they have created meeting the diverse needs of the women living with HIV? Are there any essential services missing to improve their quality of care? I first describe the roles AIDS service organizations and other community-based agencies play in the education, care, and support of people living with HIV in New Brunswick and Nova Scotia. I then discuss the changing landscape of care, or lack thereof, for women living with HIV in both provinces. Finally, I describe how these organizations are meeting the new priority agenda for persons living with HIV. The main point of this chapter is to examine the services and programs aimed at mitigating barriers-to-care.

Both groups of participants in this study provided a great deal of insight into the relevant health and social networks women navigate to meet their basic needs, which largely consist of housing, income and employment support, health care, and food security. Asking questions of community sector employees about the availability of front-line services for people living with HIV not only was useful for understanding the impact community-based organizations have on the lives of people living with HIV, but also the continuing role these social resources play in helping persons navigate the complex health care system.

Impact of Community-based HIV Agencies for People Living with HIV

AIDS service organizations were among the first support groups to be used by

people living with HIV in the 1980s, and continue to be the first point of contact in many

cases after a positive diagnosis, largely as sources for information on harm reduction and

referrals to other appropriate community support services to meet their long-term needs.

In lieu of direct services, and in the face of shifting programs towards an integrated care

model in an effort to meet the new federal response to HIV/AIDS, all of the community

sector employees in this study spoke about their continuing efforts to support people

living with and affected by this disease.

Donna is the longest serving community sector employee I interviewed and most

familiar with community resources in southern New Brunswick. Her observations about

helping persons living with HIV navigate across the care continuum bring into view

inadequate funding as a major challenge organizations encounter in developing and

managing services.

> I think that the services we offer are probably ones that are more advocacy-based…helping people to see that there's a way out of their problem[s]. Let's sit down and talk about it. What are the options...The organization is not funded for support work [by the federal government]. There's no money for support work. It's all fundraised. [Donna, New Brunswick]

Her comments reveal that the current federal funding and subsidies received by

AIDS service organizations are not intended for the development and management of

social support interventions; instead, the federal government has mandated organizations

to use the funds to cover costs associated with rent, utilities (gas, electricity, and water),

and wages. Conversations with long-term community sector employees like Donna,

Cynthia, Lori, and Melissa corroborate this point and underline their organizations'
growing reliance on fundraising efforts and private sector funding to provide frontline
support services in prevention, education, care, and support for persons living with HIV.

The annual Walk for Life, for example, is a primary funding source for all AIDS
service organizations for social support programs, such as the sex worker drop-in in Saint
John on Thursday evenings. This is the only peer-based outreach service for sex workers
of its kind in the two provinces to provide women with safer sex education, healthy foods,
counseling, and testing. Most of the fundraising efforts go to covering employees' wages
for the overtime they work on Thursdays. Donna described the drop-in service as one of
the most regularly accessed supports by all people living with HIV because of its
extended hours of availability for clients. Each organization independently organizes its
own fundraising strategy to increase social support interventions. Further, core
government funding does not go toward financing support groups for individuals living
with HIV, clothing exchange or on-site food programs or the emergency funds upon
which women have come to rely. This is a main reason why community-based
organizations work in partnership with other agencies to bridge the gap in the HIV care
continuum.

Douglas provides another perspective on the impact on persons living with HIV of
support services provided by community-based organizations. He has formed strong
relationships with clients seeking harm reduction supplies (e.g., condoms, swabs, cookers,
Vitamin C), wound care, addiction-related support, health education, and community
referral support. He points out that informal guidance has long played an important role in

the counseling process of people living with HIV, a gateway to care, treatment, and

support after diagnosis.

> Sometimes people just want to vent or just talk about what's going on in their life.
> [For example, they] getting kicked out of their apartment and don't know what to
> do. I can give them some advice [like information and referral services] or go online
> and look for apartments that are available, but sometimes they just want someone to
> listen…Talk about their health problems or just life in general. I'm not a trained
> counselor and I don't claim to be [one], but I will sit and listen to people if they
> want to talk. [Douglas, Nova Scotia]

Douglas's comment, coupled with conversations I had in the offices of

organizations, draws awareness to the importance of community sector employees as

effective counselors for many people living with HIV, largely when the organization is

their first point of contact. Women's reliance on organizations to meet their basic needs

and improve their quality of life has created a level of trust between employees and

clients that is difficult to replicate with a registered therapist. Trust is the main reason

why women continue to seek counseling and support from community sector employees

after diagnosis.

All of the employees in this study are competent and willing to counsel clients to

the degree they see is relevant to help them navigate health and support services in the

community. I think wider generalized training in counseling for community sector

employees is needed. New community sector employees like Douglas may be entering

the community labour market with higher levels of education but, from my observations

in the field, know little about people living with the disease and would benefit from

online training to help clients cope with the presence of the disease and improve their

quality of life. The Canadian AIDS Treatment Information Exchange currently offers

online courses on general STBBIs information (https://www.catie.ca/en/educatie), but

needs to expand online course offerings further to make sure community sector

employees are prepared to meet clients' needs.

It was also clear during my fieldwork, and from the scope of social service

delivery in New Brunswick and Nova Scotia, that community sector employees over time

come to know their clients very well. Lori is a case in point.

> What we provide here is one-on-one [support] as needed. They may come by and need someone to talk to. Sometimes they may be having landlord issues and they might need help finding [community resources]…it is always around food, shelter, and clothing… We had a partnership with a Sobeys dietitian to increase people's knowledge of nutrition and we thought it would also help them learn a different way of using the food that they get from [the Fresh for Less program], but also the food they get from the food bank. It was a total failure though people said they were interested [in the program]. We only had one client come and [access the Fresh for Less food program] and after two or three times of that one client coming in, it just wasn't a good use of the resources from Sobeys. And so we stopped [the food program]… it's a real struggle to find programs and support services that people are interested in. Clients talk about wanting to have social supports, but we have such a small population [of people living with HIV], which is hugely diverse…as an agency when we're told [by the federal government] that we must involve and do programming [to support people living with HIV], how do I that? [Lori, New Brunswick]

Through one-on-one counseling with individuals living with HIV, Lori and other

community sector employees consulted during this research, are well aware of the support

services women require to meet their needs (e.g., food, shelter, and clothing) and continue

to work towards addressing these gaps in the care continuum by developing social

support interventions in their organizations. Fundraising efforts, or the acquisition of

additional subsidies, are key to closing gaps in the HIV care continuum. The food

program partnership with a Sobeys' dietitian she mentions is just one example of a failed

attempt to fill a community need. The poor uptake of this social support is a direct result of not involving the community in the planning and decision-making of a program.

On the other hand, inclusion of persons living with HIV, HCV, and other STBBIs has become more common in the decision-making structures of the organization. For example, a growing number of people living with or affected by these diseases sit on community boards to ensure their needs are visible in the epidemic, largely in the face of an expanding federal mandate for AIDS service organizations. This is an important approach for organizations if they are to remain relevant to the immediate needs of clients, but also raises critical issues and complexities around the long-term health-related needs of people living with HIV.

Sandra has been working closely with other community sector employees in New Brunswick to expand the capacity of its programs to persons living with HCV and other STBBIs. All of the HIV-positive women in this study are in treatment and in stable health. Her remarks below highlight the growing challenge organizations face in providing social support interventions for persons in stable health who are navigating the existing community care system.

> It makes sense that what we offer [in support services] helps the clients that we serve…If I were a person living with HIV and were to call [the AIDS organization] to ask what they can do for me, I [would] say well we can offer you internet access, we can help with cab fare [to medical appointments], we can give [them] information, [and] we can do referrals [in the community]. But for a lot of people that are stable [with their diagnosis], we can't do very much…I think that can be one of the real challenges of meeting their needs is the fact that their [support] needs are very wide and can be very different from one person to the next. [We often struggle to support peoples changing needs, but do our best to do so]. [Sandra, New Brunswick]

The new integrated approach to care, treatment, and prevention of STBBIs by

125

community-based organizations is aimed at persons newly diagnosed with HIV, in the stabilization phase of treatment, or confronted with barriers-to-care like transportation to and from medical appointments. Once health stability has been achieved with an undetectable viral load and CD4 count above 350 cells/mm^3, and the long-term needs for women living with HIV are established, they no longer need to access social support interventions from community-based organizations unless there is an immediate need, such as navigating food and housing insecurity. Doris, for example, is in stable health and does not frequently access support services. Her urgent need to access permanent affordable housing in the city was the main reason for seeking help from a community organization. Doris's access of community services continued sporadically once her immediate housing need was met.

Strengthening relationships with other community-based agencies and sharing resources helps these organizations meet the long-term needs of their clients in stable health in the absence of additional resources and government funding. AIDS services organizations rely heavily on referrals to other community-based agencies, including Mainline Needle Exchange, Direction 180, and the Mobile Outreach Street Health (MOSH), as a modality for engagement in care, health education, and to promote adherence to treatment and disclosure of HIV status. All of the AIDS service organizations and other community-based agencies in this study expressed concern about the federal government's mandate expansion to include HCV and STBBIs in the care continuum. They note that there is no clear action plan for how to implement each new intervention component and worry about its effect on the support services upon which

126

people living with HIV depend, particularly in the face of women's low uptake of current existing services. Some of the long-term employees for the community-based organizations went on to explain how a shift in focus from treatment support to prevention in their communities could exacerbate HIV-related stigma and deepen its invisibility even further, particularly in the context of the lowest total disease prevalence in Canada.

Stigma is a complicated barrier for service organizations to address directly, but it continues to render women and women's concerns medically and socially invisible. Early beliefs around women's increased immunity to HIV infection and a focus on the demands of gay men, since they account for the highest proportion of those living with the disease, continue to permeate society and adversely affect women's health, including delayed testing or missed appointments with their infectious disease specialists because of fears associated with disclosing their HIV status (Arend, 2005; Johnson et. al., 2015; Scharf & Toole, 1992; Terrence Higgins Trust & Sophia Forum, 2018). An understanding of the larger social forces underlying stigma and its effect on women living with HIV, including racism, sexism, violence, and poverty, is a crucial starting point for AIDS service organizations to address HIV-related stigma in the community. Making peer support programs available in rural and remote areas, coupled with continued general HIV education at community-based agencies in partnership women living with HIV offer avenues to lessen existing HIV-related stigma and increase access to support services for women (Loutfy et al., 2016). A more recent tool to address stigma reduction, entitled *Women, HIV, and Stigma: A Toolkit for Creating Welcoming Spaces*, by the Women and

HIV/AIDS Initiative (2017) is a general HIV education guide for community organizations to reduce a woman's feeling of isolation and enhance their capacity to improve their wellbeing by creating a safe and welcoming space for clients. The Women and HIV/AIDS Initiative (2017, p. 28) advocates, "Creating welcoming spaces involves making a commitment to address the factors that make women vulnerable to HIV…being able to provide accessible HIV resources, [and] being able to make trusted referrals." Creating a safe space in the offices of community organizations involves making changes to office layouts and environments, such as increased indoor and outdoor lighting, and gender neutral signs, making available gender equitable services and resources, and clear policies and procedures to ensure women's safety (Women and HIV/AIDS Initiative, 2017). Such safe spaces are simply places where women living with HIV can access community resources, counseling, testing, and support services without stigma and discrimination. Discussions around how to address HIV-related stigma fall outside of this thesis topic; all of the women in this study, as a reminder to the reader, found it particularly difficult to discuss experiences of social stigma and how to bring about change with me.

A combination of insufficient resources, a change in the investment mandate of existing funds for AIDS service organizations and other community-based agencies, and a relatively low prevalence of HIV among women in the New Brunswick and Nova Scotia has resulted in the loss of HIV support programs, the growing challenge of addressing HIV-related stigma in the community, and increasingly difficulty to create women-

specific health strategies. This is a central reason why community referral networks are necessary to meet women's needs across the life course.

The Loss of HIV Support Programs

The policy shift away from providing services specific to the needs of people living with HIV/AIDS towards an integrated approach to addressing STBBIs remains a central concern for AIDS service organizations, largely because of the loss of assistance programs HIV-positive women have come to depend on to meet their basic food, shelter, clothing, and medical care needs. All of the participants in this study, both women with HIV and the employees of community-based organizations, describe particularly poor uptake and implementation of women-centered HIV/AIDS programs.

A higher prevalence of HIV among men having sex with men in New Brunswick and Nova Scotia influences the direction of support systems involved in HIV caregiving away from women-centered care. Doris, for example, has been accessing social supports in the community regularly since she was diagnosed with HIV 11 years ago. Her interview describes inadequate support for women living with HIV because of the higher incidence rates of new HIV cases in men in the province. Like the other women in this study, Doris would like to access women-centered HIV care services; instead, she is the only participant who actively uses online social supports to fill this gap in the care continuum, experience a greater sense of empowerment, and meet other woman living with HIV in Canada. Accessing online social support services is a convenient and feasible way for Doris and other women to exchange information and emotional support in the

face of integrated care services and a lower prevalence of women living with this disease in both provinces.

AIDS service organizations and other community-based agencies acknowledge how the absence of women's programs heightens their invisibility in the epidemic. Community sector employees cite the low prevalence of HIV infection among women as the barrier to creating women-centered services, and the need to instead rely on strengthening existing referral networks in the community. Sandra's comment on the overall lack of services for people living with HIV in New Brunswick stems from her experience working to meet the new federal guidelines.

> I think that it will be a challenge for people living with HIV [to access services because] it's no longer going to be an organization that is set up to working with HIV… we certainly will still be working with HIV [positive people], but programs will be [a little] different…But I think that the core idea is that we are really trying to make this a safe place to whomever walks through our door. [Sandra, New Brunswick]

Other community sector employees share her optimism. There is no doubt that organizations will continue to have safe spaces for clients to access counseling, education programs, and outreach services in their offices; however, the burden of their activities will grow with the need to generalize programming to include persons living with hepatitis C and other STBBIs who will be accessing their services. Organizations are now struggling to meet the needs of persons living with HIV and to retain their visibility of the HIV/AIDS epidemic. The loss of dedicated HIV care and support programs, from the perspective of the women in this study, has instead disempowered and rendered them invisible and neglected in the epidemic. The loss of these programs has serious consequences.

There was a time when I could come here and get my fruits and vegetables from the market [and bus tokens to travel to my medical appointments]. Once a month, I would get a coupon for the city market [from the organization] to stay healthy... There's nothing now [no food subsidy programs]…there's no health and wellness…there's not too much now [for people living with HIV]. [Nancy, New Brunswick]

I'm just scraping by my teeth [each month]. I think there should be extra money for people to live with HIV and hepatitis C. I know I have a special diet with social services and stuff like that. Even when I first started [going to the AIDS organization], they used to have a health fund where every two months we were given $75 for hygiene products…that doesn't exist anymore [and] it hasn't been a year. I phoned up one day and they told me there was no longer a health fund. Holy shit! I've been getting this for 10 years and now you're telling me [it doesn't exist anymore]… and I think the government doesn't care. [Edna, Nova Scotia]

I was accessing money from the [AIDS organization]. They were giving us $75 every second month, but that was stopped three months ago. They stopped the program because they said that they didn't have the funding for it anymore because so many new people were being diagnosed with the disease, which I don't believe it is true at all. But, if they say so, I guess you have to listen. [Lois, Nova Scotia]

The loss of support programs offered by the AIDS service organizations was a surprise for people living with HIV. Nancy, Edna, and Lois had no forewarning about the cessation of food and funding programs upon which they had come to rely. Subsequent conversations also revealed some of the hidden feelings they were experiencing around the changes being made to AIDS service organizations, including loneliness, abandonment, and sadness. These feelings were perhaps not only associated with existing HIV-related stigma, but also with the uncertainty about how they would cope with food insecurity and poverty.

Community sector employees were equally divided in their responses to women's reactions regarding the loss of HIV support services. They were mostly shocked and amazed that announcements sent out in the monthly newsletter about the realignment of

their organizational structure did not reach everyone affected by the changes. This is an

example of access issues linked to income levels. Most of the HIV-positive women in this

study do not have computers, email addresses or even phones. The underlying issue here

is poverty and the need to have alternative ways of informing people about program

changes beyond computer-based systems. Simple methods, such as posting notices on the

office doors of the organization and mailing letters directly to clients, are needed.

The loss of HIV support programs has resulted in invisible suffering of HIV-

positive women and the loss of a sense of belonging. All of the HIV-positive women in

this study lacked a support group in their community within which they could discuss

health problems unique to women, such as abnormal cervical cytology and bacterial

vaginitis, disease progression and changes in the female body, and women's health needs

and human rights. These are common issues women face and want to discuss with others

who share similar experiences. Mary and Edna, for example, describe the challenges they

face in meeting other women living with HIV in their community.

> I find people [living with HIV] keep to themselves. I don't…like I've said I've only met a few [other] women through the AIDS Coalition of Nova Scotia, which had women's meetings [in the past] for us to get together, but generally only two or three of us show up [to the events]…those happen a few times a year, but they have been cancelled because women don't show up…I think it's kind of a shame that women don't get together because I'd like to meet some of the other women with HIV and talk to them like I've said I've only really met two others, so that a women's get together would really be something for me anyways. [Mary, Nova Scotia]

> I'm trying to [meet] people who are living with HIV [and] they may know others because in New Brunswick they I don't. The woman I [have] spoken to doesn't know other women with HIV [either]. They felt very isolated in their experiences and I'm trying to understand if Nova Scotia is the same…there are really no groups that you can [join to meet] other HIV women and speak freely with [about women's

health issues]. That's why I would like to start a group just for women…for me [and] have people living with HIV join [to talk about] how they cope with it and how they live with it. I don't know why someone hasn't come up with that idea. [Edna, Nova Scotia]

These comments highlight the need for women to improve their health status and quality of life by knowing and sharing their experience with other women living with HIV. Barriers to care (e.g., affordable housing, food insecurity, transportation, and stigma), a low prevalence of HIV-positive women in New Brunswick and Nova Scotia, and the loss of HIV support services poses major challenges for women to participate in HIV support groups and general meetings organized by the community-based organizations. Support group initiatives at the time of this study did not meet the needs of the women living with HIV because issues that were being raised (e.g., testing, treatment, and mental health and addictions) were no longer relevant to their lives and services were tailored mainly to men who account for the highest prevalence of HIV in both provinces. This finding further heightens the invisibility of HIV-positive women in the epidemic and leads to negative health outcomes.

A Lack of Continuity in Women-Centered HIV Care

All of the women living with HIV in this study have come to rely on local health and social care services to meet their needs. These organizations do not offer a gender-specific framework. The women living with HIV in this study expressed an overwhelming interest for women-only programs focused on the management of HIV, caregiving, reproductive and sexual health, health needs related to aging and menopause, and HIV disclosure to spouses and family members. These same concerns were expressed

during my MA research (Medeiros, 2012) and more recently in the O'Brien et al. (2017) publication on women-centered HIV care in Canada.

Program and support initiatives for women living with HIV were offered by AIDS service organizations at one time, but are no longer available because of the underrepresentation of women in decision-making structures, poor uptake of programs resulting from transportation-related barriers to care and relevance to their immediate and long-term needs, and the low prevalence of HIV infection in women (Medeiros, 2012). These factors, and the higher incidence of HIV infection among men, continue to contribute to a care landscape where women's comprehensive needs are not prioritized. Yet, in the face of a rising proportion of women living with HIV in Canada, there is a need for gender equitable services to better meet women's diverse needs rather than homogenize the care of all people with this disease.

Lori articulated the core values she believed a women-centered care approach should take, based on her long experience delivering support services to women living with HIV.

> It's about facilitating access. You'll hear stories [from your interviewees] about how we helped pass on the [community development] paperwork or connect people that we serve whether HIV-positive or Hep C [with access to] social supports. Probably one of the reasons we're so good at [providing referrals and community resources] is that we offer harm reduction services and we're totally non-judgmental [towards our clients]. We understand [their experiences of] addictions, poverty and mental health. We don't have all the answers, but it is really about treating the person with respect and dignity…often the feedback we're been given is that one of the greatest things about our organization is that people feel we provide a safe space for them and I think that's key to getting people to open up and share [their life experiences]. [Lori, New Brunswick]

Lori envisions a women-centered care model as a safe and enabling environment in which women can disclose their HIV status. Creating an environment that is warm, welcoming and nurturing is an important component of care for women living with HIV. Subsequent conversations with Lori reveal how challenging it is to establish this space in the current care landscape when men account for the highest proportion of people living with the disease and often frequent the same support services as women. A one-stop approach to care would further allow women to access ongoing supports after diagnosis, inclusive of treatment, education outreach, and housing and addiction services. That said, such an approach would arguably elevate the costs for travel for treatment or appointments by locating services in one area rather than distributing them throughout an entire region. Continuing research by the Canadian HIV Women's Sexual and Reproductive Health Cohort Study team is underway to refine a model of women-centered HIV care in Canada (Loutfy et al., 2013; O'Brien et al., 2017; O'Brien et al., 2018).

Participants demonstrated not only the importance of understanding women's experiences of seeking care, but also the need to develop a women-centered approach to HIV care to maintain their visibility in the epidemic. Lois has been navigating the HIV care continuum for the least number of years, but her comments about the absence of women-only support services echo the sentiments of other women in this study.

> There's really nothing new [in terms of women's programs and support since the 1980s]. There's nothing for women with HIV…there's not really anything actually…I think that a lot of women that have HIV [like me like to talk to people about it [the absence of women-centered care] and I know that for a fact and [that] they don't have enough of women's groups or things to do with women. The [AIDS service organization in the community] used to have all that women stuff and they

> don't anymore…[There needs to be] more services for women [and] just women. Maybe the [AIDS service organization] can do more… I've noticed that they do more things for men [then women, like] they have meetings for only men, but why not women? [Lois, Nova Scotia].

Doris's point of view not only echoes the challenges women face in navigating an increasingly complex health and social services system in the face of established silos of care, but she also emphasizes the value of creating a women-centered care model.

> I just try to think back to where I was [after I was diagnosed with HIV]…I didn't really know where to go [for information or community referrals] or what to do. [I don't want other HIV-positive women to experience the same challenges I did after diagnosis]. It would be nice if newly diagnosed women could talk to [other women living with HIV]. Just a simple phone call in your community or even in a different province that they could put you in a buddy system, and they could email you…I'm not really sure what it would look like, [but I feel it improve the health outcomes of women]. [Doris, New Brunswick]

Lois and Doris see the value of women-centered care as residing in assisting newly diagnosed women to meet others living with the disease. Subsequent conversations with Lois, Doris, and other women living with HIV revealed painful feelings of ostracism, exclusion, rejection, discrimination, and stigmatization in the wake of the loss of women-centered initiatives, such as the New Brunswick HIV-positive women's retreat of 2003. This retreat was the only support gathering in the two provinces for HIV-positive women to learn how HIV affects them throughout their life and that provided women with a chance to meet others living with the disease. When the New Brunswick AIDS service organizations were asked to explain why the women's retreat ended, their responses to the question were surprising. The following excerpt is from my interview with Cynthia.

> [The three AIDS service organizations in the province] held a women's retreat in 2003 [for the sharing of HIV-positive women's experiences and information]. I

believe 14 women and 12 caregivers came to Square Lake and we had just a wonderful time together. I know that women would like to do that more, but there are very few resources accessible to do that sort of thing again. Actually the last time we proposed a women's retreat, there were a group of men who wrote letters to all [three] of our boards saying that it was discriminating [to have a women's retreat] and not fair. When I tried talking to many of the men over the years about HIV and all the supports [already] offered are geared towards men [it was met with resistance]. [Cynthia, New Brunswick]

Cynthia's comments highlight the persisting structural bias and inequity women face in the community when promoting the need for an individualized and women-focused care landscape. Subsequent conversations with Cynthia revealed that the group of men she mentioned do not consider there to be significant differences in the treatment and long-term health needs of men and women that require a gendered and tailored approach to care. This finding was unexpected, given the availability of information on the experiences and needs of HIV-positive women globally (Loutfy et al., 2017; Simmons, Farmer, & Schoepf, 2011; UNAIDS, 2014).

Although the medical management of HIV disease and comorbidities (e.g., mental health, addiction, and hepatitis C) is the same for both men and women, their experiences differ with respect to sexual and reproductive health counseling, routine screenings, health needs related to aging experiences of HIV-related stigma, and parental responsibilities. The perspective of this one group does not reflect the viewpoint of all men living with HIV in New Brunswick, based on my observations in the field, nor should it influence the landscape of care for women living with HIV. However, annual meetings organized by the AIDS service organizations are male-dominated because men account for the highest proportion of people living with the disease. Cynthia also admitted

that this is a reason why certain workshop events or activities are targeted towards men, and women no longer attend the events.

Community sector employees like Cynthia recognize that they are contributing to the invisibility of women in the current structure of their organization, but are constrained by funding and increased demand by persons living with HCV and other STBBIs to consider the integration of women-centered care services for their organizations. Lori explained the budgetary constraints associated with federal funding to AIDS service organizations.

> [The AIDS service organizations] receives about $113,000 a year of funding from the Public Health Agency of Canada that pays about 75% of staffing, rent, and the other expenses of the organization. Plus we get $50,000 from the province of New Brunswick, but that's the collective pot for the three organizations. Anything else we need to do [like social programs and supports] we fundraise for, which is a huge struggle…Often times what happens is that you're asked to do more [by the community] with the same [amount of funding]. [Lori, New Brunswick]

The federal funding organizations receive continues to be insufficient to meet the immediate and long-term support service intervention demands by persons living with HIV, even in the face of an increase in federal funding to broaden organizations' responses to HIV in Canada (Government of Canada, 2004). As discussed earlier, organizations have come to rely on sharing resources with other community-based agencies, annual fundraising efforts, and seeking additional monies to meet the changing needs of their clients. These are the means whereby the three AIDS service organizations in New Brunswick funded the 2003 women's retreat. The resource impact did not fall on the organizations or require the redirection of funds from other projects. Whether or not a women's retreat will happen again will depend upon community sector employees

devoting voluntary time to planning this initiative because it falls outside of their new federal mandate.

Conflicting resource priorities, and low uptake or failure of previous women's-only education and prevention programs, explain why AIDS service organizations are hesitant to plan all-women's initiatives. Jennifer is a long-serving community sector employee, but has also navigated the same social supports as women living with HIV. Her comment speaks to her organization's attempts, and failures, to provide a gendered and tailored approach to care.

> We have tried over the years to have a women's group - just a women's group and a men's group, but we don't have that captured audience here. I think it would be nice too that's one of the things I would like [to have a women's-only group], but I mean we've been trying to do this for 15 years and it hasn't worked yet…so we've given up on that initiative…I think we're at a point that we're doing all we can right now [for the community] as far as supportive services. [Jennifer, Nova Scotia]

Jennifer's comment underlines the efforts community organizations have made to create women-only programs, but to no avail. It was clear from my observations in the field and subsequent conversations with community sector employees that two significant challenges prevent women from sitting down with men in roundtable discussions about the possibility of a gendered approach to care in the province: the dominance of men serving on community development committees, and women's fears and experiences regarding disclosure of their HIV status in their communities.

Women often face misogyny from some men who serve as board members. None of the women in this study have ever been asked by community organizations for their opinion on an issue that affects them directly, including the recent loss of a main social support they have come to rely on to meet their basic needs for food and shelter, the

emergency fund. The result is a complete absence of women's voices in any decision-making structures.

Because of these circumstances, women living with HIV do not want to become involved in program development and decision-making even though their participation would create visibility for women in the epidemic and result in changes to the care continuum. Community sector employees understand why women are extremely hesitant about becoming involved as board members, but are uncertain how to address the problem. Some organizations, like Mainline Needle Exchange, have given up on the initiative entirely because it does not meet the new federal guidelines for organizations. Developing a women-only initiative would require a certain percentage of work time and funding that the organizations do not have in their current budget.

Other AIDS service organizations, such as the Ally Centre of Cape Breton, continue to envision a women-centered care approach to care in their communities because they have seen a significant impact on the continuity of care for women through their admittedly limited social initiative in education and harm reduction. Sandra's experience as a community sector employee has given her valuable insight into how different and complex women's health issues are compared to those of men.

> We have tried [many medical and social responses to the disease since the 1980s]. I mean we always make education available specific to women because there are so many separate issues there [for them]. Because the numbers are few, we do not offer [women-centered care], but we certainly facilitate access to [HIV care and] programming. We have knowledgeable staff here that can answer questions or help out in any way possible. So support is still there, but the programming to women with HIV no [we don't have that]. [Sandra, New Brunswick]

As discussed earlier, limited resources and a new federal mandate for AIDS service organizations make it difficult for employees to develop and manage gendered approaches to care. Yet, all of the community sector employees in this study acknowledge that the specific needs of women in health care are different from those of men. Counselling support and a more generalized approach to care, such as the availability of a clothing exchange or on-site food programs and emergency fund, are ways for organizations to continue providing relevant services to women, but these programs do not meet their long-term needs.

HIV Education and Peer Outreach

All of the AIDS service organizations and other community-based agencies provide a crucial component of outreach and support services to people living with or vulnerable to HIV infection in New Brunswick and Nova Scotia, which are characterized by vast geography and dispersed low-density populations. Remote and hinterland communities often present distinctive barriers to the delivery of outreach and education services. Mobile outreach services are a unique harm reduction service in Nova Scotia. The program involves delivering primary care services to underserved populations in Halifax and surrounding areas; mobile outreach is unavailable for people in the rural areas of New Brunswick. The training of natural or peer helpers by community-based agencies further contributes to the delivery of HIV prevention information and harm reduction supplies in rural areas.

Jill and Susan contribute to the peer education-training program for their organizations.

The peer education training program…it covers [the use of] birth control, STIs, HIV, hepatitis C, substance misuse, teen pregnancy, healthy relationships, and cultural awareness. During those two days [of training], the youth go through all of our workshops on those topics…[and] walk away [from the workshop] with all of the information that we covered in the manual that is close to 60-70 pages [on HIV and sexually transmitted and blood borne infections prevention and education]. The goal is for them to go and teach [other] peers [and the community] about the things that they've learned. [Jill, Nova Scotia]

The ideal way that a peer-to-peer piece would work is that you train youth [with] all of the basics [around HIV prevention, substance use, and harm reduction]…and incorporate it and make it matter into their lives…We train them to talk publically [about the basics of health] and how to teach people about all this stuff in the hopes that we can get them to actually teach in formal ways. [Susan, New Brunswick]

The provincial governments are committed to funding peer support in low

resource, poor, rural and isolated communities in New Brunswick and Nova Scotia that

would otherwise be underserved. The training of peer helpers by AIDS service

organizations and other community-based agencies goes beyond peer-to-peer education

of youth to deliver HIV prevention and education information in their communities. Peer

helpers are persons who either regularly access needle exchange services or in recovery

and are familiar with the social networks of those who use injecting drugs. They undergo

training for disease prevention, substance use, and harm reduction methods, and serve as

volunteers for community-based agencies like Mainline Needle Exchange, Direction 180

Bailey Bus, and the MOSH unit. Peer helpers respond to community-based health and

safety needs in rural and remote communities that organizations do not have the capacity

to visit; their efforts greatly extend harm reduction outreach services.

In spite of the success and support of the peer helper program in remote areas, all

of the AIDS service organizations and other community-based agencies in this study have

turned to assessing the value of mobile medical and preventative care services. Some of

the agencies expressed a need for mobile outreach-style health care services to enhance

access to health workers and supplies in remote or underserved areas, and improve

adherence to therapy and retention in care. Melissa argued strongly for the need for

mobile clinics in rural areas:

> I think that [the organization] should be offering a mobile clinic [service]. I think
> that we should be on the streets and because of the distance thing there's no reason
> why [we cannot serve rural areas]…People who are marginalized are often
> stigmatized within healthcare as well. Some people with an abscess do not want go
> to emergency right away because they know damn right they got that abscess
> through dirty injection and [do not want to face stigma and discrimination when
> accessing health care]…They would rather be half dead before [facing that]…so if
> we had a mobile service that could go to them [would help to address poor health
> outcomes in rural areas]…We need more outreach [services] like Direction 180
> here…That's what I would like to see. [Melissa, Nova Scotia]

Inaccessible communities, lengthy wait times for primary and emergency health

care in Northern Nova Scotia, and long travel distances to specialized care in Halifax are

reasons why Melissa and other community sector employees in New Brunswick argue the

need for mobile care units in remote communities that are underserved by their current

testing, education outreach, and needle exchange services.

Although the peer-to-peer model is arguably a more cost-effective approach to the

management of HIV because it does not require the redirection of funds from other

programs or projects, the extent and range of services delivered through this approach are

limited to providing education and harm reduction supplies, such as condoms, swabs,

cookers, and Vitamin C.

The pressing need for peer-to-peer and mobile outreach approaches in the urban-

rural fringe or remote communities collides with the reality of funding such initiatives in

have-not provinces. The Mainline Needle Exchange in Halifax recently received an increase of $247,000 in provincial funds to expand its central mobile outreach program to remote communities in the southern region of the province (Previl, 2017). Their current annual budget for the mobile service is $290,000; this amount is inclusive of the cost of safe use supplies and $3,000 per month in travel costs. The main source of funding for this program comes from Nova Scotia Public Health ("An Outreach Van", 2016). To develop a similar initiative for New Brunswick would involve the purchase of a vehicle outfitted into a clinical space with a medical chair and storage equipment to provide clients with testing, counseling, medical treatment or addiction treatment, and community referral services. All three AIDS service organizations in New Brunswick expressed an interest in modeling their mobile outreach service after the Nova Scotia approach to community care; the input costs would arguably be similar ("An Outreach Van", 2016).

The desirability of expanding outreach work to address inequalities in access to care is a common topic of discussion among workers at the three community-based agencies that provided mobile outreach services to rural and remote communities in Nova Scotia (Mainline Needle Exchange, Direction 180 Bailey Bus, and the MOSH unit). Outreach workers in this study, including some community sector employees in locations without mobile services, consistently reported the need to broaden services to include HIV-1/HIV-2 antibody point-of-care testing on the custom vehicle and to extend their operating hours on nights and weekends to serve more people living in their communities; however, in the face of a new federal response to HIV/AIDS and budgeting decisions, this

expansion may not be possible. Jennifer spoke about the ideal future direction for mobile

outreach services in Halifax and its surrounding communities.

> I think more outreach [is needed in the community and surrounding area]. I think it
> would be great if the office could be open seven days a week until at least three
> o'clock [in the morning because] I think the areas that we're not reaching [and] the
> times that we're not reaching people is at two o'clock in the morning. Then we
> could have the outreach van [open] until eight o'clock [at night], but it's at two
> o'clock in the morning or twelve o'clock at night that people are running out of
> needles and [needing clean supplies], so they don't contract hepatitis C [or HIV]…I
> think that's something in the future that would be great. [Jennifer, Nova Scotia]

The availability of point-of-care HIV testing and an extension of operating hours

would not only improve the quality of care in underserved populations, but also enhance

early intervention in disease diagnosis and treatment in the province. A delay in diagnosis

and treatment resulting from barriers-to-care, such as the lack of transportation, not only

negatively affect the health outcomes of people living with HIV, but also the costs to the

health system. Point-of-care HIV testing is currently unavailable in Nova Scotia, but is a

gap community-based organizations are pursuing to fill. An increase in provincial funding

and support has made it possible for Mainline Needle Exchange, for instance, to expand

its program to include new rural locations.

Peer helpers and mobile outreach programs play an important role in HIV, HCV,

and other STBBIs prevention and management through the distribution of resources like

information, condoms, and needle supplies to underserved populations that are mostly

located in rural areas. The training program for peer helpers and mobile outreach service

also includes learning information on appropriate care and support resources in the

community. All of the outreach providers in this study expressed how essential referral

and community resources are to mobile outreach, especially in places where health and

support services are not available, because of how overwhelming and increasingly complex the health care system can be to navigate after a diagnosis of HIV.

Referrals and Community Resources to Health and Social Services

All of the AIDS service organizations in this study work closely with other community-based agencies to avoid duplication in services and keep up-to-date on resources to improve their referral programs for persons in the community. With a changing federal government mandate for AIDS service organizations to expand its services to include HIV, HCV, and other STBBIs programs, creating a strong referral base in the community will become very important for meeting the diverse health priorities of the population.

Nearly all of the community sector employees in this study stated that current referral networks help to identify and fill gaps in the distribution of HIV care services. Mainline Needle Exchange, for example, logs the nature of each encounter with clients to learn about the changing needs of the population and how to improve their current referral network. The following comment is taken from the organization's June 12, 2014 navigator log to illustrate how assistance is provided and referrals are made in the community. "Client called the office [and] said she had no food for her and kids, [and] that Brunswick Street Mission had food for her. She asked Mainline [Needle Exchange] to pick food up from there and deliver to her home in Spryfield [a community in Halifax], which staff did." This is one example of how community sector employees assist clients with the essentials of their everyday lives, without which they would fall through the cracks. The delivery of food to a client may appear to be a simple act of assistance, but

for people living in poverty with poor health status, it is an important service to help them overcome a large structural barrier in their pursuit of stability of their condition.

The following comment from Dale also speaks to the importance of shared resources and collaborations with other community-based agencies to increase access to care and improve health outcomes. Since the 1980s, Dale has been involved in bridging the gaps in the HIV care continuum, largely aimed at improvements in education outreach and access to treatment for persons living with HIV.

> [The] gaps [in the care continuum] they're numerous. The interesting thing about [the AIDS service organization] is that we service the [entire] province. And when you are talking about gaps, they are often gaps that can't be addressed on a community basis because they are not [occurring only] within the community per se. But we do have issues around housing security. We also have issues around food security, poverty, education, [and] all [of the] social determinants of health [in the province]. The partnerships that we have created [are diverse]…we work with the sexual assault crisis center, youth in transition, [provincial] housing, the community action group against homelessness, the community health center, the [communities] regional resource center, which is a specifics women's resource center, the multicultural association …we have a partnership with public health [etc.]…and then of course we do a lot of education and outreach within middle school, high school, [and] post-secondary institutions. So basically, we have a finger in a lot of pots [in the community]. [Dale, New Brunswick]

Figure 5.1 illustrates the most common referrals and community resources made by community-based organizations to HIV-positive women and others living HCV and STBBIs. HIV-positive women are clearly relying heavily on a wide range of social services to meet their health priorities after diagnosis, as the cope with housing and financial instability, inadequate nutrition, transportation problems to attend medical appointments, and the demands of childrearing.

Figure 5.1: Relative size of social, medical, and housing services in New Brunswick and Nova Scotia.
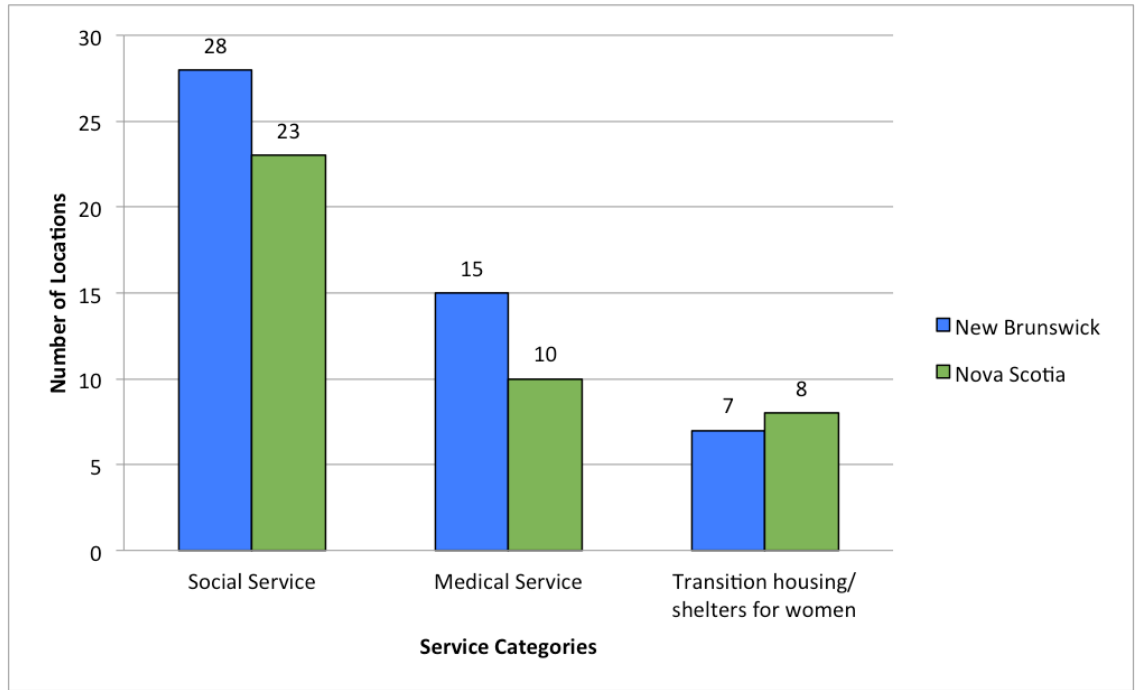

Data for Figure 5.1 were collected through observations made in the offices of the organizations or mobile outreach settings (such as pamphlets made available to clients), and through conversations with HIV-positive women and employees of the community-based agencies. A complete list of the referrals and community resources for HIV-positive women in the two provinces can be found in Appendix H. Figures 5.2 and 5.3 provide a more detailed view of the three types of networks women living with HIV potentially access to meet their social, medical, and housing support needs.

Figure 5.2: Referral network locations for women living with HIV in New Brunswick. Created by P. Medeiros© using ArcGIS 10.2.
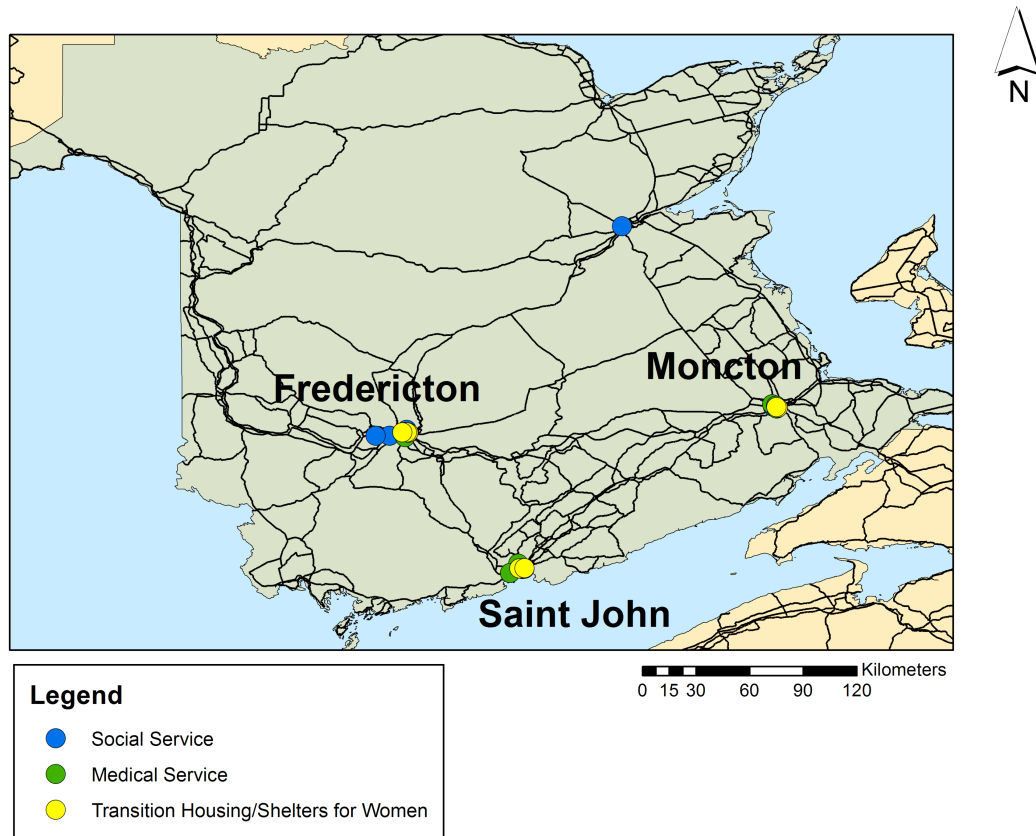
Social services account for the highest proportion of supports women access in the existing referral network in both provinces. Medical services refer to the specialized care women will continue to access after diagnosis. Women also depend heavily on housing to improve their quality of life, particularly to meet the treatment demands and needs after HIV diagnosis.

Figure 5.3: Referral network locations for women with HIV in Nova Scotia. Created by P. Medeiros© using ArcGIS 10.2.
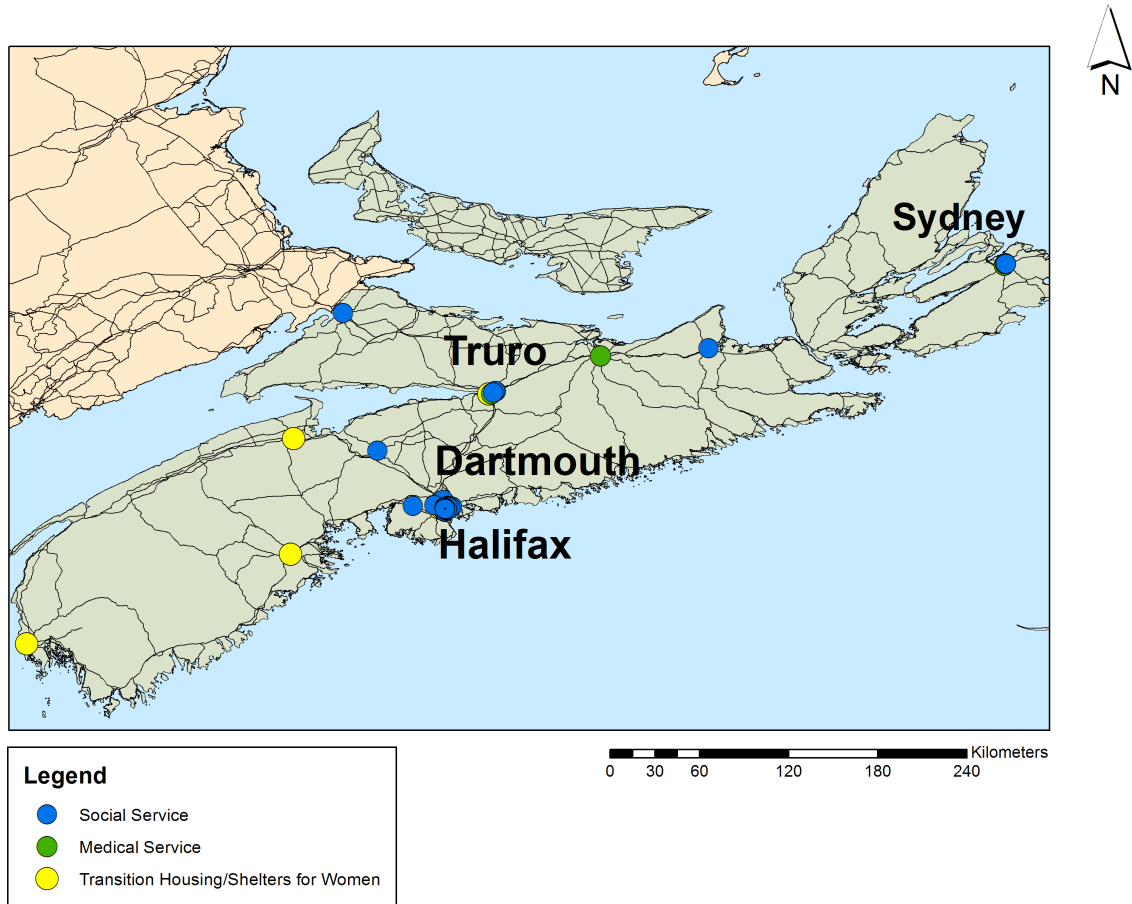
Figures 5.2 and 5.3 demonstrate that the existing referral networks for an HIV-positive woman in the two provinces are mainly located in urban areas. The HIV referral networks are relatively the same in size in both provinces and are similarly structured to address the core needs of women living with HIV. Both maps reveal a duplication of services through the clustering of points that adds further complexity to navigating the system, particularly from the point-of-view of community organizations making referrals to local supports.

To ease the navigation of the care system for HIV-positive women and lessen

some of the confusion associated with the large number of duplicate social services,

service providers in this study are working closely with other organizations to better build

the capacity of the referral network. As Gregory notes, "We would not want to duplicate

their services [or programs] in any way. I feel the new federal funding guidelines will

lead to more duplication of services because community organizations will be applying

for the same grant applications. I really don't think that's the way to go" [Nova Scotia].

All of the participants from AIDS service organizations and community-based agencies in

this study shared his perspective; in addition, they aim to acquire public grants to

determine whether there are unmet needs among their client population and enhance

programs aimed at filling the gaps in the care continuum.

In spite of the wide variety of services to meet the core needs of women living

with HIV, only 15% of the existing referral network displayed in Figures 5.2 and 5.3 are

found in remote communities of the province. These services are located roughly two-

hours distance by vehicle from Halifax. The support service interventions available in

Yarmouth, Kentville, New Glasgow, Amherst, Antigonish or Bridgewater are not

women-specific or focused on the management of HIV, but have became part of the

existing referral network to help women living with HIV who face transportation-related

problems to access necessary supports in urban areas of Nova Scotia.

Women in this study regularly access 23 of the 91 programs in New Brunswick

and Nova Scotia (see Appendix H). Data for Figure 5.4 were gathered through interviews

with women living with HIV. Figure 5.4 illustrates the referrals and community services

women most frequently access to meet their long-term and shifting needs after diagnosis;

these referral services are starred in Appendix H.

Figure 5.4: Community resources accessed by HIV-positive women in New Brunswick and Nova Scotia.
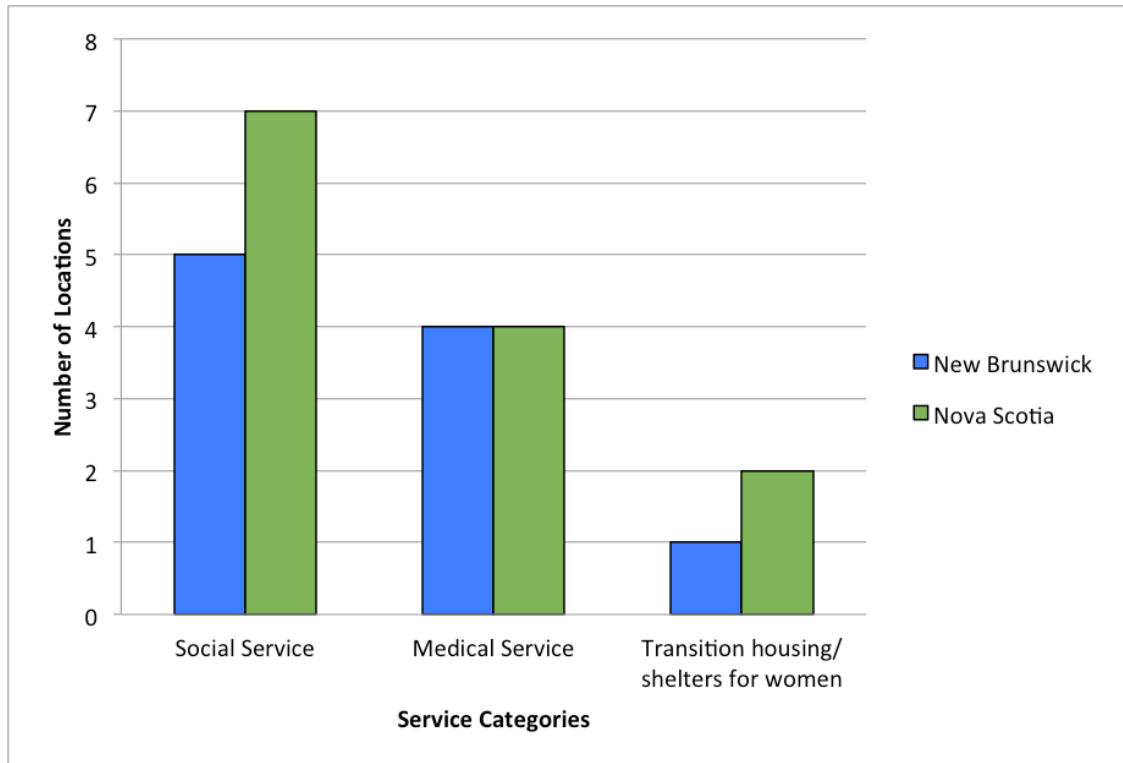
Owing to unfamiliarity with new care and support services, precarious finances, and transportation-related barriers to care, women are often unable to access necessary social support services, including counselling, education, and support and crisis intervention services as frequently as they need to improve their quality of life after diagnosis. The difficulty of travelling to access specialized care or social supports has resulted in a number of negative consequences, such as disease progression and changes in the body, and worsening of life circumstances from continued substance abuse and domestic violence.

The community services women are more frequently accessing run along fixed routes of the public transit system in urban areas, which are often less than a five kilometer distance to their specialized care. Women lessen the costs of travel for treatment or appointments by walking a short distance to access services. Participants in this study were reluctant to discuss their inability to access health and social services on a regular basis not only because of their distrust of my intentions, but also because of their worries about how the information might impact their access to future services.

Figure 5.4 further describes the most common community social supports women living with HIV are accessing: The Salvation Army, St. Vincent de Paul Society, and local food banks. The social services they access are also the most common site referrals made by community sector employees to all persons living with HIV. None of the women were self-referring out of the network or seeking care and support services from other providers not listed in Appendix H.

Both provinces have established a strong referral network to meet the immediate needs of women living with HIV, but their capacity to support long-term needs remains in question. My interactions and conversations with women in the offices of the organizations revealed that they all increasingly value the referral activities of AIDS service organizations and other community-based agencies, and are confident in the uptake of referrals made by providers to meet their health priorities. Women living with HIV in this study also expressed feelings of hope that even in the face of an expanding federal mandate for AIDS service organizations, their absence from roundtable discussions about the response to HIV, and the overall low incidence of HIV infection

among women in New Brunswick and Nova Scotia, their needs would have to remain at the forefront of a changing care landscape to ensure their visibility in the epidemic. This optimism may be difficult to reconcile with the shrinking budgets of organizations and the heightened objection from some men in the community to a gendered approach to care.

Summary

This chapter explores the roles AIDS service organizations and other community-based agencies play in the lives of women living with HIV after diagnosis in the two provinces. The discussion not only highlights the growing capacity and intensification of partnerships within the referral network in both provinces, but also highlights existing gaps in the care continuum that continue to persist. Current efforts to provide support to women living with and affected by HIV are failing to meet their long-term needs, which include the management of HIV, caregiving, reproductive and sexual health, health needs related to aging and menopause, and HIV disclosure to spouses and family members.

The following chapter provides concluding remarks on the significant findings of this study and general recommendations on the reimagining of HIV service delivery to better meet the needs of women living with HIV. Chapter 6 also considers the ways forward for future research and how medical anthropology can contribute to work in this area.

Chapter 6 Conclusion

This study addresses two broad issues with respect to health care for women living with HIV in New Brunswick and Nova Scotia: barriers-to-care and the role played by service organizations in the landscape of care. The stories of women and employees of AIDS service organizations, uncovered through interviews and participant-observation research, bring into view a widening gap in the HIV care continuum for people living with HIV and the structural inequities that continue to affect their quality of life after diagnosis.

Barriers to Care

The first research question in this study builds on a series of conversations with a former community support worker in New Brunswick: what are the barriers-to-care for women living with HIV? Affordable housing, food insecurity, transportation issues to and from medical appointments, and stigma emerged as the main challenges women face when trying to meet their basic needs and improve their quality of life. These inter-related issues not only underscore women's poor health outcomes, but also draw attention to their continuing dependence on community organizations to navigate a complex landscape of care services.

Services and Programs

The three inter-related questions posed in Chapter 5, include: What roles do AIDS service organizations and other community-based agencies play in the lives of women living with HIV? Are the services and programs that have been created meeting the

diverse needs of women living with HIV? Are there any essential services missing to improve the quality of care for women with HIV?

The stories of HIV-positive women who participated in this study reveal that community-based AIDS organizations play a central role in their lives, even in the absence of women-specific HIV/AIDS programs and the loss of assistance programs they have come to depend on, such as food vouchers, transit tickets or monthly passes, and sources for emergency funds. Community-based agencies nevertheless have insufficient resources to meet the basic food, shelter, clothing, and medical care needs of HIV positive women, and are forced to develop strategies to strengthen existing relationships with other local organizations to alleviate gender-based disparities in access to care and lessen women's invisibility in the epidemic. Organizations have also had to find creative ways to shore up their capacity to help women overcome their difficulties, such as implementing referral systems and peer helper programs.

The women living with HIV in this study increasingly value the referral activities of AIDS service organizations and other community-based agencies, especially in the absence of a gendered approach to care. AIDS service organizations work closely with other community-based agencies to meet the long-term needs of their clients (e.g., establishing partnerships for acceptable food, clothing, and housing support) and to address the gaps in the HIV care continuum in lieu of additional resources and government funding. In spite of these efforts to improve women's access to necessary social support services through sharing resources with other community-based agencies, their generalized approach to care does not meet women's long-term needs. The women

instead expressed a desire for women-only programs that acknowledge the differences between women and men in health needs and experiences. They envision a women-centered care model inclusive of treatment, education outreach, and housing and addiction services, to increase their visibility in the epidemic and better meet their diverse health needs.

The lack of affordable housing, food insecurity, and transportation issues that impact women's ability to access to health and social services, in addition to continuing stigma surrounding HIV, are structural difficulties women face. Community organizations thus continue to play a significant role in helping people navigate their way around the complex, sometimes contradictory, care landscape. It is unclear what effect new federal guidelines will have had on women living with HIV, but I expect that it will be even more challenging for HIV-positive women to get the care they need, and heighten their invisibility in the epidemic.

The perspectives of Indigenous peoples however are absent from the debates on women's health issues related to HIV in this study because of my failure to recruit more than one Indigenous woman living with HIV, even though the HIV epidemic is highly indigenized in the Maritime Provinces and elsewhere (Haddid, Li, Totten, & McGuire, 2018; Nova Scotia Health and Wellness, 2012; Public Health Agency of Canada, 2013). To my knowledge, Indigenous women's issues and experiences living with HIV is largely absent from the HIV/AIDS research agenda in New Brunswick and Nova Scotia, where the focus is instead on gay men and LGBTQ issues because of recent federal calls for targeted research on these groups (Gahagan, Humble, Gutman, & De Vries, 2018;

Gahagan & Subriana-Malaret, 2018; Murray, Numer, Merritt, Gahagan, & Comber, 2011; Numer & Gahagan, 2009). I think it is vital fir future studies to include Indigenous women's voices on issues relating to HIV in the Maritime Provinces to better understand how they experience and interpret social marginalization that extends to their access to health care and disease outcomes.

Recommendations: Expanding Services for Women

In the absence of sufficient funding, community-based agencies rely on building a strong referral network and sharing resources to help HIV-positive women access necessary support services. These strategies are an effort by organizations to deliver better continuity of care and to reduce duplication and gaps in programs. The value of strengthening the existing referral network is its potential to link community-based organizations across provincial borders to improve services for women in the absence of women-centered care. In the face of extremely limited funding, rising rates of HIV, and increased demand for support services, collaborating across provincial borders between two 'have-not' provinces is a way to meet the new federal funding guidelines, and expand their programs. Organizations were discussing this possibility at the end of my fieldwork.

Increasing Outreach Efforts

The participants in this study emphasized the need for community-based organizations to develop or expand outreach efforts, including mobile and peer-to-peer outreach-style health care services, to improve access to the wide array of community services women require. Enhanced mobile outreach programs will allow community sector employees and specialist care professionals (i.e., nurses, doctors, and social

workers) to provide wound care, addiction-related support, counselling, testing, education, and community referral support to persons who are isolated, either geographically or socially, from health services. Such programs could be modeled on or adapted from the MOSH or Mainline Needle Exchange program for delivering care in Halifax. People living with HIV in New Brunswick, which currently has no mobile van outreach, would particularly benefit from services provided to isolated and rural communities.

Peer helpers emerged in this study as important partners in helping women navigate the AIDS continuum of care. Training more peer helpers to deliver health education on the management of HIV and to distribute harm reduction supplies (e.g., condoms, swabs, cookers, Vitamin C) would assist community organizations to support underserved communities and persons who might not be comfortable approaching AIDS service organizations. Training peer helpers should be an essential part of organizations' comprehensive response to women's health issues. Doris, Edna, Phyllis, and Beatrice for example, often meet and counsel women about life after diagnosis on behalf of their AIDS service organization, and they would benefit from additional training on health education and community referral support systems to help the women they counsel. AIDS Saint John is the only agency in New Brunswick that relies on peer helpers to deliver education outreach and resources to underserved communities. Peer volunteers are important for reducing distrust and closing gaps in service delivery that exist province-wide (AIDS Coalition of Cape Breton, 2000; Kirkland et al., 2006). Community-based organizations in Nova Scotia work closely with peer helpers to identify the changing needs of the population they serve and expand mobile outreach services into rural regions

of the province where people are living or affected by HIV and HCV (Bickerton,

Dechman, McKay, & Porter, 2017; Kirkland, Ploem, & Patten, 2017; Smillie, 1998). This

information is crucial for evaluating the need for a mobile outreach services in the two

provinces.

Women-Centered HIV Care

Women living with HIV who participated in this study were strongly in favour of

women-centered HIV care. Women-centered HIV care is largely absent from the medical

systems in the Atlantic Provinces because current approaches to service delivery and

funding are silo-based. This balkanization of services fails to promote a system of

integrated care. A women-centered HIV care model is informed by women's lives and

experiences; it empowers women to make their own decisions around health and well-

being. Further, this care model not only refers to the provision of women-specific care

and support services, such as sexual and reproductive health, in an all-female

environment, but also includes sensitivity training of all staff in HIV-related issues

(Carter et al., 2013).

A number of recent studies on women-centered HIV care in Canada demonstrate

the importance of gendered approaches, and their implications for women's health

outcomes and quality of life (Carter et al., 2018a; Loutfy et al., 2017; O'Brien et al.,

2017). Gendered approaches to HIV care for women attend to their health care priorities

beyond the processes of sexual and reproductive health, identify structural barriers that

may limit women's access to treatment and care services, and acknowledge that women's

experiences living with HIV differ from those of men (O'Brien et al., 2017).

The O'Brien et al. (2017) study is the first of its kind in Canada to consider how gendered care for women living with HIV can be integrated into the current health system. Their conceptual model (Figure 6.1) of women-centered HIV care is novel in its inclusion of peer support persons to promote medication adherence, create safe and accessible spaces for status disclosure, and strengthen community care referrals. All of these are totally absent or disjointed in the current health system. The O'Brien et al. (2017) study is a starting point for assessing which services are the best to improve women's quality of life and delivered in a cost-effective way. There is limited work to-date evaluating the best models of patient-centered care for people living with HIV in Canada. The involvement of HIV positive women as peer research assistants in the O'Brien et al. (2016) study was instrumental for identifying the health needs of HIV positive women and making the case for women-centered care as an extension of patient-centered care models.

Women who participated in my study also supported the idea of a one-stop health center with referral to a wide array of services (e.g., food, clothing, and shelter). Such a center would reduce duplication of services and make it possible to redirect these funds to other programs to close the gaps in women's HIV care, including the management of HIV, and reproductive and sexual health.

Figure 6.1: Defining the women-centered HIV care model (O'Brien et al., 2017).
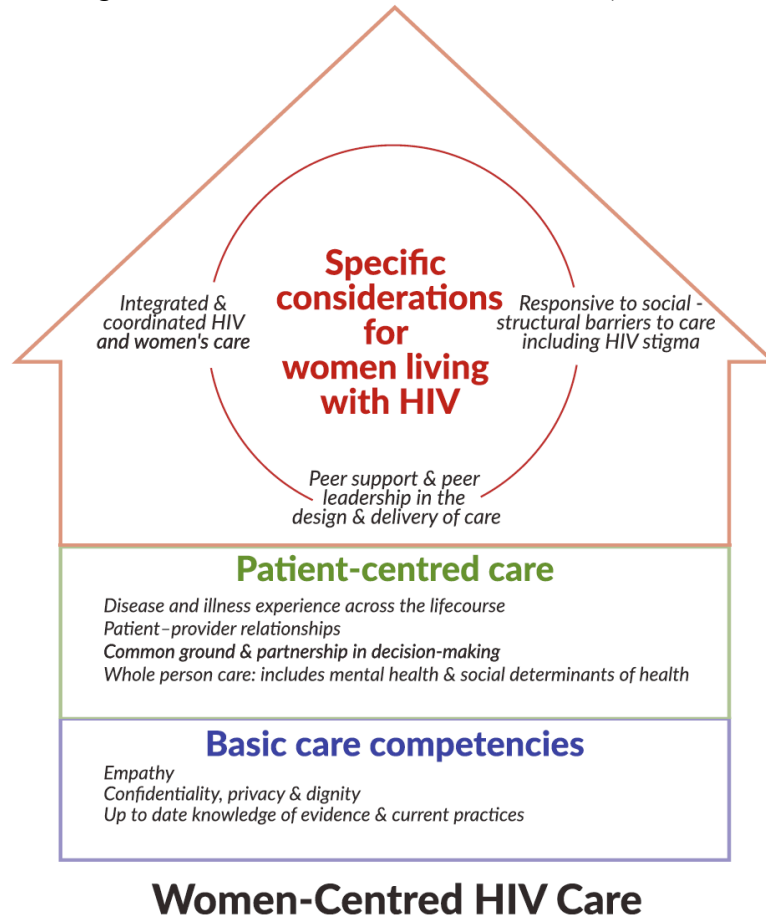
A women's health center not only would further enhance women's visibility in the epidemic, but also reveal how different women's long-term needs are compared to men's, beyond the medical management of HIV disease. The Oak Tree Clinic (Vancouver), Maple Leaf Medical Clinic (Toronto), Women's Health in Women's Hands Health Centre (Toronto), and the Centre for AIDS Services of Montreal currently deliver a one-stop care approach to women's health as described in Figure 6.1, inclusive of testing, counseling, treatment, and support referral services in different capacities (Carter et al., 2013; Carter et al., 2016). The Carter et al. (2013, 2018a) and O'Brien et al. (2017, 2018) studies are in

the early stages of determining not only the features of a women-centered care model, but further research is needed to examine its feasibility as a primary care approach for the management of HIV.

Women-only HIV support groups have never existed in New Brunswick and Nova Scotia. Providing space in the offices of organizations for women to hold monthly social gatherings is a feasible solution and would incur no costs to organizations. All of the AIDS service organizations and community-based organizations that participated in my study have multi-purpose office spaces commonly used for different activities, training, and meetings that can be repurposed as gathering places for women. This would require that interested women in the community or organizations manage and facilitate the initiative to ensure continuity and relevance. Creating safe spaces in which HIV positive can meet may help reduce the social stigma that continues to effect women's uptake of HIV care and treatment.

Community sector employees who participated in this study are aware of the impact of stigma on the willingness of women to seek basic services, but their efforts to reduce stigma related to living with HIV continues to be met with resistance. I would argue that making continuous general HIV education available, together with community member involvement in developing or expanding women-only programs, will reduce stigma in the community and improve the lives of people living with HIV, particularly those living in rural regions. The latest resource, the Women and HIV/AIDS Initiative (2017), is intended to assist community organizations to foster knowledge about women's experiences with stigma and lessen its presence in the community by creating safe spaces

for clients to access counseling, education programs, and outreach services in their offices.

All of my interviews with women and community sector employees reveal feelings of

optimism and hope for bridging the gap between significant barriers to care, such as

stigma, and increasing access to support services for women.

Contributions to the Field

It is a sad commentary on the neglect of HIV and women's health in New

Brunswick and Nova Scotia that I am the only anthropologist to have studied this issue

there, so many decades after the epidemic began. Because of this gap in scholarly

research, it was necessary to draw extensively on the grey literature on women's health in

both provinces and bring often-buried findings to bear on this analysis. Anthropologists

nonetheless have examined HIV and AIDS in other parts of Canada, notably Laura

Bisaillon (2010a, 2010b, 2011, 2013; Amaratunga et al., 2011; Mykhalovskiy, Hastings,

Sanders, Hayman, & Bisaillon, 2016), Pamela Downe (2010, 2011, 2017), Robert Hogg

(Ma et al., 2018; Palmer et al., 2018; Willoughby et al., 2018), Robert Lorway (2017; Yu,

Hatala, Reimer, & Lorway, 2018), and Eric Roth (2018a, 2018b; Card et al., 2018; Carter

et al., 2017; Carter et al, 2018b; Lachowsky et al., 2017).

Because men account for the largest proportion of people living with HIV in

Canada, most of these researchers have studied men's experiences; seven of the more

recent publications focus on cause and effect relationships, treatment as prevention,

sexual behaviors, general health status, access to care, and poor health from a quantitative

perspective (Card et al., 2018; Carter et al., 2017; Lachowsky et al., 2017; Lorway, 2017;

Roth, 2018, 2018b; Yu et al., 2018). Four of these publications were part of a wider male-

only study of HIV in British Columbia, the Momentum Health Study in Vancouver, which looks closely at the complex, sometimes contradictory, experiences of men (Carter et al., 2017; Lachowsky et al., 2017; Roth, 2018a, 2018b).

Research on men has dominated the literature on HIV/AIDS in Canada. Yet, a growing body of work has emerged on women because women have a very different set of experiences than those of men living with HIV (Baran et al., 2014; Carter et al., 2013; Carter et al., 2014; Carter et al., 2018b; CHIWOS, 2016; Downe, 2010, 2011, 2017; Jaworsky et al., 2018; Kronfil et al., 2017; Loutfy et al., 2016). The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) was started in 2011 in response to the Momentum Health Study to bring to light the lived experiences of women in Canada, which has received little attention in the HIV and AIDS impact studies.

Most of the national HIV studies use statistical techniques to calculate correlations between explanatory variables. Exceptions to this general rule are found in the work of Laura Bisaillon (2010a, 2010b, 2011, 2013; Amaratunga et al., 2011), Pamela Downe (2010, 2011, 3017), and Robert Lorway (2017; Yu et al., 2018). Connors (2011, p. 92) maintains that "statistics often lose the immediacy and concreteness of the tales told about an individual life, but can provide insights about the spread of the disease." The use of qualitative research methods instead gives participants a voice to express and understand their experiences living with HIV.

Through the lens of Applied Medical Anthropology, this study provides a different understanding of women's health experiences from previously published studies in Nova Scotia and New Brunswick. Other studies on HIV/AIDS in these two provinces

focus on the analysis of data from the systems perspective (Archibald & Halverson, 2013; Arthur et al., 2013; Gahagan & Ricci, 2011; Kirkland et al., 2006; McWilliam, 2002), grounded theory (Colman, 2003; Gahagan, 2013; Gahagan & Proctor-Simms, 2013; Hayward & Colman, 2003; Medeiros, 2012; Medeiros, 2017; Nicol & Butler, 2005; Olivier & Stanciu, 1999), and feminist critique (Bourassa & Bulman, 2005; Bulman, 2004, 2005; Jane, 1994; Nova Scotia Advisory Council, 2003).

This thesis is best described as a mixed methods blend of ethnographic and health studies approaches (GIS), and seeks to understand the experiences of women living with HIV in New Brunswick and Nova Scotia while recognizing the deep structural roots of social suffering that adversely affect their health. To explain the negative social and health effects of suffering, Farmer (2015, p. 678) insists "one must embed individual biography in the larger matrix of culture, history, and political economy." The use of CMA and the structural violence orientation in this study, under the applied anthropology umbrella, brings to light the larger social and structural inequalities – the lack of services, resources, coordination, and provider knowledge – that continue to exist and marginalize women living with this disease in the two provinces.

The CMA and structural approaches used in this study also offer a critical feminist perspective through the voices of women living with HIV. Participants revealed women's feelings of disempowerment in a landscape of care focused on men's issues, their perseverance to have agency in a changing care landscape, and their longing to make connections with other women living with HIV in their communities through the availability of safe spaces and social gatherings, which align with the broader feminist

studies on women and HIV in Canada (Bulman, 2004, 2005; Downe, 2010, 2011, 2017; Gahagan, 2013). The size of the group of women with HIV/AIDS in this study, however, made it feasible to use intersectionality as a theory to analyze how larger structural forces cause health inequities through class, race, and social status.

The circumstances faced by women with HIV in these two provinces, nevertheless, are profoundly political, driven by inequality, marginalization, and the uneven distribution of social power (Singer, 1995). The lenses of CMA and structural violence however reveal how women with HIV face the challenges of navigating the existing health care system, bringing into view how harmful structural inequalities impede their access to care through the intersection of gender, precarious finances, housing instability, food insecurity, inadequate transportation, and stigma. Ultimately, this research highlights the need to integrate women's voices in the development of a women-centered care approach for service delivery as a way to increase women's visibility in the epidemic.

The value of the CMA perspective in this study is its presentation of a different reading of women's health issues, a reading guided by the critical gaze[8], and involvement in seeing the larger social and structural contexts that continue to exist and marginalize women in the disease. Campbell (2011) reasons that this involves participant observation to collect data on the everyday activities of individuals' lives; these experiences often remain hidden in the literature. Singer (1995, p. 99) further suggests that the critical gaze of medical anthropologists, "[expands] the focus of health-related struggles from

---

[8] Focuses on the existing power and inequality in society (Singer & Baer, 1995).

immediate to ultimate causes of illness and disease." The intent of adopting the critical

gaze is to draw awareness to the historical and cultural contingencies that continue to

influence women's health across their life course (Singer & Baer, 1995). In doing so, the

critical gaze provides new ways of thinking about how political and economic forces

shape patterns of disease within and across populations (Hardon & Moyer, 2014).

Viewed in this light, this study reveals that HIV/AIDS in women is a neglected

disease[9] in Nova Scotia and New Brunswick. Women living with HIV constitute a small

fraction of the total disease burden in two the provinces, face increasingly invisibility in

the epidemic, and receive less federal investment for gendered approaches to care. I think,

however, that the loss of dedicated HIV care and support programs in New Brunswick

and Nova Scotia, and the consequences for women's health outcomes, is an example of

how women in this study and their health priorities are simply ignored by their

communities, and the federal government, in lieu of other rising communicable diseases

like hepatitis C. Yet, women should represent the most pressing health priority in the face

of rising rates of infection among this group in Canada.

The use of GIS in this study was important for visualizing the distribution and

duplication of health and social services, and exploring health data interactively. To my

knowledge, this is the first use of this geographic technique to study women's needs and

resources in Atlantic Canada; yet, this method is in common practice in health research

and used to visualize all types of geographically referenced data. Its use in this study

---

[9] Lesser-known tropical diseases (e.g., Chagas disease, dengue, leprosy, and lymphatic filariasis) that are more prevalent among the poorest populations (Manderson, Aagaard-Hansen, Allotey, Gyapong, & Sommerfeld, 2009; Manderson, 2012).

provides new ways for describing and understanding the changing spatial organization of the health system for women living with HIV, for examining the relationships between access to care and poor health outcomes, and for exploring how community organizations can enhance access to support services for their clients in both provinces (Cromley, 1999; McLafferty, 2003). The inclusion of qualitative data from interviews to create maps that show the availability of services in relations to needs of people and measure geographical access for persons in the community (also known as geo-ethnographies), is a relatively new spatial framework for researchers to visualize and contextualize the lived experience. Geo-ethnographies involve a synthesis of demographic, economic, epidemiological, geographic and ethnographic aggregate data in the existing capabilities of GIS software (Cromley & McLafferty, 2002; McLafferty, 2003; Teixeira, 2018).

Generating source maps that combine traditional GIS spatial analyses with qualitative health information from interviews offers an alternative to statistical formats for presenting health information and is particularly useful to community organizations and policy makers in decision-making. In the case of this study, the maps are helpful for AIDS service organizations in the two provinces as they try to meet the new federal funding initiatives and the needs of women living with HIV. Teixeira (2018, p. 11) suggests that "it [qualitative GIS] has the potential to allow us to challenge existing explanations for social problems and look at issues from multiple vantage points, engaging with multiple meanings and realities that comprise macro level phenomena." The GIS maps presented here also provide information for community organizations for developing strategies to expand outreach services or develop women-centered care

facilities. In so doing, the maps contribute to making women more visible in the epidemic, especially as spatial data collection on demographics and health care usage becomes more widely available.

Future Directions of Research

More research is needed on the spread of HIV in New Brunswick and Nova Scotia given that the topic has received little attention in the literature and in view of the recent increase in newly reported HIV cases. New Brunswick has seen a 175% increase in positive cases of HIV and Nova Scotia an increase of 100% of new HIV cases (CBC News New Brunswick, 2018; MacLean, 2018). Among all new HIV diagnoses in New Brunswick and Nova Scotia for 2018, women account for 29% or 10 out of 35 of all cases to-date (T. Arnason, personal communication, October 31, 2018; P. Baker, personal communication, October 16, 2018). The rise in the number of new cases is a growing concern and phenomenon occurring in other provinces like Saskatchewan (800% in one region) and Manitoba (50%) (Coubrough & Glowacki, 2018; McKenna, 2018; Soloducha, 2017; Winnipeg Free Press, 2018).

The significant increase in HIV infections in both provinces is a main reason for my plan to return to the two provinces to continue studying the experiences and needs of HIV-positive women. It is important to gain up-to-date information on the affect the enhancement of programs and services have had on their lives and others living with STBBIs. Continuing to work closely with these community organizations, where I developed good working relationships, would offer greater insight into how these agencies are bridging the gap between their structural changes and meeting the needs of

women. It would allow for the expansion of themes about women's health identified in this research. Collecting research data outside of the winter months would be a main change to the original fieldwork design.

Second, I will be starting a CIHR-funded postdoctoral fellowship in January 2019 to extend the national reach of the CHIWOS women's health study to the Maritime Provinces. The goal of the study is to identify key features of women-centered HIV care, using the previous work of CHIWOS, and to develop a health model that meets the diverse needs of women living with HIV in New Brunswick, Nova Scotia, and Prince Edward Island. I hypothesize that an absence of women-centered HIV services not only delays disease diagnosis, but also affects the quality of care for women in the Maritime Provinces. The first phase of the CHIWOS project is complete in British Columbia (BC), Ontario (ON), and Quebec (QC), and more recently has been expanded to Saskatchewan and Manitoba (Loutfy et al., 2017).

Phase one of the study in New Brunswick and Nova Scotia will involve the application of GIS to the original CHIWOS data from the provinces of BC, ON, and QC, to measure the distribution of health system resources for women living with HIV. The results will be analyzed from the point of view of applied anthropology to contribute a different theoretical perspective for understanding the needs of women living with HIV. Phase two will use the technique of body mapping to learn more about the life experiences of women and determine the features of care they require to meet their basic needs. Three body-mapping workshops in the Maritime Provinces will be carried out. Training to deliver the body-mapping workshop took place with members from CHIWOS

from June 3 to June 6, 2018. The three-day workshop will require women, through a use of images and text, to reveal their understanding of women-centered care and untold stories living with HIV. We will apply for a small grant and aim to hire peer research associates to assist with the planning and enrollment efforts in each province. Each peer research associate will receive training in research ethics and body mapping that follows CHIWOS procedures, an approach that may increase the number of women recruited in my PhD study. The results of my postdoctoral study will contribute to a growing body of literature on the topic of HIV and bring into view the varied experiences of women living with HIV across Canada.

Conclusion

There is a lack of attention to women living with HIV in the current health systems care model; women need better access to health information and support service resources that fit with their daily realities and experiences. Despite increases in HIV infections among women in Canada, there continues to be a limited focus on women-specific HIV issues in federal government policies and community-based organization programs. To increase the visibility of women in the Canadian HIV epidemic, women living with or at risk for HIV not only need their own spaces to come together to learn about treatment, care, and support networks, but also need to be consulted and fully integrated in the ground as new programs are developed; these conclusions come directly from women involved in this study. The reinstatement of social services offered by AIDS service organizations including, women's-only retreats, health funds, nutritional programs, and financial assistance for low-income individuals to travel to appointments is

a way forward for community-based agencies to meet the expanding mandate to serve people living with HIV, HCV, and other STBBIs.

Women living with HIV in this study speak to a list of programs and service changes that would need to be made to meet their health priorities and improve their quality of care, including: safe spaces for women to share information and resources, affordable housing located near comprehensive health care and supportive services, availability of food programs to meet their dietary needs, improving transportation services within and between communities to access care, and addressing attitudes around stigma and discrimination in the general community to reduce the risk of adverse outcomes and reduce the stigma already present with HIV infection. Nevertheless, although the widespread implementation of these suggestions may not always be feasible, continuing to regard women living with HIV as a homogenous group with identical HIV needs to other populations will negatively influence their health outcomes and quality of life.

References Cited

2014 budget highlights. (2014, April 4). *The Chronicle Herald*, p. A6.

Access and coverage of antiretroviral drugs through Canada's provincial and territorial drug programs. (2017). Retrieved January 2, 2017, from http://www.hivclinic.ca/main/drugs_reimbuse_files/HIV%20medication%20coverage%20across%20Canada.pdf.

AIDS Coalition of Cape Breton. (2000). *The natural helper model a rural remedy: A guide to reaching rural injection drug users*. [Hard copy]. Halifax, Nova Scotia.

AIDS New Brunswick. (2013). *From all walks of life: Annual report 2013-2014*. Retrieved January 6, 2017, from http://www.aidsnb.com/wp-content/uploads/2011/09/2013-2014-Agency-Annual-Report-EN.pdf.

AIDS New Brunswick. (2017). *Sexual health resources*. Retrieved January 2, 2017, from http://www.aidsnb.com/en/education/stbbi.

Aldenderfer, M., & Maschner, H. (1996). *Anthropology, space, and geographic information systems*. New York, NY: Oxford University Press.

Allen, J. (1994). *Women and HIV/AIDS in Nova Scotia: Needs assessment report*. [Hard copy]. Halifax, NS: Nova Scotia Women and AIDS Project.

Amaratunga, C., Bisaillon, L., Murangira, F., Kalinda, L., Rowe, M., & Farber, A. (2011). The story of the GOAL 'unproject': The global AIDS Ottawa link project and the empowerment of the African and Caribbean communities. In D. Spitzer (Ed.), *Engendering migrant health: Canadian perspectives* (pp. 213-230). Toronto, ON: University of Toronto Press.

An Outreach Van for Waterloo Region. (2016). Retrieved December 2, 2017, from http://www.communitybasedresearch.ca/resources/534/outreach%20van%20summary%20report%20revised.pdf.

Archibald, C. (2009). *Overview of HIV/AIDS epidemiology in Canada*. Paper presented at the 18th Annual Canadian Conference on HIV/AIDS Research. Retrieved May 6, 2018, from http://librarypdf.catie.ca/PDF/P48/24918.pdf.

Archibald, C., & Halverson, J. (2013). The current state of women and HIV in Canada: An overview of HIV/AIDS epidemiology in Canada. In J. Gahagan (Ed.), *Women and HIV prevention in Canada: Implications for research, policy and practice* (pp. 5-13). Toronto, ON: Women's Press.

Arend, E. (2005). The politics of invisibility: Homophobia and low-income HIV-positive women who have sex with women. *Journal of Homosexuality*, 49(1), 97-122.

Arthur, J., Beausoleil, K., Guay, J., & Gahagan, J. (2013). An overview of determinants of health impacting women and HIV infection in Canada. In J. Gahagan (Ed.), *Women and HIV prevention in Canada: Implications for research, policy and practice* (pp. 15-47). Toronto, ON: Women's Press.

Baer, H., Singer, M., & Susser, I. (2003) *Medical anthropology and the world system*. Westport, CT: Praeger Publishers.

Baran, R., Mulcahy, F., Krznaric, I., Monforte, A., Samarina, A., Xi, H., Cassetti, I., Madruga, J., Zachry, W., Van Wyk, J., & Martinez, M. (2014). Reduced HIV symptoms and improved health-related quality of life correlate with better access to care for HIV-1 infected women: The ELLA study. *Journal of the International AIDS Society,* 17 (Suppl 3), 19616.

Bisaillon, L. (2010a). Human rights consequences of mandatory HIV screening policy of newcomers to Canada. *Health and Human Rights*, 12(2), 119-134.

Bisaillon, L., (2010b). *Working from within endemic HIV stigma: Developing Canadian social workers' understanding of the challenges faced by newcomers managing HIV*. Canadian Social Work, 12(1), 32-44.

Bisaillon, L. (2011). Mandatory HIV testing and everyday life: A look inside the Canadian immigration medical examination. *Aporia*, 3(4), 5-14.

Bisaillon, L. (2013). *Disease, disparities and decision making: Mandatory HIV testing of prospective immigrants to Canada*. Retrieved September 10, 2018, from https://papyrus.bib.umontreal.ca/xmlui/bitstream/handle/1866/9733/10.pdf?sequence=1&isAllowed=y.

Bickerton, J., Dechman, M., McKay, M., & Porter, C. (2017). *Those who often need the most receive the least: A community needs assessment*. Retrieved June 3, 2018, from http://www.allycentreofcapebreton.com/wp-content/uploads/2014/04/Outreach-Streetreport_ALLYCENTREAugust2017_fullreportwithcover.pdf.

Blaisa, M., Ferneta, M., Proulx-Bouchera, K. Lebouchéb, B., Rodriguea, C., Lapointec, N., Otisa, J., & Samsonc, J. (2015). Barriers to health-care and psychological distress among mother living with HIV in Quebec (Canada). *AIDS Care*, 27(6), 731-738.

Bourassa, C., & Bulman, D. (2005). *The views of women and their experiences concerning HIV/AIDS*. [Hard copy]. Moncton, NB: AIDS/SIDA Moncton.

Bourassa, C., & Provencher, Y. (2014). *Minimum wage and welfare incomes in New Brunswick. How to survive?* Retrieved June 6, 2017, from http://frontnb.ca/Document/Analyse_en/MinimumwageandwelfareincomeinNB.pdf.

Broeckaert, L., & Challacombe, L. (2015). *Rapid point-of-care HIV testing: A review of the evidence*. Retrieved January 8, 2017, from http://www.catie.ca/en/pif/spring-2015/rapid-point-care-hiv-testing-review-evidence#bios.

Brown, P., & Closser, S. (2016). Medical anthropology: An introduction. In P. Brown & S. Closser (Eds.), *Understanding and applying medical anthropology: Biosocial and cultural approaches* (pp. 13-24). New York, NY: Taylor & Francis.

Bulman, D. (2004). *Learning about HIV/AIDS in the Maritimes Provinces of Canada: Hearing women's voices* (unpublished doctoral dissertation). University of Nottingham, United Kingdom.

Bulman, D. (2005). A constructivist approach to HIV/AIDS education for women within the Maritime Provinces of Canada. *International Journal of Lifelong Education* 24(6), 475-487.

Campbell, D. (2010). Anthropology's contribution to public health policy development. *McGill Journal of Medicine,* 13(1), 76-83.

Campbell, D. (2011). Anthropology's contribution to public health policy development. *McGill Journal of Medicine*, 13(1), 76.

Canadian Institutes of Health Research. (2008). *HIV/AIDS research initiatives strategic plan 2008-2013*. Retrieved August 2, 2018, from http://www.cihr-irsc.gc.ca/e/documents/hiv_strat_plan_0813_e.pdf.

Canadian Institute for Health Information. (2017). *National health expenditure trends, 1975 to 2017*. Retrieved August 11, 2018, from https://www.cihi.ca/sites/default/files/document/nhex2017-trends-report-en.pdf.

Canada Without Poverty. (2016). *New Brunswick poverty progress profile*. Retrieved December 1, 2017, from https://www.cwp-csp.ca/resources/sites/default/files/resources/New%20Brunswick-%20PPP%202016.pdf.

Card, K., Armstrong, H., Lachowsky, N., Cui, Z., Sereda, P. Carter, A., Montaner, J., Hogg, R., Roth, E., & Moore, D. (2018a). Belief in treatment as prevention and its relationship to HIV status and behavioral risk. *Journal of Acquired Immune Deficiency Syndromes*, 77(1), 8-16.

Card, K., Lachowsky, N., Hawkins, B., Jollimore, J., Baharuddin, F., & Hogg, R. (2018b). *Predictors of Facebook user engagement with health-related content for gay, bisexual, and other men who have sex with men: Context analysis*. Retrieved September 2, 2018, from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5910534/.

Carter, A., Bourgeois, S., O'Brien, N., Abelsohn, K.,Tharao, W., Greene, S., Margolese, S., Kaida, A., Sanchez, M., Palmer, A., Cescon, A., de Pokomandy, A., Loutfy, M., & on behalf of CHIWOS Research Team. (2013). Women-specific HIV/AIDS services: Identifying and defining the components of holistic service delivery for women living with HIV/AIDS. *Journal of the International AIDS Society,* 16(1), 1-13.

Carter, A., Greene, S., Nicholson, V., O'Brien, N., Dahlby, J., de Pokomandy, A., Loutfy, M., Kaida, A., & on behalf of the CHIWOS Research Team. (2016). 'It's a very isolating world': the journey to HIV care for women living with HIV in BC, Canada. *Gender, Place and Culture*, 23(7), 941-954.

Carter, A., Lachowsky, N., Forrest, J., Cui, Z., Sereda, P., Kaida, A., Armstrong, H., Card, K., Montaner, J., Moore, D., & Roth, E. (2017). A latent class analysis of sexual and romantic relationships among HIV-positive and HIV-negative gay and bisexual men in Vancouver. *The Canadian Journal of Human Sexuality*, 26(2), 78-96.

Carter, A., Loutfy, M., de Pokomandy, A., Colley, G., Zhang, W., Sereda, P., O'Brien, N., Proulx-Boucher, K., Nicholson, V., Beaver, K., Kaida, A., & CHIWOS Research Team. (2018a). Health-related quality-of-life and receipt of women-centered HIV care among women living with HIV in Canada. *Women and Health*, 58(5), 498-518.

Carter, A., Min, J., Chau, W., Lima, V., Kestler, M., Pick, N., Money, D., Hogg, R., & Kaida, A. (2014). Gender inequalities in quality of care among HIV-positive individuals initiating antiretroviral treatment in British Columbia, Canada (2010-2010). *PLoS One*, 9(3), e92334. Retrieved July 5, 2018, from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3958538/.

Carter, A., Roth, E., Ding, E., Milloy, M., Kestler, M., Jabbari, S., Webster, K., de Pokomandy, A., Loutfy, M., Kaida, A., & on behalf of the CHIWOS Research Team. (2018b). Substance use, violence, and antiretroviral adherence: A latent class analysis of women living with HIV in Canada. *AIDS and Behavior*, 22(3), 971-985.

CATIE. (2017a). *The epidemiology of HIV in Canada*. Retrieved January 3, 2017, from http://www.catie.ca/en/fact-sheets/epidemiology/epidemiology-hiv-canada.

CATIE. (2017b). *The epidemiology of HIV in gay men and other men who have sex with men*. Retrieved January 23, 2017, from http://www.catie.ca/en/fact-sheets/epidemiology/epidemiology-hiv-gay-men-and-other-men-who-have-sex-men.

CBC News. (2018, August 10). *HIV/AIDS groups fear federal funding shift could lead to higher rates*. Retrieved November 20, 2018, from https://www.cbc.ca/news/health/hiv-aids-rates-feds-funding-shift-1.4780596.

CBC News New Brunswick. (2013, April 25). *Province to boost welfare benefits by 7 percent*. Retrieved November 28, 2017, from http://www.cbc.ca/news/canada/new-brunswick/province-to-boost-welfare-benefits-by-7-per-cent-1.1339009.

CBC News New Brunswick. (2014, October 29). *AIDS New Brunswick starts new sexual health testing*. Retrieved January 3, 2017, from http://www.cbc.ca/news/canada/new-brunswick/aids-new-brunswick-starts-new-sexual-health-testing-clinic-1.2816628.

CBC News New Brunswick. (2018, September 14). *HIV cases show sharp increase in Fredericton, Oromocto areas*. Retrieved November 10, 2018, from https://www.cbc.ca/news/canada/new-brunswick/nb-hiv-cases-fredericton-oromocto-1.4824214.

CBC News Nova Scotia. (2013a, March 1). *Demand surges at Halifax needle exchange: 100,000 more needles distributed this year over last*. Retrieved January 3, 2017, from http://www.cbc.ca/news/canada/nova-scotia/demand-surges-at-halifax-needle-exchange-1.1386198.

CBC News Nova Scotia. (2013b, August 28). *Hep C rise baffles experts in Nova Scotia: Infection spread by blood contact damages the liver*. Retrieved February 7, 2017, from http://www.cbc.ca/news/canada/nova-scotia/hep-c-rise-baffles-experts-in-nova-scotia-1.1369517.

CBC News Nova Scotia. (2015, April 29). *Direction 180 mobile methadone clinic to get new bus*. Retrieved December 10, 2017, from http://www.cbc.ca/news/canada/nova-scotia/direction-180-mobile-methadone-clinic-to-get-new-bus-1.3054455.

CBC News Nova Scotia. (2017, May 18). *Cape Breton doctors say medical system is ailing under one health authority*. Retrieved December 7, 2017, from http://www.cbc.ca/news/canada/nova-scotia/doctor-shortage-specialists-health-care-cape-breton-recruitment-1.4117057.

CBC News PEI. (2014, February 6). *Food insecurity in Canada growing worse*. Retrieved November 29, 2017, from http://www.cbc.ca/news/canada/prince-edward-island/food-insecurity-in-canada-growing-worse-1.2525300.

CHIWOS. (2016). *Clinic service utilization by women living with HIV in BC*. Retrieved July 3, 2017, from https://pacificaidsnetwork.org/files/2016/06/bc_clinic_utilization_infographic_23Feb2016.pdf.

Chiu, E. (2016, September 8). Mainline Needle Exchange hands out more needles but rations some supplies. *CBC News Nova Scotia*. Retrieved from http://www.cbc.ca/news/canada/nova-scotia/mainline-funding-supplies-rationed-1.3752592.

Chung, K. & Lounsbury, D.W. (2006). The role of power, process, and relationships in participatory research for statewide HIV/AIDS programming. *Social Science and Medicine*, 63(8), 2129-2140.

Colman, R. (2000). *Women's health in Atlantic Canada: A statistical portrait*. Retrieved February 8, 2017, from https://cdn.dal.ca/content/dam/dalhousie/pdf/diff/ace-women-health/Archive/ACEWH_women_health_atlantic_canada_statistical_portrait.pdf.

Colman, R. (2003). *A profile of women's health indicators in Canada: July, 2003*. Retrieved November 3, 2017, from http://www.gpiatlantic.org/pdf/health/womens/whbreport.pdf.

Community Sector Council of Nova Scotia. (2016). *NS non-profits*. Retrieved April 20, 2018, from http://csc-ns.ca/ns-non-profits/.

Connors, M. (2011). Sex, drugs, and structural violence: Unraveling the epidemic among poor women in the United States. In P. Farmer, M. Connors, and J. Simmons (Eds.), *Women, poverty, and AIDS: Sex, drugs, and structural violence* (pp. 91-124). Monroe, ME: Common Courage Press.

Cordeaux, E. (2017). *Young people and non-profit work*. Retrieved May 1, 2018, from http://www.imaginecanada.ca/sites/default/files/imaginecanada_youthpaper_en_final.pdf.

Coubrough, J. & Glowacki, L. (2018, March 2). *HIV rates continue to rise in Manitoba: New report*. Retrieved November 9, 2018, from https://www.cbc.ca/news/canada/manitoba/hiv-rates-manitoba-1.4559181.

Cromley, E. (1999). Mapping spatial data. In J. Schensul, M., LeCompte, R. Trotter, E. Cromley & M. Singer (Eds.), *Mapping social networks, spatial data, and hidden populations* (pp. 51-124). Plymouth, UK: AltaMira Press.

Cromley, E. & McLafferty, S. (2002). *GIS and public health*. New York, NY: The Guilford Press.

Dinshaw, F. (2017, August 7). Cape Breton doctor disputes hiring. *The Chronicle Herald*, p. A1.

Direction 180. (2017). *Bus schedule*. Retrieved February 9, 2017, from http://www.direction180.ca/bus-schedule/.

Doucette, K., & Tutton, M. (2017, September 26). $10.5-billion Nova Scotia budget sees slight increase in health spending. *Globe and Mail*. Retrieved August 9, 2018, from https://www.theglobeandmail.com/news/national/slight-increase-in-health-spending-in-105-billion-nova-scotia-budget/article36396993/.

Downe, P. (2010). Mothering in the context of maternal HIV/AIDS. In S. Geissler, L. Loutzenheiser, J. Praud, and L. Streifler (Eds.), *Mothering Canada: Interdisciplinary voices* (pp. 153-162). Toronto, ON: Demeter Press.

Downe, P. (2011). Feminist anthropology anew: Motherhood and HIV/AIDS as sites of action. *Anthropology in Action*, 18(1), 6-16.

Downe, P. (2017). "Bad Mothers" and the HIV/AIDS epidemic in Saskatchewan, Canada. In M. Hughes, T. Hager & R. Bromwich (Eds.), *Bad mothers: Regulations, representations, and resistance* (pp.103-120). Bradford, ON: Demeter Press.

Easton, R. (2016, October 24). *Dozens of community organizations lose funding as Public Health Agency shifts focus to prevention*. Retrieved November 20, 2018, from https://www.cbc.ca/news/health/hiv-funding-changes-aboriginal-1.3806641.

Farmer, P. (2003). *Pathologies of power: Health, human rights, and the new war on power*. Berkeley, CA: University of California Press.

Farmer, P. (2004). An anthropology of structural violence. *Current Anthropology, 45*(3), 305-325.

Farmer, P., Nizeve, B., Stulac, S., & Keshavjee, S. (2006). Structural violence and clinical medicine. *PLoS Medicine*, 3(10), 1686-1691.

Farmer, P. (2015). Structural violence and the embodiment of inequality. In Fran Collyer (Ed.), *The Palgrave Handbook of Social Theory in Health, Illness, and Medicine* (pp. 675-690). New York, NY: Palgrave Macmillan.

Gahagan, J. (2013). Women and HIV in Canada: Reflections on an epidemic. In J. Gahagan (Ed.), *Women and HIV prevention in Canada: Implications for research, policy and practice* (pp. 1-4). Toronto, ON: Women's Press.

Gahagan, J., Humble, A., Gutman, G, & De Vries, B. (2018). Older LGBT adults' end-of-life conversations: Findings from Nova Scotia, Canada. *Atlantis: Critical Studies in Gender, Culture and Social Justice*, 39(1), 31-40.

Gahagan, J., & Proctor-Simms, M. (2013). *HIV testing in low prevalence settings: Considerations for post-AIDS exceptionalism in Atlantic Canada. A policy debate*. Retrieved January 28, 2017, from https://cdn.dal.ca/content/dam/dalhousie/pdf/Diff/gahps/Atlantic%20Policy%20Symposium%20Summary%20Report%20for%20Ottawa%20Symposium%20FINAL.pdf.

Gahagan, J., & Ricci, C. (2011). *HIV/AIDS prevention for women in Canada: Meta-ethnographic synthesis*. Retrieved January 20, 2017, from http://www.airn.ca/uploads/8/6/1/4/86141358/hiv-aids-prevention-for-women-in-canada-2011.pdf.

Gahagan, J., & Subriana-Malaret, M. (2018). Improving pathways to primary health care amongst LGBTQ populations and health care providers: Key findings from Nova Scotia, Canada. *International Journal for Equity in Health*, 17(76), 1-9

Government of Canada. (2004). *The federal initiative to address HIV/AIDS in Canada: Strengthening federal action in the Canadian response to HIV/AIDS*. Retrieved December 7, 2017, from http://publications.gc.ca/collections/collection_2017/aspc-phac/H124-2-2004-eng.pdf.

Government of New Brunswick. (2012). *Developing a drug plan for uninsured New Brunswickers*. Retrieved February 10, 2017, from http://www2.gnb.ca/content/dam/gnb/Corporate/pdf/DrugPlan-RegimeDassuranceMedicaments/DevelopingDrugPlan.pdf.

Government of New Brunswick. (2017). *Prescription drug program – HIV/AIDS plan*. Retrieved January 15, 2017, from http://www2.gnb.ca/content/gnb/en/services/services_renderer.8937.html.

Haddid, N., Li, J., Totten, S., & McGuire, M. (2018). HIV in Canada – Surveillance report, 2017. *Canada Communicable Disease Report*, 44(12), 324-332.

Hardon, A., & Moyer, E. (2014). Anthropology of AIDS: Modes of engagement. *Medical Anthropology*, 33(4), 255-262.

Harris, G. (2006). Practicing HIV/AIDS community-based research. *AIDS Care*, 18(7), 731-738.

Hatala, A., Erickson, L., Isbister-Bear, O., Calvez, S., Bird-Naytowhow, K., Pearl, T., Wahpasiw, O., Engler-Stringer, R., & Downe, P. (2017). The interpersonal skills of community-engaged scholarship: Insights from collaborators working at the University of Saskatchewan's community engagement office. *Journal of Community Engagement and Scholarship*, 10(1), 44-58.

Hayward, K., & Colman, R. (2003). *The tides of change: Addressing inequality and chronic disease in Atlantic Canada a discussion paper*. [Hard copy]. Population and Public Health Branch Atlantic Canada.

Hill, L. (2011, December 1). *Taking the fight to the streets: A mobile medical van is helping to treat hard-to-reach people for HIV/AIDS in Halifax and Dartmouth*. The Coast. Retrieved January 11, 2017, from http://www.thecoast.ca/halifax/taking-the-fight-to-the-streets/Content?oid=2781915.

Housing Nova Scotia. (2015). *Housing Nova Scotia business plan 2015-2016*. Retrieved December 8, 2017, from https://housing.novascotia.ca/sites/default/files/9.%20Crown%20Corps%20%28Housing%29%20WEB_0.pdf.

Jane, A. (1994). *Women and HIV/AIDS in Nova Scotia: Needs assessment report*. [Hard copy]. Halifax, NS: Nova Scotia Women and AIDS Project.

Jaworsky, D., Logie, C., Wagner, A., Conway, T., Kaida, A., de Pokomandy, A., Webster, K., Proulx-Boucher, K., Sereda, P., Loutfy, M., & the CHIWOS Research Team. (2018). Geographic differences in the experiences of HIV-related stigma for women living with HIV in northern and rural communities of Ontario, Canada. *Rural and Remote Health*, 18(3), 4522.

Johnson, M., Samarina, A., He, X., Madruga, J., Hocqueloux, L., Loutfy, M., Fournelle, M., Norton, M., Van Wyk, J., Zachry, W., & Martinez, M. (2015). Barriers to access to care reported by women living with HIV across 27 provinces. *AIDS Care*, 27(10), 1220-1230.

Kephart, G., Asada, Y., Atherton, F., Burge. F., Campbell, L., Campbell, M., Dowling, L., Lawson, B., Lethbridge, L., Levy, A., & Terashima, M. (2016). *Small area variation in rates of high-cost healthcare use across Nova Scotia*. Retrieved August 10, 2018, from http://www.spor-maritime-srap.ca/sites/default/files/SARV%20Final.pdf.

Kingston-Reichers, J. (2011). *The economic cost of HIV/AIDS in Canada*. Retrieved August 8, 2018, from http://www.cdnaids.ca/wp-content/uploads/Economic-Cost-of-HIV-AIDS-in-Canada.pdf.

Kirkland, S., Gahagan, J. C., Dykeman, M., Mugford, J. G., Jackson, L. A., Sketris, I., MacDonald, J., Marshall, C., McWilliam, S., Rogers, E., Cutler, S., Myles, A. & AIRN Research Team. (2006). *HIV/AIDS and hepatitis C: A scan of policies, programs, and research in Atlantic Canada*. [Hard copy]. Halifax, NS, Canada.

Kirkland, S., Marshall, C., & AIRN Research Team. (2008). *HIV/AIDS and hepatitis C in Atlantic Canada: Community consultations 2007*. [Hard copy]. Halifax, NS, Canada.

Kirkland, S., Patten, S., Krahn, T., Peddle, S., & Gaspar, M. (2014). *Exploring the landscape of communicable diseases in Atlantic Canada*. Retrieved January 2, 2017, from http://www.airn.ca/uploads/8/6/1/4/86141358/exploring-the-landscape-of-cds-in-atl-canada-summary-report-dec-2014-en-final-9_5.pdf.

Kirkland, S., Ploem, C., & Patten, S. (2017). *Towards a provincial model for needle distribution and disposal and safer consumption sites: Findings and recommendations*. Retrieved January 6, 2018, from http://www.airn.ca/uploads/8/6/1/4/86141358/ndd_and_scs_models_final_report_-_sept_21-_2017_sub-amend.pdf.

Kronfil, N., Lacombe-Duncan, A., Wang, Y., de Pokomandy, A., Kaida, A., Logie, C., Conway, T., Kennedy, V., Burchell, A., Tharao, W., Pick, N., Kestler, M., Sereda, P., Loutfy, M., & on behalf of the CHIWOS Research Team. (2017). Access and engagement in HIV care among a national cohort of women living with HIV in Canada. *AIDS Care,* 29(10), 1235-1242.

Lachowsky, N., Dulai, J., Cui, Z., Sereda, P., Rich, A., Patterson, T., Corneil, T., Montaner, J., Roth, E., Hoggs, R., & Moore, D. (2017). Lifetime doctor-diagnosed mental health conditions and current substance use among gay and bisexual men living in Vancouver, Canada. *Substance use and misuse*, 52(6), 785-797.

Lammam, C., & MacIntyre, H. (2016). *An introduction to the state of poverty in Canada*. Retrieved April 3, 2018, from https://www.fraserinstitute.org/sites/default/files/an-introduction-to-the-state-of-poverty-in-canada.pdf.

Leading Together. (2013). *Leading together: Canada takes action on HIV/AIDS*. Retrieved October 1, 2017, from http://www.catie.ca/sites/default/files/Leading%20Together_Final%20EN%20November%202013.pdf.

Lorway R. (2017). *AIDS Activism, science and community across three continents*. New York City, NY: Springer Publishing Company.

Loutfy, M., de Pokomandy, A., Logan Kennedy, V., Carter, A., O'Brien, N., Proulx-Boucher, K., Ding, E., Lewis, J., Nicholson, V., Beaver, K., Greene, S., Tharao, W., Benoit, A., Dubuc, D., Thomas-Pavanel, J., Sereda, P., Jabbari, S., Shurgold, J., Colley, G., Hogg, R., Kaida, A., & Chiwos Research Team. (2017). Cohort Profile: The Canadian HIV Women's Sexual and Reproductive Health and Cohort Study (CHIWOS). *PLoS ONE*. Retrieved online November 29, 2017, from http://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0184708&type=printable.

Loutfy, M., Johnson, M., Walmsley, S., Samarine, A., Vasque, P., Hao-Lan, H., Madihlaba, T., Martinez-Tristani, M., & van Wyk, J. (2016). The association between HIV disclosure status and perceived barriers to care faced by women living with HIV in Latin America, China, Central/Eastern Europe, and Western Europe/Canada. *AIDS Patient Care,* 30, 435-444.

Ma, H., Villalobos, C., St-Jean, M., Evawo, O., Lavergne, M., Ti, L., Hull, M., Yip, B., Wu, L., Hogg, R., Barrios, R., Shoveller, J., Montaner, J., & Lima, V. (2018). The impact of HCV co-infection status on healthcare-related utilization among people living with HIV in British Columbia, Canada: A retrospective cohort study. *BMC Health Services Research*, 18(1), 319.

MacLean, A. (2018, July 18). *Nova Scotia experiencing 'significant increase' in newly-diagnosed HIV cases*. Retrieved November 9, 2018, from https://globalnews.ca/news/4339150/hiv-increase-nova-scotia/.

Matthew, N., Murray, E., Gahagan, J., & Merritt, B. (2011). Healthy-aging among LGBT seniors in Nova Scotia. *International Journal of Health, Wellness and Society*, 1(4), 179-192.

Mainline Needle Exchange. (2002). *Mainline needle exchange provincial needs assessment.* [Hard copy]. Halifax, NS, Canada.

Mainline Needle Exchange. (2012). *Mainline Needle Exchange 1992-2012: "And they said it wouldn't last…".* Retrieved May 18, 2018, from http://www.mainlineneedleexchange.ca/20th.pdf.

Manderson, L. (2012). Neglected diseases of poverty. *Medical Anthropology*, 31(4), 283-286.

Marshall, C. (2006). *Income support and HIV/AIDS: The experience of persons living with HIV/AIDS in Nova Scotia.* Retrieved January 5, 2017, from https://novascotia.ca/aids/documents/Income_Support_HIV-AIDS.pdf.

Martorell, H. (2017). *Policy responses to food insecurity in Canada.* Retrieved November 26, 2017, from https://foodsecurecanada.org/sites/foodsecurecanada.org/files/files/discussion_paper_policy_responses_to_food_insecurity_in_canada_2017.pdf.

McKenna, R. (2018, August 13). *New HIV diagnoses in Sask. increase for 3rd straight year.* Retrieved November 10, 2018, https://www.cbc.ca/news/canada/saskatchewan/sask-hiv-rates-1.4783435.

McLafferty, S. (2003). GIS and health care. *Annual Review of Public Health*, 24(1), 25-42.

McLeod, P. (2013, February 1). N.S. leads in level of health spending. *The Chronicle Herald*, p. B1.

McWilliam, S. (2002). *Hidden in the data: Exploratory study of the care, treatment and support needs of women living with HIV/AIDS in Nova Scotia* (unpublished master's dissertation). Dalhousie University, Nova Scotia.

Medeiros, P. (2012). *A cross-cultural comparison of illness narratives of seropositive women in Kenya, Africa, and New Brunswick, Canada* (unpublished master's dissertation). University of New Brunswick, New Brunswick.

Medeiros, P. (2017). Living with HIV: Women's health in New Brunswick. *Journal of New Brunswick Studies*, 8, 175-192.

Mobile Outreach Street Health. (2017). *Where to find us*. Retrieved December 27, 2016, from http://moshhalifax.ca/where-to-find-us/.

Murray, E., Numer, M., Merritt, B., Gahagan, J., & Comber, S. (2011). Healthy-aging among LGBT seniors in Nova Scotia. *International Journal of Health, Wellness and Society*, 1(4), 179-192.

Mykhalovskiv, E., Hastings, C., Sanders, C., Hayman, M., & Bisaillon. (2016). *'Callous, cold and deliberately duplicitous': Racialization, immigration and the representation of HIV criminalization in Canadian mainstream media*. Retrieved September 6, 2018, from https://www.publicimpactpr.com/images/clients/can/callous_cold_report_final.pdf

New Brunswick. (2013). *Social development*. Retrieved December 6, 2017, from http://www2.gnb.ca/content/gnb/en/departments/social_development/promos/social_assistancereform/october2013.html.

New Brunswick. (2016). *New Brunswick report on sexually transmitted and blood borne infections, 2016*. Retrieved July 7, 2018, from http://www2.gnb.ca/content/dam/gnb/Departments/h-s/pdf/en/CDC/STBBI-Report-2016.pdf.

New Brunswick Advisory Council on the Status of Women. (2007). *Women's groups in the non-profit and voluntary sector*. Retrieved April 18, 2018, from https://www2.gnb.ca/content/dam/gnb/Departments/eco-bce/WEB-EDF/pdf/en/NonProfitVoluntarySector.pdf.

New Brunswick Department of Health. (2010). *Needle distribution service in NB: An external review*. [Hard copy]. Moncton, NB, Canada.

New Brunswick Health Council. (2016). *The cost of chronic health conditions to New Brunswick*. Retrieved January 2, 2017, from https://www.nbhc.ca/sites/default/files/documents/june_2016_the_cost_of_chronic_health_conditions_to_nb_-_final.pdf.

New Brunswick HCV Advisory Board. (2014). *New Brunswick hepatitis C strategy*. [Hard copy]. Saint John, New Brunswick, Canada.

New Brunswick Housing Corporation. (2010). *Hope is a home: New Brunswick's housing strategy*. Retrieved December 2, 2017, from http://www2.gnb.ca/content/dam/gnb/Departments/sd-ds/pdf/Housing/housingstrategy-e.pdf.

Nicol, A., & Butler, J. (2005). *Needs assessment with clients living with HIV/AIDS in New Brunswick*. [Hard copy]. Fredericton, NB: AIDS New Brunswick.

Nova Scotia. (2015). *Nova Scotia Health Profile*. Retrieved December 28, 2016, from https://novascotia.ca/dhw/publichealth/documents/Population-Health-Profile-Nova-Scotia.pdf.

Nova Scotia Advisory Commission on AIDS. (2006). *Income support and HIV/AIDS: The experience of persons living with HIV/AIDS in Nova Scotia*. Retrieved December 21, 2016, from https://www.novascotia.ca/aids/documents/Income_Support_HIV-AIDS.pdf.

Nova Scotia Advisory Commission on AIDS. (2013a). *Nova Scotia strategy on HIV/AIDS*. Retrieved December 21, 2016, from http://novascotia.ca/aids/strategy.asp.

Nova Scotia Advisory Commission on AIDS. (2013b). *Information for persons living with HIV/AIDS about income assistance in Nova Scotia*. Retrieved December 21, 2016, from http://0-nsleg-edeposit.gov.ns.ca.legcat.gov.ns.ca/deposit/b10676880.pdf.

Nova Scotia Advisory Commission on AIDS. (2016). *Background: Frontline services to address HIV and other sexually transmitted or blood-borne infections (STBBIs)*. Retrieved December 28, 2016, from http://novascotia.ca/aids/documents/Backgrounder_Frontline_Services.pdf.

Nova Scotia Advisory Council on the Status of Women. (2003). *Gender and HIV/AIDS Gender and HIV/AIDS a backgrounder*. [Hard copy]. Halifax, Nova Scotia, Canada.

Nova Scotia Advisory on AIDS. (2014). *Review of Nova Scotia's strategy on HIV/AIDS: Looking back and moving forward*. Retrieved December 8, 2017, from http://novascotia.ca/aids/documents/Review-of-Nova-Scotia-Strategy-on-HIV-AIDS-Full-Report.pdf.

Nova Scotia Department of Health and Wellness. (2016). *Notifiable diseases in Nova Scotia 2016 surveillance report*. Retrieved August 3, 2018, from https://novascotia.ca/dhw/populationhealth/documents/Annual-Notifiable-Disease-Surveillance-Report-2016.pdf.

Nova Scotia Health and Wellness. (2012). *Surveillance report in HIV/AIDS in Nova Scotia: 1983 to 2011*. Retrieved December 21, 2016, from https://novascotia.ca/dhw/populationhealth/documents/HIV-AIDS-Surveillance-Report.pdf.

Nova Scotia Health and Wellness. (2014). *Notifiable diseases in Nova Scotia 2014 surveillance report*. Retrieved December 21, 2016, from http://novascotia.ca/dhw/populationhealth/documents/Annual-Notifiable-Disease-Surveillance-Report-2014.pdf.

Numer, M., & Gahagan, J. (2009). The sexual health of gay men in the post-AIDS era: Feminist, post-structural and queer theories. *International Journal of Men's Health*, 8(2), 155-168.

O'Brien, N., Greene, S., Carter, A., Lewis, J., Nicholson, V., Kwaramba, G., Ménard, B., Kaufman, E., Ennabil, N., Andersson, N., Loufty, M., de Pokomandy, A., Kaida, A, & CHIWOS Research Team. (2017). Envisioning women-centered HIV care: Perspectives from women living with HIV in Canada. *Women's Health Issues*, 27(6), 721-730.

O'Brien, N., Nha Hong, Q., Law, S., Massoud, S., Carter, A., Kaida, A., Loutfy. M., Cox, J., Andersson, N., & de Pokomandy, A. (2018). Health system features that enhance access to comprehensive primary care for women living with HIV in high-income settings: A systemic mixed studies review. *AIDS Patient Care*, 32(4), 129-148.

Olivier, C., & Stanciu, M. (1999). *HIV/AIDS in New Brunswick: The impact of the changing epidemic: Assessment of persons living with HIV/AIDS, their caregivers and groups at risk of HIV infection*. [Hard copy]. Fredericton, NB: AIDS New Brunswick.

Palmer, A., Gabler, K., Rachlis, B., Ding, E., Chia, J., Bacani, N., Bayuomi, A., Closson, K., Klein, M., Cooper, C., Burchell, A., Walmsley, S., Kaida, A., Hogg, R., & the Canadian Observational Cohort Collaboration. (2018). *Viral suppression and viral rebound among young adults living with HIV in Canada*. Retrieved September 10, 2018, from https://journals.lww.com/md-journal/fulltext/2018/06010/Viral_suppression_and_viral_rebound_among_young.3.aspx.

Paquette, D. (2014). *Integrated approach to the prevention and control of sexually transmitted and blood borne infections (STBBIs)*. Retrieved May 3, 2018, from http://www.catie.ca/sites/default/files/2-845-1-DanaPaquette.pdf.

Pellowski, J. (2013). Barriers to care for rural people living with HIV: A review of domestic research and health care models. *Journal of the Association of Nurses in AIDS Care*, 24(5), 422-437.

Previl, S. (2017, March 10). N.S. ramps up opioid crisis support with $1.1 M in funding. *Global News*. Retrieved April 3, 2017, from http://globalnews.ca/news/3301423/n-s-ramps-up-opioid-crisis-support-with-1m-in-funding/.

Province of New Brunswick. (2013). *Rebuilding health care together: The provincial health plan 2013-2018*. Retrieved January 2, 2017, from https://www.gnb.ca/0212/values/pdf/9129%20english.pdf.

Province of Nova Scotia. (2009). *Preventing poverty. Promoting prosperity. Nova Scotia's poverty reduction strategy*. Retrieved November 29, 2017, from https://novascotia.ca/coms/specials/poverty/documents/poverty_report_2009.pdf.

Provincial HIV/AIDS Strategy Steering Committee. (2003). *Nova Scotia's strategy on HIV/AIDS*. Retrieved November 2, 2016, from https://www.novascotia.ca/aids/documents/HIV-AIDS%20Stratgy-Full%20Report.pdf.

Public Health Agency of Canada. (2012). *Population-specific HIV/AIDS status report: Women*. Retrieved November 4, 2016, from http://librarypdf.catie.ca/pdf/ATI-20000s/26407.pdf.

Public Health Agency of Canada. (2013). *Population-specific HIV/AIDS status report: People living with HIV/AIDS*. Retrieved November 29, 2017, from http://www.catie.ca/sites/default/files/SR-People-Living-with-HIV.pdf.

Public Health Agency of Canada. (2014a). *How the AIDS community action program (ACAP) contributes to HIV/AIDS knowledge & behaviour change and improved access: Results of an outcome assessment*. Retrieved May 29, 2018 from http://publications.gc.ca/collections/collection_2014/aspc-phac/HP35-42-2013-eng.pdf.

Public Health Agency of Canada. (2014b). *Chapter 3: Population-specific HIV/AIDS status report: Women –status of HIV/AIDS*. Retrieved May 27, 2018, from http://www.phac-aspc.gc.ca/aids-sida/publication/ps-pd/women-femmes/chapter-chapitre-3-eng.php.

Public Health Agency of Canada. (2015a). *HIV and AIDS Canada surveillance report to December 31, 2014*. Retrieved May 27, 2018, from https://www.canada.ca/content/dam/canada/health-canada/migration/healthy-canadians/publications/diseases-conditions-maladies-affections/hiv-aids-surveillance-2014-vih-sida/alt/hiv-aids-surveillance-2014-vih-sida-eng.pdf.

Public Health Agency of Canada. (2015b*). Summary: Estimates of HIV incidence, prevalence, and proportion undiagnosed in Canada, 2014*. Retrieved May 26, 2018, from http://healthycanadians.gc.ca/publications/diseases-conditions-maladies-affections/hiv-aids-estimates-2014-vih-sida-estimations/alt/hiv-aids-estimates-2014-vih-sida-estimations-eng.pdf.

Ramin, B. (2007). Anthropology speaks to medicine: The case of HIV/AIDS in Africa. *McGill Journal of Medicine*, 10(2), 127-132.

Rogers, T. (2013). *Integrated approaches to HIV prevention and treatment*. Retrieved February 19, 2017, from https://www.catie.ca/en/hiv-canada/9/9-2.

Roth, E., Cui, Z., Rich, A., Lachowsky, N., Sereda, P., Card, K., Moore, D., & Hogg, R. (2018a). Repeated measures analysis of alcohol patterns among gay and bisexual men in the momentum health study. *Substance use and misuse*, 53(5), 816-827.

Roth, E., Cui, Z., Rich, A., Lachowsky, N., Sereda, P., Card, K., Jollimore, J., Howard, T., Armstrong, H., Moore, D., & Hogg, R. (2018b). Seroadaptive strategies of Vancouver gay and bisexual men in a treatment as prevention environment. *Journal of Homosexual*, 65(4), 524-539.

Rylko-Bauer, B., & Farmer, P. (2016). Structural violence, poverty, and social suffering. Retrieved May 3, 2018, from http://www.oxfordhandbooks.com/view/10.1093/oxfordhb/9780199914050.001.0001/oxfordhb-9780199914050-e-4?print=pdf.

Rylko-Bauer, B., Singer, M., & Van Milligen, J. (2006). Reclaiming applied anthropology: Its past, present, and future. *American Anthropologist,* 108(1), 178-190.

Scharf, E., & Toole, S. (1992). HIV and the invisibility of women: Is there a need to redefine AIDS? *Feminist Review*, 41, 64-67.

Schensul, J. (2010). Engaged universities, community based research organizations and the third sector of science in a global system. *Human Organization,* 69(4), 307-320.

Scheper-Hughes, N. (1990). Three propositions for a critically applied medical anthropology. *Social Science and Medicine*, 30(2), 189-197.

Sharif, N., Dar, A., & Amartunga, C. (2000). *Ethnicity, income and access to health care in the Atlantic Region: A synthesis of the literature*. Retrieved December 29, 2016, from https://www.dal.ca/content/dam/dalhousie/pdf/diff/ace-women-health/ACEWH_ethnicity_income_access_to_health_care_lit_review.pdf.

Silva, S. (2016, September 19). Hepatitis C rate increased in Nova Scotia, national rate decreased. *Global News*. Retrieved January 5, 2017, from https://globalnews.ca/news/2949777/hepatitis-c-rate-increased-in-nova-scotia-national-rate-decreased/.

Simmons, J., Farmer, P., & Schoepf, B. (2011). A global perspective. In P. Farmer, M. Connors, and J. Simmons (Eds.), *Women, poverty, and AIDS: Sex, drugs, and structural violence* (pp. 39-90). Monroe, ME: Common Courage Press.

Singer, M. (1995). Beyond the ivory tower: Critical praxis in medical anthropology. *Medical Anthropology Quarterly,* 9(1), 80-106.

Singer, M. (2001). The development of critical medical anthropology: implications for biological anthropology. In A. Goodman and T. Leatherman (Eds.), *Building a new biocultural synthesis: political-economic perspectives on human biology* (pp. 93-123). Ann Arbor, MI: The University of Michigan Press.

Singer, M., & Baer, H. (1995). *Critical medical anthropology*. Amityville, NY: Baywood Publishing Company.

Singer, M., & Baer, H. (2007). *Introducing medical anthropology: A discipline in action*. Lanham, MD: Altamira Press.

Sinha, P., Gupta, U., Sing, J., & Srivastava, A. (2017). Structural violence and women: An impediment to women empowerment. *Indian Journal of Community Medicine*, 42(3), 134-137.

Smillie, C. (1998). *Natural helpers and the health agenda: Connecting health educating work with sustained community health programming* (unpublished master's dissertation), University of Toronto, ON, Canada.

Smylie, L. (2014). *Community action fund update, delivery model components and engagement priorities*. [Hard copy]. Ottawa, ON: Public Health Agency of Canada.

Soloducha, A. (2017, October 12). *Saskatchewan's HIV rate highest in Canada, up 800% in 1 region*. Retrieved November 13, 2018, from https://www.cbc.ca/news/canada/saskatchewan/saskatchewan-hiv-rate-highest-canada-1.4351057.

Statistics Canada. (2015a). *Employment by major industry group, seasonally adjusted, by province (monthly) (New Brunswick)*. Retrieved December 2, 2017, from https://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/labr67e-eng.htm.

Statistics Canada. (2015b). *Employment by industry, monthly, seasonally adjusted and unadjusted, and trend-cycle, last 5 months (x 1,000)*. Retrieved December 2, 2017, from https://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/labr67d-eng.htm.

Statistics Canada. (2015c). *Rural area*. Retrieved August 9, 2018, from https://www150.statcan.gc.ca/n1/pub/92-195-x/2011001/geo/ra-rr/ra-rr-eng.htm.

Teixeira, S. (2018). Qualitative Geographic Information Systems (GIS): An untapped research approach for social work. *Qualitative Social Work*, 17(1), 9-23.

Terrence Higgins Trust & Sophia Forum. (2018). *Women and HIV invisible no longer: A national study of women's experiences of HIV*. Retrieved November 10, 2018, from https://www.tht.org.uk/sites/default/files/2018-04/women-and-HIV_report_final.pdf.

Treasury Board of Canada Secretariat. (2015). *The federal initiative to address HIV/AIDS in Canada*. Retrieved May 16, 2018, from https://www.tbs-sct.gc.ca/hidb-bdih/plan-eng.aspx?Org=46&Hi=25&Pl=247.

UNAIDS. (2007). *Policy brief: The greater involvement of people living with HIV (GIPA)*. Retrieved December 22, 2016, from http://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_gipa.pdf.

UNAIDS. (2014). A focus on women: A key strategy to preventing HIV among children. Retrieved August 3, 2018, from http://www.unaids.org/sites/default/files/media_asset/JC2538_preventingHIVamongchildren_en_0.pdf.

Van Willigen, J. (2002). *Applied anthropology: An introduction*. Westport, CT: Bergin & Garvey.

Wiley, A., & Allen, J. (2009). *Medical anthropology: A biocultural approach*. New York City, NY: Oxford University Press.

Winnipeg Free Press. (2018, March 3). *Manitoba sees staggering rise in reported HIV cases*. Retrieved November 11, 2018, from https://www.winnipegfreepress.com/local/manitoba-sees-staggering-rise-in-reported-hiv-cases-475726943.html.

Witeska-Mlynarczyk, A. (2015). Critical medical anthropology – A voice for just and equitable healthcare. *Annals of Agricultural and Environmental Medicine*, 22(2), 385-389.

Women and HIV/AIDS Initiative. (2017). *Women, HIV and stigma: A toolkit for creating welcoming spaces*. Retrieved November 14, 2018, from http://www.whai.ca/ModuleFile?id=263.

Yu, D., Hatala, A., Reimer, J., & Lorway, R. (2017). 'I'm more aware of my HIV risk than anything else': Syndemics of syphilis and HIV among gay men in Winnipeg. *Culture, Health and Sexuality*, 20(9), 1036-1048.

APPENDICES

Appendix A: Meeting minutes for live webinar with community-based agencies.

AIRN OPEN MEMBERSHIP TELECONFERENCE CALL
Wednesday, April 9th, 2014
2:00-3:00pm ADT

Presentation and discussion with Priscilla Medeiros, a PhD Candidate from McMaster University, about her upcoming doctoral data collection in the Atlantic Region

Title: The Shifting Paradigm of HIV/AIDS: Perspectives of Community-based Organizations and Women
(See slides for complete details)
Purpose: Evaluate how policy and funding agreement changes affect service delivery.
Research Questions:
AIDS Service Organizations:
- In what ways will service delivery change for AIDS Service Organization?
- How will the integration of client-centered services affect service delivery for ASOs?
- What are the current gaps in service delivery for ASOs?
- Women Living with HIV:
  How will the integration of client-centered services affect women living with HIV?

Methodological Approach
Sample Population Includes:
1. Employees working for ASOs in Atlantic Canada (full-time and part-time)
2. Women Living with HIV

Participant Observation:
- Work in the offices of ASOs to learn about programs, policies, and the allocation of funds
- Access community reports

Semi-structured Interviews:
- Employees working for ASOs (n=30)
- Women living with HIV (n=50)
- About 60 to 90 minutes in length at a mutually agreeable location
- Recording interviews using a digital recorder

Research contributions:
1. Results will inform policy makers, ASOs, and people living with HIV
2. Provides data to understand the affect of changing service delivery on women living with HIV
3. Use of participatory research approach
4. Dissemination of findings using pamphlets and summary reports

For additional questions, please feel free to contact me:
medeirp@mcmaster.ca

Questions and discussion:
- Interesting to see the connection and similarity to the changing landscapes project and some extension of it. The changing landscapes study involved the completion of Interviews and focus groups with ASOs (and Hepatitis C projects), clients, and referral/partner organizations, to look at the current and changing delivery of services in the Atlantic region with an eye to the identification of gaps and challenges moving towards the integration of STBBIs.
  - Results of the landscapes study may help refine some of the questions when in the field
  - Where there is no overlap is the focus on women living with HIV so this will be a great extension to this work

- GIS component – Geographical Information Software (GIS) – ASOs will be asked to provide the first three digits of postal codes for women living with HIV that they support. Use first three digits to locate nearest Canada Post to calculate distance to services and then a visual map demonstrating the distance women must travel to access healthcare services will be created.
  - Mapping various services, not just ASOs. Priscilla has been working with a specialized group at McMaster to create categories and overlapping services to reduce the points on the map. Will be working with ASOs as well to identify these services.
  - Currently, the plan is only to use GIS to map distance – suggested that there are other ways that people access services such as by phone and internet so those layers may need to be explored as well to get a full picture. Challenge in rural areas – encouraged to access services via the internet (home or public library). High speed internet in rural areas is not always available. Could add this as part of the interview questions if it

194

          can't be part of the GIS to better understand how people are accessing
          services.
- Priscilla plans to work it in as an additional sub-question
  - The GIS results will provide a profile of organizations to show the variability.
    - Suggested that Instead of mapping organizations that individual services could be mapped.
      - That's the end point Priscilla hopes to reach and is still learning about GIS so cannot promise this aspect at this point.

- Recruiting 50 women – within ASOs as a starting point but going outside of ASOs to access women who don't directly access ASOs for support. A joint learning to branch out from ASOs to referral organizations.
  - Tend to hear from the people who are well connected and engaged in these services but the voices of those who don`t access services don`t have their voices heard. To do that would be a very beneficial.
  - Suggest connecting with the ID clinics sooner rather than later to get them on board with making these connections with women who are not currently accessing services through ASOs.
  - Immigrant settlement organizations (e.g., Halifax), and Corrections would also be good connects

- Fieldwork (estimate of 2 months in each province) data/the ethnographic experience, will be captured via a fieldwork diary that will be completed throughout the day and analyzed similar to the algorithms inherent in Nvivo to seek out overarching concepts and experiences being observed or encountered.
  - Suggested that both verbal consent and written consent be obtained from EDs to do the ethnographic data collection in the field.

- Participants: Suggested that, in addition to speaking with employees of the ASOs, seek input from the Board level as long-term board members may offer a unique and potentially different perspective.
  - Questions put together for the employees could transcend into questions for the board as well. Will add to the diversity of responses.

- Informal vs formal supports – Informal as well as formal support will be explored. For example, are women forming their own peer support networks or seeking support from the internet (e.g., Australia).

- Terminology caution: The changing landscapes project is using the term integration as well but in a very different way. It spears that this study is looking at integration as the continuum of services (prevention –> support –> care –>

treatment) whereas the landscapes project is looking at it from a service delivery standpoint and the integration of HIV with other STBBIs.

- Start date: Planning to begin in New Brunswick May 15, 2014 (latest – June – depending on ethics approval)

Appendix B: McMaster University research ethics clearance form.

MREB Clearance Certificate   https://ethics.mcmaster.ca/mreb/print_approval_catherine.cfm?ID=3299

McMaster University	**McMaster University Research Ethics Board (MREB)**
Inspiring Innovation and Discovery	c/o Research Office for Administrative Development and Support, MREB Secretariat, GH-305, e-mail: ethicsoffice@mcmaster.ca

CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH

Application Status: New ☐ **Addendum** ☑ **Project Number:** 2014 070

TITLE OF RESEARCH PROJECT:

The Shifting Paradigm of HIV/AIDS: Perspectives of Community-based Organizations and Women Living with HIV in Atlantic Canada

Faculty Investigator(s)/ Supervisor(s)	Dept./Address	Phone	E-Mail
A. Herring	Anthropology	23915	herring@laurentian.ca

Student Investigator(s)	Dept./Address	Phone	E-Mail
P. Medeiros	Anthropology	519-716-812	medeirp@mcmaster.ca

The application in support of the above research project has been reviewed by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster University Policies and Guidelines for Research Involving Human Participants. The following ethics certification is provided by the MREB:

☐ The application protocol is cleared as presented without questions or requests for modification.

☑ The application protocol is cleared as revised without questions or requests for modification.

☐ The application protocol is cleared subject to clarification and/or modification as appended or identified below:

COMMENTS AND CONDITIONS: Ongoing clearance is contingent on completing the annual completed/status report. A "Change Request" or amendment must be made and cleared before any alterations are made to the research.

Reporting Frequency:	**Annual:** May-09-2015	**Other:**

Date: May-09-2014 **Vice Chair, C. Anderson:**

Appendix C: New Brunswick Horizon Health Network research ethics clearance form.

Research Ethics Board
Horizon Health Network, 5DN SJRH,
400 University Avenue, Saint John, New Brunswick, Canada E2L 4L2
Research Office - 506-648-6094 Tel 506-648-6173 Fax

August 26, 2014

Priscilla Medeiros
83 Lorraine Drive
Cambridge, ON
N1R 6P2

Dear Priscilla

Re: The Shifting Paradigm of HIV/AIDS: Perspectives of Community-Based Organizations and Women Living with HIV in Atlantic Canada
Protocol Number: N/A
File #: 2014-2037

The above noted study has been reviewed and approved via the delegated review process. **Final Approval** is now granted by the Research Ethics Board. Re- approval should be initiated prior to August 26, 2015.

APPROVED:

- **Research Study Application**: signed and dated August 21, 2014
- **Protocol:** version 1 dated April 1, 2014
- **Informed Consent:** version dated August 20, 2014
- **Appendix A – Recruitment Poster:** version undated
- **Project Information Booklet:** version undated
- **Appendix C1 – Interview Guide for AIDS Service Organizations:** version undated
- **Appendix C2 – Interview Guide for Women Living with HIV:** version undated
- **E-mail Recruitment Script:** version undated
- **Appendix E – Researcher's Log for Recording Verbal Consent:** version undated
- **Data Access Agreement:** version undated
- **Appendix G – Recruitment Script for AIDS Service Organizations:** version undated
- **Appendix H – Study Information Card:** version undated
- **Appendix J – List of Support Services for Participants:** version undated
- **Appendix K – Participant Observation Consent For AIDS Service Organizations:** version undated

Research Ethics Board (REB)
(Address correspondence c/o Ethics Services)

Membership
Jeff Jennings
Chairperson/Methodological Expert
Eileen Malone
Vice Chair
Dr. Sohrab Lutchmedial
Interventional Cardiologist
Dr. Sanjay Siddhartha
Psychiatrist
Dr. Keith Wilson
Medical/ Family Medicine
Dr. Peter Martenyi
Medical/ Family Medicine
Dr. Glendon Sullivan
Medical
Dr. Hala Makary
Medical / Neonatologist
Dr. Amber Swan
Medical / Oncology
Diane Brideau-Laughlin
Pharmacist//Content Expert
Gisia Pisegna
Pharmacist/Content Expert
Mary Reeves
Content Expert
Jonathon Chase, Q.C.
Law
Mario DiCarlo
Law
Dr. Timothy Christie, MHSc, PhD
Ethics Expert
Dr. Marc Smith, PhD
Ethics Expert
Michael Coster
Non-Scientific
Marie-Nicole LeGresley
Non-Scientific
Dr. James Croll
Methodological Expert
Marlene Mercer
Nursing/Scientific
Gordon Friars
Community
David Hanson
Community
Al Kavanaugh
Community
Audrey Lampert
Community
J. Maurice Legere
Community
Lloyd Sutherland
Community

RESEARCH - BUILDING THE FOUNDATION FOR QUALITY PATIENT CARE

Page 2 of 2
RS 2014-2037
Priscilla Medeiros
August 26, 2014

Also on file:

- **Cover Letter :** signed and dated August 21, 2014
- **McMaster University Research Ethics Board Certificate of Ethics Clearance to Involve Human Participants in Research:** signed and dated May 9, 2014
- **Letter of Support Lise Dupuis:** signed and dated July 29, 2014
- **Letter of Support Duncan Webster:** signed and dated July 28, 2014
- **Field Research Budget:** version undated
- **Letter for the Waiver of REB fees for Horizon Health Network:** signed and dated July 25, 2014
- **Curriculum Vitae Priscilla Medeiros:** signed and dated August 20, 2014
- **Curriculum Vitae Duncan Webster:** signed and dated November 20, 2013
- **Medical License Duncan V. Webster # 3486:** expires December 31, 2014

The Research Ethics Board for the Horizon Health Network is organized and operates according to the principles of the ICH Harmonized Tripartite Guidelines: Good Clinical Practice, Tri-Council Policy Statement and Division 5 of the Food and Drug Regulations.

With kind regards,

Timothy Christie BA (hons). MA, MHSc, PhD
Regional Director – Ethics Services
Horizon Health Network REB

TC/ty

Appendix D: New Brunswick Horizon Health Network waiver approval of application fee.

Research Ethics Board

Horizon Health Network, 5DN SJRH,
400 University Avenue, Saint John, New Brunswick, Canada E2L 4L2
Research Office - 506-648-6094 Tel 506-648-6173 Fax

July 25, 2014

Priscilla Medeiros
638 Forest Hill Road, Apt # 3
Fredericton, New Brunswick
E3B 5X9

Dear Ms. Medeiros:

Re: Changing of HIV services in Atlantic Canada through the perspective of employees working for AIDS Service Organizations and women living with HIV
Protocol ID: TBD
Principal Investigator: Priscilla Medeiros
Our File #: TBD

This is to acknowledge your request for the REB to waive the REB fees for the above noted study which was received July 25, 2014.

After careful consideration the REB has approved your request for a waiver of REB fees.

The Research Ethics Board for the Horizon Health Network is organized and operates according to the principles of the ICH Harmonized Tripartite Guidelines: Good Clinical Practice, Tri-Council Policy Statement and Division 5 of the Food and Drug Regulations.

With kind regards,

Timothy Christie, BA (hons), MA, MHSc, PhD
Regional Director – Ethics Services
Research Ethics Board
Horizon Health Network

TC/nld

Research Ethics Board (REB)
(Address correspondence c/o Ethics Services)

Membership

Jeff Jennings
Chairperson/Methodological Expert
Eileen Malone
Vice Chair
Dr. Sohrab Lutchmedial
Interventional Cardiologist
Dr. Sanjay Siddhartha
Psychiatrist
Dr. Keith Wilson
Medical/ Family Medicine
Dr. Peter Martenyi
Medical/ Family Medicine
Dr. Glendon Sullivan
Medical
Dr. Hala Makary
Medical / Neonatologist
Dr. Amber Swan
Medical / Oncology
Diane Brideau-Laughlin
Pharmacist/Content Expert
Gisia Pisegna
Pharmacist/Content Expert
Mary Reeves
Content Expert
Jonathon Chase, Q.C.
Law
Mario DiCarlo
Law
Dr. Timothy Christie, MHSc, PhD
Ethics Expert
Dr. Marc Smith, PhD
Ethics Expert
Michael Coster
Non-Scientific
Marie-Nicole LeGresley
Non-Scientific
Dr. James Croll
Methodological Expert
Marlene Mercer
Nursing Scientific
Gordon Friars
Community
David Hanson
Community
Al Kavanaugh
Community
Audrey Lampert
Community
J. Maurice Legere
Community
Lloyd Sutherland
Community

RESEARCH - BUILDING THE FOUNDATION FOR QUALITY PATIENT CARE

Appendix E: Newfoundland and Labrador course on research ethics certificate.

PANEL ON
RESEARCH ETHICS
Navigating the ethics of human research

TCPS 2: CORE

Certificate of Completion

This document certifies that

Priscilla Medeiros

has completed the Tri-Council Policy Statement:
Ethical Conduct for Research Involving Humans
Course on Research Ethics (TCPS 2: CORE)

Date of Issue: **13 June, 2014**

Appendix F: Interview guide for women living with HIV.

1. Tell me about your experience of living with HIV and accessing services or programs offered by [*insert name of AIDS Services Organization*].

2. How many years have you been accessing services or programs related to HIV?

3. What other services or programs are you accessing in your community?

4. How often do you access these services or programs?

5. If you do not access services, please explain why.

6. How did you learn about these services or programs?

7. How far do you travel to access these services? Please identify the mode of transportation you are using to access these services.

8. What do you feel are some of the gaps in programming and services for women living with HIV in [*insert name of province*]?

9. How have the services you access changed in the past few years? Please provide me with an example.

10. What are the key issues facing women living with HIV in your community? How do the current services and programs available by AIDS Service Organizations or other service providers meet these needs?

11. In your opinion, have there been any improvements in service delivery for women living with HIV in your community? Please provide me with an example.

12. How would you improve the accessibility of services or programs for women living with HIV?

13. What are the key issues facing AIDS Service Organizations from offering services that are more appropriate for women living with HIV?

14. What are your thoughts and/or feelings about accessing client-centered services at [*insert name of AIDS Service Organization*]?

15. How will the implementation of client-centered services affect your experience as a female client?

16. Do you have any further comments or suggestions on how programs and services can be improved for women living with HIV?

Appendix G: Interview guide for community sector employees.

1. How many years have you been involved in this work? Please tell me about your role with the organization.

2. What are the broad categories of clients that your organization serves?

3. Approximately how many women are registered with your organization?

4. What services and programs are currently available for female clients in your organization?

5. What referral services are your clients accessing in your region?

6. What do you feel are some of the gaps in programming and services for your clients?

7. What are the current strengths and weaknesses of this referral system?

8. Are there any programs or services you would like to be able to offer and cannot?

9. In your opinion, what are the key issues facing women living with HIV in your community? Probe: How do your current services and programs meet these needs?

10. In your opinion, what are the key issues facing AIDS Service Organizations from offering services that are more appropriate for women living with HIV?

11. What resources or changes would need to be made to address these gaps in service delivery?

12. What are some of the changes in service delivery or program funding you have seen or assisted to implement since working for a community-based HIV agency?

13. In your opinion, what are the reasons for changes to service delivery? Provide an example.

14. What are your thoughts and/or feelings about implementing client-centered services?

15. How will the integration of client-centered services for sexually transmitted infections affect service delivery at AIDS Service Organizations?

16. How does the absence or presence of a HIV/AIDS preventative strategy affect service and program delivery?

17. What is the future direction of services and programs for your organization during the program transition period? Please provide an example of a new initiative that will be available at your organization.

Appendix H: Community resource directory for women living with HIV in New Brunswick and Nova Scotia.

Name	City	Service Category
New Brunswick		
AIDS New Brunswick*	Fredericton	Social service
Social Development Centre	Fredericton	Social service
Multicultural Association of Fredericton*	Fredericton	Social service
Chimo Helpline Inc.	Fredericton	Social service
Family Enrichment and Counseling Services	Fredericton	Social service
Fredericton YMCA	Fredericton	Social service
Capital Region Mental Health and Addictions Association	Fredericton	Medical service
Liberty Lane	Fredericton	Social service
Opal Family Services	Fredericton	Social service
Public Health Education and Information Service of New Brunswick	Fredericton	Social service
Women in Transition House	Fredericton	Transition housing/shelters for women
Grace House for Women	Fredericton	Transition housing/shelters for women
Victim Services	Fredericton	Social service
Fredericton After-Hours Mobile Crisis Team	Fredericton	Medical service
Canadian Mental Health Association	Fredericton	Social service
Community Health Clinic*	Fredericton	Medical service
Gignoo Transition House	Fredericton	Transition housing/shelters for women
Fredericton Non-profit Housing Organization	Fredericton	Social service
Public Legal Education and Information Service of New Brunswick	Fredericton	Social service
Fredericton Sexual Assault Crisis Centre	Fredericton	Social service
Miramichi Needle Exchange	Mirimachi	Social service
AIDS/SIDA Moncton*	Moncton	Social service

John Howard Society	Moncton	Social service
Salvus Clinic*	Moncton	Medical service
YMCA of Greater Moncton	Moncton	Social service
New Brunswick Housing	Moncton	Transition housing/shelters for women
Crossroads for Women Inc.	Moncton	Transition housing/shelters for women
Moncton Hospital HIV Clinic*	Moncton	Medical service
Dr. George L. Lumont University Hospital Centre-Infectious Diseases Clinic	Moncton	Medical service
New Brunswick Social Development	Moncton	Social service
Sexual Health Centre	Moncton	Medical service
Employment and Social Development Canada	Moncton	Social service
AIDS Saint John*	Saint John	Social service
Saint John Women's Empowerment Network: Power Up Program	Saint John	Social service
Saint John Infectious Disease Clinic*	Saint John	Medical service
Sophia Recovery Centre	Saint John	Medical service
Saint John Sexual Health Centre	Saint John	Medical service
Hestia House	Saint John	Transition housing/shelters for women
Coverdale Centre for Women	Saint John	Social service
Ridgewood Addiction Services	Saint John	Medical service
Centre for Research, Education and Clinical Care of at-risk Populations (R.E.C.A.P.)	Saint John	Medical service
St. Vincent de Paul Women's Centre	Saint John	Social service
Romero House*	Saint John	Transition housing/shelters for women
John Howard Society of New Brunswick Saint John Branch Inc.	Saint John	Social service

Sexual Health Centre	Saint John	Medical service
Fresh Start Services for Women Inc.	Saint John	Social service
Phoenix Recovery Centre	Saint John	Medical service
Ridgewood Addiction Services Detox	Saint John	Medical service
Salvation Army*	Saint John	Social service
New Brunswick Social Development/ Mental Health Services	Saint John	Social service
Nova Scotia		
Maggie's Place Family Resource Centre	Amherst	Social service
Antigonish Women's Resource Centre	Antigonish	Social service
South Shore Transition House	Bridgewater	Transition housing/shelters for women
Healing Our Nations	Dartmouth	Social service
Elizabeth Fry Society of Mainline Nova Scotia	Dartmouth	Social service
Feeding Others of Dartmouth: Margaret House	Dartmouth	Social service
Helping Hands Food Bank	Dartmouth	Social service
Salvation Army Food Bank	Dartmouth	Social service
Hepatitis Outreach Society of Nova Scotia	Dartmouth	Social service
AIDS Coalition of Nova Scotia*	Halifax	Social service
Mobile Outreach Street Health (MOSH)*	Halifax	Medical service
Mainline Needle Exchange*	Halifax	Social service
Hope Cottage	Halifax	Social service
North End Community Health Centre*	Halifax	Medical service
Halifax Sexual Health Centre	Halifax	Medical service
Reproductive Care Program of Nova Scotia	Halifax	Social service
Avalon Sexual Assault Centre	Halifax	Social service
Bryony House	Halifax	Transition housing/shelters for women
QEII Health Sciences	Halifax	Medical service

Centre - Infectious Disease Clinic*		
Direction 180*	Halifax	Medical service
The Salvation Army*	Halifax	Social service
Manna for Health*	Halifax	Social service
Barry House*	Halifax	Transition housing/shelters for women
Adsum for Women and Children	Halifax	Social service
Parker Street Food and Furniture Bank*	Halifax	Social service
Brunswick Street Mission*	Halifax	Social service
St. Vincent de Paul Society*	Halifax	Social service
Feed Nova Scotia	Halifax	Social service
Dalhousie Dental Clinic	Halifax	Medical service
Stepping Stone*	Halifax	Transition housing/shelters for women
Metropolitan Regional Housing Authority	Halifax	Transition housing/shelters for women
Nova Scotia Advisory Commission on AIDS	Halifax	Social service
Mi'kmaw Native Friendship Centre	Halifax	Social service
Metro Non-profit Housing Support Centre	Halifax	Social service
Halifax Housing Help Non-profit Housing	Halifax	Social service
Nova Scotia Legal Aid	Halifax	Social service
Dalhousie Legal Aid Service	Halifax	Social service
Chrysalis House Association	Kentville	Transition housing/shelters for women
Pictou County Centre for Sexual Health	New Glasgow	Medical service
The Ally Centre of Cape Breton	Sydney	Social service
Every Woman's Centre	Sydney	Social service
Well Women's Clinic	Sydney	Medical service
Cape Breton Centre for Sexual Health	Sydney	Medical service
Marguerite Centre	Timberlea	Social service
Northern Healthy	Truro	Social service

Connections Society		
Third Place Transition House	Truro	Transition housing/shelters for women
Central Nova Scotia Women's Resource Centre	Truro	Social service
Central Nova Scotia Women's Resource Centre	Truro	Social service
Child, Adolescent and Family Service: Mental Health Services	Truro	Social service
Mental Health & Addiction Services: Crisis Response Service	Truro	Medical service
Juniper House	Yarmouth	Transition housing/shelters for women

Appendix I: Needle Exchange Programs (NEPs) in New Brunswick from 2013 to 2014.[10]

| Name of Organization | # of Needles | | # of New Clients | # of Clients | | # of Clients by Age Groups | | | | | | | Crack Kits | Condoms |
	In	Out		Male	Female	≤19	20-29	30-39	40-49	50-59	60-69	70+		
AIDS New Brunswick*	90032	130382	182	576	383	22	283	335	184	102	33	0	1100	28721
AID Saint John	50409	78947	2000	199	1217	693	22	513	426	353	106	5	4694	27842
AIDS/SIDA Moncton	61281	79353	199	862	443	16	297	376	320	202	49	18	2107	8855

* Represents information for Fredericton and Miramichi.

[10] The AIDS service organizations listed above kindly emailed me their needle exchange program data at the end of my fieldwork in New Brunswick.

Appendix J: Needle Distribution Services in Nova Scotia for Year-end 2014.[11]

Name of Organization	# Needles In	# Needles Out	# New Clients	# of Clients		Crack Kits*	Condoms
				Male	Female		
Mainline Needle Exchange	822914	844209	1298	16348	8948	N/A	14590
Northern Healthy Connections Society	1241	1266	N/R	N/R	N/R	10	835

* Crack-smoking kits include materials like glass stems, screens, matches, ties, metal filters, alcohol swabs, and cookers.

N/R = not recorded.

N/A = not applicable.

[11] The community-based organizations listed above kindly emailed me their needle distribution services data at the end of my fieldwork in Nova Scotia.