PERINATAL CARE FOR WOMEN LIVING WITH HIV IN ONTARIO

THE SOCIAL ORGANIZATION OF PERINATAL CARE FOR WOMEN
LIVING WITH HIV IN ONTARIO: AN INSTITUTIONAL ETHNOGRAPHY

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LAY ABSTRACT

In Ontario, the maternity care that women living with HIV receive during pregnancy, childbirth, and early postpartum (also known as the perinatal period) is located in "high-risk" clinical settings within regional, academic teaching hospitals. The organization of such care has important implications for women's daily lives. This inquiry begins from the personal experiences of pregnant women and mothers living with HIV in Ontario and explores the concerns that women have as they navigate HIV and maternity care during the perinatal period. The inquiry shows how the troubles that women face are produced through institutional conditions and the routine practices of healthcare providers. This dissertation also examines how institutional arrangements related to reducing the risk of HIV to the fetus and infant, and lingering fears about HIV as "contagion," shape women's care experiences. Implications for the organization and delivery of perinatal care to women living with HIV is discussed.

ABSTRACT

My doctoral research begins from the standpoint of pregnant women and mothers living with HIV in Ontario, Canada and explores the concerns that women living with HIV have as they navigate healthcare during pregnancy, childbirth, and early postpartum. Moving beyond a description or abstracted theorization of women's experiences, I have used institutional ethnography to explicate how women's concerns are connected to and organized by ruling relations such as the ideological discourses that underpin the work practices of healthcare providers operating within healthcare institutions.

This dissertation follows three "threads" that were discovered in the overall institutional ethnographic inquiry, and that form the basis of three manuscripts. The first thread (Chapter Three) focuses on HIV disclosure, which all women who participated in this research expressed as a concern, and uncovers how the issue of HIV disclosure is accounted for in healthcare providers' work activities. In this analysis, I show how both the women's and healthcare provider's concerns about and actions related to HIV disclosure are connected to discourses such as "fear of contagion" and "AIDS hysteria" that continue to permeate public consciousness. The second thread (Chapter Four) focuses on the discourse of "risk" as organizing women's experiences and healthcare providers' work, which became visible through medications women were prescribed, the prenatal clinic appointment schedule women were expected to follow, and the medical interventions that were applied to women's bodies during childbirth and

early postpartum. In a third line of inquiry (Chapter Five), I outline how the current organization of "high-risk" maternity care that is delivered by specialists and is located in regional hospitals has particular implications for women's pregnancy and motherhood experiences, especially for women who live at a distance from these services and/or find it challenging to attend appointments because of employment and familial responsibilities. This analysis shows how the discourses of "risk" and "safety" are differently known and enacted by women and their healthcare providers, and calls into question the classification of pregnancies of women living with HIV as "high-risk."

In following the three threads and tracking the territory of perinatal care for women living with HIV, I illuminate points of disjuncture between women's and healthcare providers' ways of knowing HIV in the context of pregnancy and childbirth, and identify possibilities for how healthcare practices can be augmented to respond to the concerns and challenge that women expressed. In the Conclusion chapter, I draw attention to the tensions between the meta-level ideological discourses of "HIV exceptionalism" and "HIV normalization" that run through Chapters Three, Four, and Five, and that are generalized across the HIV and maternity care services that women living with HIV encounter. I end this dissertation with my thoughts regarding implications for the organization of perinatal care for women living with HIV in Ontario.

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LIST OF ABBREVIATIONS

AIDS   Acquired immune deficiency syndrome

ART   Antiretroviral therapy

AZT   Zidovudine

cART   Combination antiretroviral therapy

CD4   Cluster of differentiation 4 (immune system cell type)

HIV   Human immunodeficiency virus

MFM Clinic   Maternal Fetal Medicine Clinic

MUMC   McMaster University Medical Centre

PrEP   Pre-exposure prophylaxis

SIS Clinic   Special Immunology Services Clinic

TasP   Treatment as prevention

UNAIDS   The Joint United Nations Programme on HIV and AIDS

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Chapter One: Introduction

Introduction

One way that we come to "know" things is through literatures and what has been written about ideas and concepts. Reviewing literature is an essential exercise to make sense of what discourses, concepts, and "authorized knowledges" exist about a particular topic (Campbell & Gregor, 2008).

Through the course of conducting this institutional ethnography about the social organization of perinatal care for women living with HIV, I have come to see how HIV, pregnancy, and motherhood are differently "known" depending on one's worldview, education, and lived experiences. Furthermore, my understanding and perspective about how pregnancy and childbirth in the context of HIV are "known" have evolved with time and as I have become increasingly versed in the ontological and epistemological grounding of institutional ethnography as a critical research strategy, and Dorothy Smith's alternative sociology.

I begin this introductory chapter with a review of literatures to situate my study in a sociohistorical and institutional context where HIV, pregnancy, and perinatal care are "known" in particular ways. In describing specific literatures related to HIV, pregnancy, and motherhood, I aim to describe the discourses that have emerged regarding these topics; it is these discourses that have shaped and regulated language practices and the actual doings of specific people in specific locations. Discourses are trans-local relations that organize how individuals

understand and recognize objects of knowledge (Smith, 2005); describing discourses that are embedded within scholarly literatures related to HIV, pregnancy, and motherhood is critical to draw attention to the ways that such discourses are enacted through people's routinized, daily practices in institutional settings such as healthcare. Examining the discourses that underpin practices within healthcare also gives shape to the institutional complex that is investigated through institutional ethnography, and can provide clues about how such discourses and ways of knowing may be operating within work practices.

Importantly, I acknowledge numerous scholars who have employed the tradition of institutional ethnography to critically examine how institutional discourses and generalized, meta-level ideological discourses shape the organization of health and social services. Institutional ethnography has been a critical research strategy to illuminate the complexities and realities of people living with HIV given the dominant discourses that underpin the institutions they interface. What follows in this introductory chapter is: i) an examination of the various ways that HIV, pregnancy, and motherhood are known; ii) an overview of critiques by institutional ethnographers and other critical social scientists who have contested and disrupted the different ways that HIV, pregnancy, and motherhood are understood through biomedical interventions and dominant narratives; and iii) the identification of an opportunity to ask new questions about the social organization of perinatal care for women living with HIV given the contrasting ways that HIV, pregnancy, and motherhood are known.

How HIV and Pregnancy are "Known:" Taking Up Relevant Literatures

Different Ways of "Knowing" HIV: Examining Contrasting Standpoints

Through my experiences of working within both community-based and clinical settings where HIV care and support are delivered, I have come to appreciate how HIV is predominantly "known" in biomedical terms by people who operate within these settings. Healthcare providers who deliver care to people living with HIV use specific languages and terminologies, and are guided by bodies of medical literature and research when making decisions about treatment and the clinical management of HIV within the healthcare institutions where they practice. I have witnessed such languages and practices while working in an HIV clinic within an academic teaching hospital. Furthermore, the discourse of HIV as a medical condition has been cemented over time since the identification of the HIV virus in the 1980s and with the evolving development of medications to treat the virus. Understanding HIV in this way has been perpetuated not only in the routinized work practices of people operating within community-based and clinical settings, but also through literatures that maintain and reproduce such ways of knowing, as this review of the literature will explicate.

The first medications that demonstrated efficacy to suppress the HIV virus were developed in the 1990s and since that time biomedical research to investigate different ways to target and treat HIV has expanded exponentially. Today, numerous medications are available to treat HIV infection by inhibiting specific receptors on the HIV viral particle; a number of combination tablets have

also been developed that combine two or more active antiretroviral agents.

Because of the significant advancements in drug development that have occurred

in the last 30 years, HIV has shifted from a fatal condition if left untreated to a

complex chronic illness that can be effectively managed with antiretroviral

therapy (ART). With combination antiretroviral therapy (cART), that is, three or

more active agents in one's medication regimen, mortality rates have fallen

dramatically, and people living with HIV can expect a life expectancy

approaching that of the general population (Hull, Wu, & Montaner, 2012;

Nakagawa et al., 2013; Samji et al., 2013).

Clinical guidelines outline when HIV treatment initiation is recommended,

and guidelines released since 2013 have endorsed commencing cART as early as

possible because of the improved clinical outcomes that are observed in people

living with HIV who initiate treatment early compared to delaying treatment

(WHO, 2016a). These recommendations have ushered in shifts in practice

whereby treatment is offered and encouraged at the time of HIV diagnosis

because of the dominant scientific view that commencing treatment is a critical

factor in maintaining someone's longevity (Bärnighausen, Eyal, & Wikler, 2014;

WHO, 2016a).

The evolution of HIV into a chronic health condition is directly attributed

to the success of cART (Hull, Wu, & Montaner, 2012). As such, healthcare

providers who work in HIV clinical services continue to understand and "know"

HIV in this way, and are guided by this framing of HIV in what they do, and why

they do it, in their daily routine practices. Moreover, as this study will demonstrate, the discourses that perpetuate the framing of HIV as a chronic medical condition that can be effectively treated with cART continue to organize and coordinate the work practices of healthcare providers with whom pregnant women and mothers living with HIV interact.

George Smith was an institutional ethnographer who was active in gay liberation and AIDS organizing in the 1980s and 1990s (AAHP, n.d.). His research began from the sites of struggle of gay men and people affected by HIV and AIDS with a particular focus on the bathhouse raids in Toronto and the management of the AIDS epidemic in Ontario in the 1980s, respectively (AAHP, n.d.). George Smith's activist ethnographic work particularly in the early years of the HIV epidemic disrupted the biomedical framing of HIV and drew attention to how discourses that framed HIV in particular ways had implications for people living with HIV in terms of their access to certain treatments and services, and their experiences of care. George Smith's work about issues of access to medical treatment and broader health and social services for people living with HIV was highly influential and contributed greatly to HIV activism and the legacy of institutional ethnography in HIV research (Grace, 2019). George Smith's research began in 1988 and explored why new experimental drugs for HIV were not available in Ontario. He discovered that there was a lack of infrastructure at all levels of government to manage the access to and delivery of new experimental treatments. The lack of infrastructure was partly driven by the discourse of AIDS

as a fatal disease that was the dominant narrative at the time, and politico-administrative regimes that prioritized palliative care even though clinical trials were underway to test new medications and were demonstrating that people living with HIV could live longer with aggressive treatment (Grace, 2019; G. Smith, 1995). The findings from George Smith's research fueled the work of AIDS ACTION NOW! to help design and implement critical infrastructure to ensure people living with HIV received antiretroviral treatments that showed promise in the early years of the epidemic (G. Smith, 1995).

Viral Load, Treatment "Adherence" and "Undetectability"

Today, the effectiveness of HIV treatment is determined by monitoring a person's HIV viral load, which is defined as the amount of circulating HIV virus in one's body and is measured by counting the number of HIV viral copies per ml of blood. The goal of treatment is to achieve an "undetectable" viral load at which point currently available laboratory assays cannot detect the virus. The language and label of "undetectable" often influences the identities, life narratives, and sexual health behaviours and perceptions of people living with HIV, and has increasingly garnered attention in broad public discourses (Grace et al., 2015; Guta, Murray, & Gagnon 2016).

Within clinical settings where HIV care is delivered, it is widely known that achieving an "undetectable" viral load largely depends on maintaining "adherence" to treatment in that once treatment is initiated, the medication is to be

taken every day and exactly as prescribed (DHHS, 2019). It is widely known by HIV clinicians and is well documented in treatment literature that HIV treatment can be difficult because of the pill burden associated with the volume of tablets that people living with HIV may be prescribed and the side effect profiles of available drugs, but that taking medication is a lifelong commitment (CATIE, 2019). If people living with HIV do not maintain near-perfect adherence to their regimens they can develop drug resistance to the medication, which can reduce their long-term treatment options (CATIE, 2019). As such, much research has focused on the concept of "adherence" including observational cohort studies that have monitored rates of "adherence" in certain populations, qualitative studies that have explored the nuances and complexities of "adherence," and clinical trials that have tested behavioural interventions aimed at improving "adherence" in specific groups (Inzaule et al., 2016; Kalichman et al., 2016; Rana, van den Berg, Lamy, & Beckwith, 2016; Weiss & Stirratt, 2017). The preferred clinical marker for monitoring people who are taking cART is viral load testing, which can serve as a surrogate marker for one's treatment "adherence"; an "undetectable" viral load is indicative of treatment "adherence."

Institutional ethnographers have contested and critiqued the biomedical framing of "undetectability" and treatment "adherence" by examining the social organization of "healthwork" of people living with HIV. McCoy's research has specifically focused on access to cART and the work that people living with HIV do to take their medications and engage in HIV care (McCoy 2005, 2009).

McCoy's research examines the "work" of taking pills and claims that, although this work is private, it is socially organized through standardized pharmaceutical treatments and widely circulating discourses of adherence (McCoy, 2009). McCoy's research about managing pill taking emphasizes the different ways that ART, medication "adherence", and the work that people living with HIV do to look after their health are "known," and how these practices are organized in the context of institutional relations of healthcare and treatment (Grace, 2019; McCoy, 2009). McCoy notes that HIV treatment is "high stakes", yet demonstrates through her inquiry that begins from the standpoint of people living with HIV who take their HIV medication – dose by dose, day after day – how "adherence [to treatment] comes into view as a historically constructed category steeped in relevancies of medical power and social control" (McCoy, 2009, p. 129). Work by McCoy, as well as Mykhalovskiy, Bresalier and their colleagues (Bresalier et al., 2002; Mykhalovskiy, McCoy, & Bresalier, 2004) has been critical to tease out the complexities of the problematic of adherence, and how the everyday realities of people living with HIV who engage in care and take HIV medications make visible the "complex and creative interplay between biomedical and other ways of knowing" (Mykhalovskiy, McCoy, & Bresalier, 2004, p. 326). The present study into the social organization of perinatal care of women living with HIV builds on the work of Mykhalovskiy, McCoy, and colleagues to critically examine how women's experiences during pregnancy and childbirth are

produced by biomedical discourses and framings of HIV such as "adherence" and "undetectability."

HIV Treatment as Prevention

The practice of using HIV medication to prevent transmission has a long history in the context of pregnancy, childbirth, and early postpartum care of women living with HIV. All women living with HIV who are pregnant are recommended to be on HIV treatment in order to reduce the likelihood of HIV transmission occurring during pregnancy and at the time of childbirth. The high rates of cART utilization by pregnant women living with HIV in Canada means that the chance of perinatal HIV transmission with an undetectable viral load is less than 1% (Cooper et al., 2002; Forbes et al., 2012), and most often there are no identified perinatal transmissions per year in Canada despite infant exposure to HIV *in utero* and at the time of childbirth (PHAC, 2013).

The now-routine practices undertaken to prevent perinatal HIV transmission - administering cART to women during pregnancy, zidovudine (AZT) to women during childbirth, and AZT to infants postpartum – are obviously directly relevant to the current study (Money et al., 2014). Yet 'treatment as prevention' has wider relevance for women living with HIV as it significantly shapes the broad institutional context of HIV at this time. Because virologic suppression that is achieved through cART is associated with a decreased risk of transmission from one human to another, scientific research has expanded more recently to focus on the use of ART to prevent new HIV

infections in the context of sexual transmission between adults (Bärnighausen, Eyal, & Wikler, 2014; Hull, Wu, & Montaner, 2012), also known as pre-exposure prophylaxis, or PrEP. Treatment as prevention, also referred to as TasP, has been hypothesized to be one of the biggest mechanisms through which new HIV infections through sexual intercourse can be prevented, and has been posited as an essential strategy to end HIV altogether (Bärnighausen, Eyal, & Wikler, 2014); in fact, TasP was praised as the breakthrough of the year in the December 2011 issue of *Science* (Cohen, 2011).

Scholars caution that the success of TasP as a prevention strategy depends on "adherence" because the "Achilles heel" of PrEP is medication "adherence" (Mayer, 2012; Mayer & Krakower, 2016, p. 152); arguments made by these scholars highlight how strategies such as TasP are connected to discourses of adherence, pharmacological interventions, and social control vis-à-vis medical power and surveillance. Moreover, leading clinical researchers and proponents note that the success of TasP depends on the scale and spread of testing and linkage to care programs since it requires most people living with HIV to be tested and on treatment (Guta, Murray, & Gagnon, 2016; Hull, Wu, & Montaner, 2012).

Operationalizing TasP, therefore, is not only about expanding HIV testing and access to ART, but also implementing clinical monitoring and public health surveillance practices of people living with HIV (Guta, Murray, & Gagnon, 2016). One way that clinical settings aim to do this is by implementing the "HIV

treatment cascade" through specific practices and policies (UNAIDS, 2014). The treatment cascade is a model through which jurisdictions around the globe can monitor the proportion of people living with HIV who have achieved an undetectable viral load. The cascade positions viral undetectability as an end point of a sequential process from HIV testing to diagnosis to care linkage to access to ART to retention in care to viral suppression, and outlines a model for monitoring surveillance of people living with HIV who are engaged in care (Paparini, & Rhodes, 2016). UNAIDS set a global benchmark of achieving 90% for each tier of the cascade by 2020 (UNAIDS, 2014) and the HIV treatment cascade is increasingly being used to map the trajectory of local HIV epidemics and of different populations affected by HIV (Paparini, & Rhodes, 2016).

What this means for people living with HIV is that their HIV treatment adherence, viral load, engagement, and retention in care are increasingly being paid attention to, which in turn has implications for their experiences of care, how they interact with healthcare providers, and their local, everyday worlds. The expanding focus on treatment as a form of prevention, adherence to treatment, and achieving undetectability are key features of the work practices of people who deliver HIV care, and in other spaces where people living with HIV receive healthcare. The discourses of adherence, care engagement, and treatment to prevent HIV are embedded in institutional processes – including in the spaces of perinatal care; and I consider the salience of these wider institutional features throughout this institutional ethnographic inquiry.

Social Science Critiques of HIV Treatment and Biomedical Interventions

While the medical advancements in the treatment and clinical management of HIV have led to vast improvements in health and social outcomes for people living with HIV, and have supported the development of strategies to prevent perinatal transmission, many social scientists have developed critiques of these biomedical and public health interventions. As noted earlier, institutional ethnographers have identified that discourses such as adherence, TasP, and other biomedical interventions that have been touted to curb the HIV epidemic are important sites "through which biomedicine becomes part of a population-based politics of risk management" (Mykhalovskiy, McCoy, & Bresalier, 2004, p. 330). These critiques have shaped my thinking as a social science researcher, and burgeoning institutional ethnographer, as well as my investigation in to the social organization of perinatal care for women living with HIV.

Gagnon and Guta (2014) conducted an evolutionary concept analysis to critically examine how the concept of viral load has developed over time in the literature because of their concerns that "viral load" was an unquestioned and undertheorized concept that had been portrayed as a "neutral laboratory value" (p. 205) in clinical research and practice. Their analysis illustrated how the viral load functioned as a defining feature of life for many people living with HIV; was used to interpret people's health and illness status, behaviours (such as treatment "adherence"), and infectiousness; and served as a surrogate marker of one's

illness trajectory, risks, and outcomes (Gagnon & Guta, 2014). The authors

pointed to treatment guidelines that prioritize the achievement of a suppressed and

undetectable viral load to show how the viral load result is applied as a tool for

reading individual bodies as "targets" for biomedical and pharmacological

interventions and for monitoring treatment coverage and care engagement of

populations for public health purposes (Gagnon & Guta, 2014). Concerns have

been raised about how the conceptualization of "viral load" has been taken up in

policies, practices, and public discourse; for example, as argued by Grace et al.

(2015), achieving "undetectability" may usher in a new "elite" status within the

HIV community and facilitate further stigmatization and marginalization within

groups of people living with HIV. The "successful" virally suppressed versus the

"failed" virally unsuppressed person living with HIV are two subject positions

that are emerging in the TasP discourse and as a result of increasing

governmentality and public health surveillance (Guta, Murray & Gagnon, 2016).

The issue of undetectability and the subjective positioning of women who do and

do not achieve viral suppression are important issues to consider in the context of

perinatal care for women living with HIV and its social organization. The

emphasis in clinical research and literatures on the role of HIV treatments to

significantly reduce rates of perinatal HIV transmission is a critical orientation to

consider when examining how this way of knowing HIV may be entrenched in the

regimes that govern and organize healthcare for women living with HIV. This

orientation emerged as a point of questioning and discovery for me as I pursued threads of inquiry in this institutional ethnographic study.

Critiques of TasP and the treatment cascade as biomedical interventions and public health strategies build on critical analyses of the viral load and undetectability. TasP and the treatment cascade have generated significant debate by scholars around the world about their real-world implementation, possible clinical and ethical implications (and consequences) for people living with HIV, and contributions to biomedicalization where technological and biomedical interventions are increasingly being used to treat and prevent diseases and manage risks (Kippax & Race, 2003; Kippax & Stephenson, 2012; Nguyen et al., 2011; Paparini, & Rhodes, 2016; Persson, 2013, 2015; Young, Flowers & McDaid, 2016). Social scientists have raised concerns about social inequalities and structural barriers to treatment access and care that pose significant challenges to the widespread roll-out and success of TasP. Nguyen and colleagues (2011) caution that "it is unlikely that early diagnosis and treatment will be possible without paying serious attention to the social inequalities and stigmatization that already determine vulnerability to acquiring HIV and accessibility of diagnosis and treatment" (p. 292). Focusing on viral suppression as the ultimate outcome and ideal disregards the unique ways that HIV plays out in individuals in a biophysiological and sociocultural manner, ignores the socio-structural drivers of access to treatment and care (Guta, Murray, & Gagnon, 2016), and overlooks the broader aspects of HIV as a social condition, not only a virus, that is connected to

individual and social practices (Paparini, & Rhodes, 2016). Scholars have raised concerns about how the real-world implementation of TasP and the treatment cascade would need to account for local political and sociocontextual realities that shape how healthcare is organized and delivered in order to effectively address the HIV epidemic (Nguyen et al., 2011). Concerns that scholars have raised about narrowly focusing on viral suppression and the need to pay attention to the various ways that HIV plays out in people's lives aligns with the theoretical tenets of Dorothy Smith's alternative sociology and institutional ethnography as a research strategy. Through institutional ethnographic inquiries, researchers can bring to light the experiences of people who are objectified or excluded from ruling regimes such as biomedical strategies like TasP and viral suppression interventions and explicate how power is exerted through ruling practices (Grace, 2019).

Some social scientists have gone so far as to caution that HIV prevention strategies like TasP are "militaristic metaphors of 'biosecurity' and 'warfare'" that deploy counteroffensives in the war against HIV and, in the process, suspend civil rights (Gagnon & Holmes, 2008, p.264). Applying Foucault's concepts of governmentality, biopolitics, and surveillance, these scholars have claimed that the promise of subjective freedom that underpins many TasP and PrEP treatment awareness campaigns that promise undetectability, viral suppression, and an end to HIV are not what they seem (Guta, Murray & Gagnon, 2016). For example, the HIV care cascade implies certain expectations and responsibilities on the part of

the person living with HIV to be tested, diagnosed, engaged and retained in care, and achieving and maintaining an undetectable viral load (Paparini, & Rhodes, 2016). Gagnon and Holmes (2008) argue that the discourse of "health promotion" is operating within these public health strategies as a "mechanism for deviance amplification for individuals who do not conform to social norms in the way they care for themselves and others" (p. 267). This sentiment is shared by other critical social scientists who warn that these biomedical interventions that are designed to reduce levels of "infectiousness" and "risk" of transmission and have been framed as "liberating" and "emancipatory" are not inherently so because they actually increase public health surveillance (Guta, Murray, & Gagnon 2016; Persson, 2013). Further, the "social and legal requirements of responsibility in relation to HIV risk [reinforce] unequal forms of biomedical self-governance" (Young, Flowers, & McDaid, 2016, p. 411); for example, the person living with HIV who is not engaged or retained in care and who has a detectable viral load is categorized and seen as a "social deviant" (Guta, Murray & Gagnon, 2016).

These critiques examine dominant narratives about HIV, and how HIV is known, in literature and broader public discourses. The disruption of mainstream narratives that occurs through these critiques offers important clues about the social organization of knowledge about HIV, and the work practices of those who deliver healthcare to people living with HIV. Moreover, these critiques highlight possible points of disjuncture that may exist between what is known through

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literature and traditional sociological methodologies and what is known, lived, and practiced by people living with HIV.

Importantly for this study, broadly examining strategies, literatures, and discourses related to HIV prevention and treatment can help to sharpen focus and bring into view the possible ways through which biomedical ways of knowing HIV are connected to forms of risk management and population surveillance, as well as how biomedical interventions may be applied in the context of pregnancy, childbirth, and perinatal care for women living with HIV (Mykhalovskiy, McCoy, & Bresalier, 2004). For example, critical social scientists have shown that the HIV care cascade implies certain expectations and responsibilities of people living with HIV to be tested, diagnosed, and engaged in care, and to achieve and maintain an undetectable viral load (Paparini, & Rhodes, 2016). In this thesis I consider how these ways of knowing and practicing HIV care emerge and become significant in the spaces where women living with HIV receive perinatal care.

Different Ways of "Knowing" Motherhood in the Context of HIV: Examining Relevant Literatures

The priorities of seek, test, treat, and retain that underpin the HIV treatment cascade (Hull, Wu, & Montaner, 2012) have operated in the prevention of perinatal HIV transmission for as long as HIV medications have been utilized in clinical practice and maternity care. When it was discovered that AZT could dramatically reduce transmission during pregnancy, childbirth, and postpartum,

HIV testing shifted from a "case-finding tool to a technology capable of interrupting transmission from mother to child" (Gagnon & Holmes, 2008, p. 265). Since this time, women who test positive and who become pregnant have been hooked into a system whereby they are systematically treated and monitored to ensure perinatal HIV transmission is interrupted (Gagnon & Holmes, 2008).

No previous research, however, has examined the social organization of perinatal care of women living with HIV using institutional ethnography, and only minimal research has employed institutional ethnography to investigate maternity care more generally and the discourses and institutional arrangements that organize and coordinate such care. MacKinnon's doctoral research sought to describe the effects of societal discourses, institutional structures, and nursing work processes on the lives of women experiencing preterm labour. She discovered the various ways that pregnant women are drawn into the discourse of "risk" whereby women experience fear, guilt, and a sense of personal responsibility to prevent preterm birth and how the risk discourse operates as a form of social control over women's bodies (MacKinnon & Coy, 2006; MacKinnon & McIntyre, 2006). MacKinnon's work also highlights how the nurses that care for pregnant women are drawn into the discourse of "risk;" the study outlined how risk as a discourse was embedded in and became visible through professional nursing practices (MacKinnon & McIntyre, 2006). MacKinnon showed how nurses' work practices reflected the view that, in pregnancy, there is "no acceptable level of risk;" MacKinnon's research also

brought to light how the nurses' understanding of risk of preterm birth did not reflect the pregnant women's and mother's concerns about the risks associated with hospitalization and medical treatments imposed on their bodies and infants (MacKinnon & McIntyre, 2006, p. 68). The study also revealed how discourses of legal risk management and institutional safety were visible in the various work activities of the nurses caring for women in terms of their focus on the chart, institutional accountability vis-à-vis documentation, and routinized work processes, and not the pregnant woman (MacKinnon & McIntyre, 2006). As a result, nurses became complicit in accepting institutional priorities and complying with the relations of ruling (MacKinnon & McIntyre, 2006).

MacKinnon's research provides some important clues and ways of thinking about the social relations that coordinate and govern the healthcare practices that pregnant women and mothers encounter. One such example is the visibility of risk as a relevant and active discourse that operates as a form of social control over pregnant women, and organizes the work of nurses and other healthcare providers who care for them (MacKinnon & McCoy, 2006). I aim to build on the work of other institutional ethnographers and HIV researchers by exploring a new area for inquiry and contributing to what and how we know HIV in the context of pregnancy and motherhood. In my inquiry that begins from the standpoint of pregnant women and mothers living with HIV, I maintain focus on the discourses that may be operating in the delivery of perinatal care for mothers living with HIV. Throughout this dissertation, I discuss the multiple ways that

ruling relations are organizing and playing out in the lives of women living with HIV. For example, I examine what kinds of expectations and responsibilities related to HIV treatment, viral load suppression, and care retention are placed on women through the actions of healthcare providers, in what way the discourse of "risk" emerges in women's experiences and in the routinized practices of healthcare providers, and how these ideological frames may influence the kinds of work that women do to engage in their care.

Current Understandings of HIV, Pregnancy & Motherhood

Much is known about pregnancy and motherhood in the context of maternal HIV infection. Similar to the literature that tracks the evolution of HIV into a chronic health condition, however, much of what is known about HIV in pregnancy and childbirth has emerged through biomedical and epidemiological scholarship and literatures.

For example, pregnancy and motherhood are a growing reality for women living with HIV in Canada because of a number of factors. First, the HIV epidemic in Canada has become increasingly feminized as noted through the rising number of positive HIV test reports among women. Since the early 2000s, females have represented about one-quarter of reported HIV cases with diagnoses generally being made at a younger age (PHAC, 2014). Second, as previously mentioned, cART has resulted in significant reductions in HIV transmission

during the perinatal period; the chance of perinatal transmission in Canada if biomedical interventions are used is less than 1% (Chen et al., 2001; Cooper et al., 2002; Forbes et al., 2012). These factors have supported the idea that pregnancy and parenting are becoming "normalized" among women living with HIV in Canada who are increasingly planning their pregnancies (Burdge et al., 2003; Loutfy et al., 2009). For instance, an Ontario survey found that 69% of women living with HIV wanted to have children and 57% fully expected to conceive in the future (Loutfy et al., 2009). Most pregnant women living with HIV in Canada are aware of their HIV-positive status, have initiated HIV treatment, and are being monitored by an HIV specialist when they become pregnant (Bitnun et al., 2018; Loutfy et al., 2012). For example, the Public Health Agency of Canada reported that in 2012, 94.2% of women living with HIV received cART in pregnancy (PHAC, 2013). Furthermore, the majority of women living with HIV are diagnosed before their third trimester and receive cART for more than four weeks of pregnancy, which significantly contribute to reducing the likelihood of perinatal HIV transmission (Bitnun et al., 2018)

The evolution of HIV into a chronic health condition, the increasing normalization of pregnancy and parenting amongst women living with HIV, and the episodic nature of the health and social challenges that people living with HIV continue to face means that people living with HIV and their families will increasingly be connected to a variety of health and social services (Krentz, Dean, & Gill, 2006; O'Brien, Bayoumi, Strike, Young, & Davis, 2008). Although HIV

specialists play an important role in care and treatment, HIV shifting to a chronic illness has implications across many settings in which care is delivered (Bradley-Springer, Stevens, & Webb, 2010; Scandlyn, 2000; Thompson, Aberg, Cahn, & Montaner, 2010) including obstetrical and maternity care for pregnant women and mothers.

Since the early years of the HIV epidemic, a significant amount of literature has explored the experiences and unique considerations of what it means to be pregnant and to parent as a woman living with HIV. Much of this literature has perpetuated pathologizing and deficit-oriented narratives regarding the "challenges" and "negative outcomes" that are observed in families where the mother is living with HIV, and how maternal HIV infection and concomitant sequalae such as anxiety and depression impact women's capacities to parent and assume caregiving responsibilities (Armistead & Forehand, 1995; Kennedy et al., 2014; Murphy et al., 2010; Murphy, Armistead, Marelich, & Herbeck, 2015; Tompkins et al., 1999). A qualitative meta-synthesis found that motherhood both heightened and alleviated the physical and social effects of HIV (Sandelowski & Barroso, 2003). Becoming a mother intensified concerns related to HIV disclosure, HIV transmission to the newborn, HIV stigma and worry about the negative impacts of maternal HIV infection on children. However, becoming a mother was also a catalyst for women to take care of themselves in order to be available to their children (Sandelowski & Barroso, 2003).

An HIV diagnosis means that mothers have to contend with unique childbirth and infant feeding decisions and procedures during the perinatal period. Practice guidelines recommend that in addition to mothers taking cART throughout pregnancy, all newborns exposed to HIV receive six weeks of oral AZT to prevent perinatal transmission and undergo serial HIV testing up to 18 months postpartum (Bitnun et al., 2014; Money et al., 2014). Furthermore, as the risk of HIV transmission through the consumption of breast milk is currently assumed to not be zero based on available scientific evidence, and it is assumed that mothers living with HIV in Canada have access to clean drinking water and infant feeding alternatives, Canadian guidelines recommend that mothers living with HIV avoid breastfeeding (Bitnun et al., 2014; Money et al., 2014; WHO, 2016b). Infant feeding recommendations are communicated within socially constructed norms of "breast is best" and a discourse of what it means to be a "good" mother (Greene et al., 2015a; Hausman, 2011; Health Canada, 2013a, 2013b; Knaak, 2006; Wall, 2001). The unique practice guidelines for women and children affected by HIV, therefore, highlight important care and support considerations during the perinatal period, which Weir (2004) defines as the period from pregnancy to one month postpartum.

Some Canadian scholars have offered counter narratives to those that exist within biomedical and epidemiological literatures by highlighting the need for equity in reproductive healthcare for all pregnant women and mothers regardless of their HIV status (Loutfy, Sonnenberg-Schwan, Margolese, & Sherr, 2013), the

need for comprehensive and family-centered care that focuses on more than the mother's HIV status (DeMatteo, Wells, Goldie, & King, 2003), and the importance of motherhood amongst women living with HIV in Canada (Kennedy et al., 2014). Framing mothering with HIV in these ways is in line with how I have come to know HIV, pregnancy, and motherhood as a community-based researcher and through my involvement with feminist critical social science research that has centered on understanding the needs and experiences of pregnant women and mothers living with HIV in Ontario. The research to which I have contributed was developed in response to the widely held belief of women living with HIV, health and social service providers, and researchers that women living with HIV have unique experiences of pregnancy and motherhood that are different from mothers who do not have HIV. For example, as previously mentioned, there are unique procedures and medical treatments that women living with HIV are expected to follow in order to reduce HIV transmission during pregnancy, childbirth, and postpartum. Concerns have been raised about how these HIV-specific procedures may contribute to women experiencing differential treatment and/or feeling "othered" and "stigmatized" because of prejudicial views held by people working in health and social services.

I have had the privilege to sit with many women living with HIV who have participated in studies to which I have contributed and learn about the challenges, tensions, and roadblocks they have encountered when getting care for themselves as pregnant woman and their babies following childbirth. Women

have shared with me their stories about feeling misunderstood when trying to communicate with a variety of their healthcare providers, and their increasing interactions with the healthcare system during pregnancy and postpartum including appointments with HIV and obstetrical specialists, frequent ultrasounds, and blood work. Women have told me about when their HIV status was disclosed by healthcare providers to family members or friends to whom they did not intend to disclose, and how they were left to manage these disclosure situations with no recourse or follow-up with the healthcare providers who openly shared their HIV status. Women have identified the difficulties they have experienced and have called for changes to occur within healthcare institutions so that their care experiences can improve. The stories that women have shared have been showcased and critically examined in a number of critical feminist publications. For example, the HIV Mothering Study team that I was a part of illuminated valuable insights into women's interactions within healthcare, child welfare, and legal systems, and identified important themes related to infant feeding, HIV-related stigma in medical settings, and how women respond to mothering under surveillance vis-à-vis acts of distancing, planning, resisting and normalizing such surveillance (Greene et al., 2015a, 2015b, 2016, 2017; Ion et al., 2016; Khosla, Ion, & Greene, 2016).These scholarly outputs that outline women's experiences have shaped my own and others' thinking and ways of knowing about HIV in the context of pregnancy and motherhood.

An Opportunity to Ask New Questions Using Institutional Ethnography as a Research Strategy

Sinding (2010) reminds us that qualitative research makes "apparent the layered consequences of inclusion and exclusion as they unfold…[yet] studies often have not detailed the processes by which some women come to not have [relevant] care resources" (Sinding, 2010, p.1657). Although much social science research has examined, described, and categorized peoples' subjective experiences, this research has fallen short of explicating why and how these experiences come to be and how the systems that produce the conditions for such experiences actually work.

Qualitative research exploring the disparities encountered by women living with HIV in the healthcare system, including the literature cited above, has focused on women's narrative accounts. Research grounded in narrative, other interpretive qualitative traditions, and critical feminist paradigms are vitally important to raise awareness about women's experiences and elevate the voices and perspectives of mothers living with HIV. This research focused on HIV and motherhood, however, has not critically examined institutional work processes nor connected women's experiences to regimes of ruling and governance. Having heard about institutional ethnography while completing my MSc degree, I was becoming increasingly aware of the practical utility and distinct form of analytic description that was possible through institutional ethnography as a critical research strategy and method of inquiry. Rather than construct meanings or

theories from people's individual experiences, institutional ethnography focuses on an analytic description and mapping of organizational processes and social relations (Grace, 2019).

Given the lack of research in this area, as well as the lingering questions and concerns that I had after hearing women's accounts about their care experiences, I felt it was important to investigate the work and regulatory structures of healthcare providers to make visible how women's experiences are produced in the routine operation of perinatal health services (Sinding, 2010). I started to question whether there were particular policies or day-to-day practices that were creating gaps in care or producing certain conditions for women living with HIV during the perinatal period. The gap in published literature and lack of institutional ethnographic investigations into this particular topic were evident; the perinatal health systems that women living with HIV interact with had not been critically examined, nor had any investigations been conducted regarding if and how women's perinatal care experiences may be connected to institutional work processes and broader institutional arrangements.

Outlining the Contents of this Dissertation

This introductory chapter sought to outline and draw attention to specific ways that HIV is "known" and has been articulated in health and social science literature. Scholarly work by leading HIV institutional ethnographers who disrupt dominant narratives about HIV and bring into view the ruling relations that

underpin such ways of knowing was also reviewed. Of particular relevance to the present study is my desire to trouble the knowledges, assumptions, assertions, and ideologies that operate in literature and that were referenced and verbalized by, and/or activated in the work of, people working within HIV and perinatal services whom I interviewed for this research.

Elucidating the social organization of perinatal care for women living with HIV is the overarching goal that informs this institutional ethnographic inquiry. This thesis pays close attention to the experiences of women living with HIV who are seen within a particular healthcare institution for their HIV and maternity care in an attempt to make visible how and why the perinatal care they receive is socially organized. This thesis explores different aspects of this social organization, and is divided into multiple parts.

In the following Methods chapter (Chapter Two), I provide an overview of how I discovered and came to settle on institutional ethnography, the ontological and theoretical influences of institutional ethnography, and the methods that were employed in this project. Three academic journal manuscripts are then presented. Each manuscript begins from the experiences of women living with HIV who participated in this research and describe three "threads" of what I learned and discovered through this overall ethnographic inquiry (Chapters Three, Four, and Five). The Conclusion chapter (Chapter Six) summarizes the broad learnings that this thesis highlights. In particular, I draw attention to a critical tension that emerged across the three "threads" of inquiry related to HIV exceptionalism and

HIV normalization as dominant, organizing discourses. I review literatures about HIV exceptionalism and HIV normalization and discuss how these discourses emerged in healthcare practices to which women living with HIV were exposed and responded. I then outline some implications for practice and policy for the organization of perinatal care for women living with HIV in Canada.

In explicating the social organization of perinatal care for women living with HIV, I aim to make a connection between the lived realities of pregnant women and mothers living with HIV and the policies and regulatory frameworks that organize the various health and social services that women living with HIV utilize. In selecting institutional ethnography as my method of inquiry, I aim to identify possibilities to direct action and organizational change in ways that take seriously and amplify women's voices and experiences. For example, it was through institutional ethnography that the ideological discourses that coordinate maternity care practices and produce the conditions of women's care experiences became visible. Importantly, through tracking the territory of women's interactions with perinatal care services and healthcare providers' activities to deliver care, it can be revealed how the discourses of "risk" and "HIV exceptionalism" operate within healthcare institutions, and how health services could be organized in ways that respond to women's lived realities. It is through analytic description like institutional ethnography that justice-oriented practice can be facilitated in spaces where women living with HIV receive perinatal care and other forms of health and social supports.

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Chapter Two: Institutional Ethnography as a Method of Inquiry

Chapter Overview

In this chapter I provide an overview of my methodological approach and the study procedures that were employed, and situate myself in the work as the ethnographer. The chapter begins with a reflection about how I came to learn about and choose institutional ethnography as my critical research strategy. I then provide an overview of Dorothy Smith's scholarship of a sociology for people and institutional ethnography in order to theoretically ground my research, and outline orienting concepts that are particularly salient in institutional ethnographic inquiries. In theoretically grounding my research, I also recognize ethnographers whose work has significantly shaped my thinking and research development. I then provide a detailed account about my journey to becoming a researcher, and how through learning about institutional ethnography I developed an ontological orientation to "see" the social organization of everyday experiences and institutional practices. Through this reflection, I discuss moments that cemented my learning about and appreciation for institutional ethnography, and influenced my motivations to discover specific issues related to perinatal care for women living with HIV through this doctoral research. In the final section of this chapter I describe my dissertation study including my participant recruitment, data collection, analytic approach, and mapping processes.

I recognize that this methods section is long and provides more detail than may be typical for a dissertation chapter. I felt it was important to provide a

detailed review of Dorothy Smith's scholarship and the concepts that underpin institutional ethnography. Developing a foundation in Smith's work was critical for me to begin to fully understand how and why to conduct an institutional ethnographic inquiry, and to unlearn and shift my ways of thinking about conducting research. Keeping in view the tenets of Smith's alternative sociology for people and institutional ethnography as a research strategy has been important in my dissertation journey to not stray off course or to return to familiar territory of conducting research from a traditional sociological orientation or positivist paradigm. I wanted to include an overview of Smith's work alongside an overview of my development as a researcher and details about the approach taken for this dissertation project in order to draw connections between these things and show how I subsequently employed institutional ethnography.

Offering this level of detail is also about the challenges that I've encountered while unlearning and reorganizing my usual ways of thinking and doing including what I know about and how I do research. I believe this is a common experience for those of us who embark on doing institutional ethnography. Institutional ethnography is not prescriptive as a method of inquiry, and there are numerous studies and texts from which one can learn about what an institutional ethnography can entail. A "how-to" guide does not exist about what George Smith refers to as the "ontological shift" (G. Smith, 1990, p. 635) in coming to know a sociology for people and institutional ethnography. I did not know what this ontological shift might look or feel like. It was through the actual

doing of this inquiry, and reflecting back on my own journey, that I fully

appreciated the moments that were pivotal in my development, and that

subsequently influenced various stages of this project. I hope by offering this

personal account, and in such detail, that I might provide some motivation and

guidance to others embarking on similar investigative journeys.

A Sociology for People and Institutional Ethnography

Coming to Learn About and Choose Institutional Ethnography as a Method of

Inquiry

In 2009 while completing my MSc, I attended a seminar hosted by the Centre for

Health Economics and Policy Analysis (CHEPA, 2009). The seminar featured Dr.

Chris Sinding who was presenting a research paper titled "Qualitative Research

on Health Care Disparities: Contributions from Institutional Ethnography." This

was the first time I heard about institutional ethnography. What piqued my

interest during this seminar was the claim that attending to people's "work"

within institutional settings could enable researchers to discover how people on

the receiving end of care experience disparities and inequities as a result of the

organization of healthcare institutions and the routinization of healthcare

providers' practices. During Chris' presentation, I recall feeling excited about and

intellectually stimulated by the prospect of employing institutional ethnography to

make connections between people's troubles and challenges in the healthcare

system and the ways that care is organized and coordinated through the work of

healthcare providers. Chris also used an analogy of creating visible "threads" within and across institutional contexts; that is, institutional ethnography could be employed as a research strategy to "thread" together the experiences of individuals, work practices and the coordination of work, and regimes of ruling and governance. This analogy of "threading" together, and the prospect of using institutional ethnography to engage in research focused on health services, stayed with me. The idea that there was something connecting people's experiences on the receiving end of care with how care practices themselves were organized and coordinated was appealing. This approach illuminated a new way of examining health services, and provided a possible mechanism to identify tangible and concrete solutions to improve healthcare experiences of those navigating such systems.

My interest to conduct health services research related to women, HIV and maternity care, and my burgeoning curiosity about institutional ethnography, propelled me to commence doctoral studies. I eventually chose institutional ethnography as my theoretical and methodological approach to understand the social organization of perinatal care for women living with HIV, and to identify and describe the social relations that produce women's experiences. By beginning from the standpoint of women living with HIV, from the site of their own experience and the "ways in which [women] actually exist" (Smith, 1990, p. 200), and engaging in an iterative investigation of inquiry and discovery, I aimed to uncover the social processes that organize and produce local situations and reach

beyond the scope of any one individual and their local, everyday world (Smith, 1987). As I learned more about Dorothy Smith's scholarship, a sociology for people, and institutional ethnography, in particular its ontological origins and grounding in critical feminist scholarship and activist movements, the appeal to take on the role of an ethnographer, to track a particular territory, and to ground my doctoral research in this paradigm deepened. Institutional ethnography was selected as my method of inquiry because it begins from women's experiences, and can identify possibilities to direct action and organizational change in ways that take seriously and amplify women's voices and experiences. It is through analytic description like institutional ethnography that justice-oriented practice can be facilitated in spaces where women living with HIV receive perinatal care and other forms of health and social supports.

Ontological Assumptions and Theoretical Influences Underpinning Institutional Ethnography

Understanding institutional ethnography must begin with an understanding of the work of Canadian feminist sociologist Dorothy Smith – her history, her scholarship, and her motivations to develop a sociology for people and institutional ethnography as a research practice. Since the mid-1970s, Dorothy Smith has generated a scholarly canon (Smith, 1974, 1978, 1987, 1990, 1999, 2005, 2006) that outlines the ontological assumptions and theoretical influences of a sociology for people and institutional ethnography.

A number of theoretical traditions and scholars have shaped Dorothy Smith's scholarship including the work of George Herbert Mead, Harold Garfinkel, and Karl Marx (Campbell, 2003; Carroll, 2010; Smith, 1987, 2005). Marx's work was grounded in the activities of people under definite material conditions and insisted that individuals could not be detached from consciousness (Smith, 1987). Marx had a particular effect on Smith's development of a sociology for women and thinking about "a world that *actually happens* and can be observed, spoken of, and returned to check up on the accuracy of an account or whether a given version of it is faithful to how it actually works" (Smith, 1987, p.123).

Traditional Sociology and the Standpoint of Women

Dorothy Smith's early work (Smith, 1974, 1978a, 1987, 1992) called for a shift in focus of sociological inquiry to begin from women's experience or standpoint. For Smith, women's standpoint invites us as researchers and sociologists to reimagine and reconstruct sociological inquiry to focus on real people who are affected or implicated in the research, to keep these people in view throughout the inquiry as active and experiencing subjects, and to preserve their presence as knowers and actors (Smith, 1987). Women's standpoint begins from an embodied subject who is located in a particular setting and in the particularities of their experience (Smith, 1987), which is a contradictory perspective from that of traditional sociology and other paradigms that are situated within and prioritize

objectified forms of knowledge (Smith, 1990). Sociology as a discipline has nurtured the development of vocabularies, concepts, theories, and ideologies that present an objective and one-sided version of knowing that is disconnected from a local context (Smith, 1987). As women, Smith (1987) reminds us that we are in our bodies; we do not inhabit an imaginary space that was constituted by a sociological mode of inquiry even if from time to time we participate in or take for granted the ruling relations that organize our lives (Smith, 1987). It is returning to that embodied experience, the doings of actual people situated in particular sites at particular times, that Smith encourages as part of her scholarly project.

Women's standpoint was a particularly salient starting point for Smith given her own experience of juggling graduate school and academic life with her life at home as a mother and caregiver. Each time she moved between academia and her experience as a caregiver, Smith crossed a chasm of knowing and confronted a bifurcation or rupture of her consciousness (Smith, 1974, 1987, 1990; G. Smith, 1990). While operating in these two very different worlds, Smith experienced different ways of knowing. One world was located in her body and arose from her direct, lived experiences including the daily practical tasks of housekeeping and childrearing (Smith, 1974, 1990). The other world was abstract, heady, and conceptual; it included the activities of research and university administration and was disconnected from thoughts, emotions, and embodied experiences (Smith, 1974, 1990). In this abstracted world, knowing constituted

factual accounts of externalized and objectified relations (Smith, 1990). It was through this bifurcated consciousness that Smith considered the social relations between men and women, deepened her critique of sociology, as well as her conviction of starting sociological inquiry from the standpoint of women.

What is significant about Smith's work, and has motivated me in conducting my own research, is its contributions to feminist scholarship, elevating women's voices, and critiquing traditional sociological approaches. For Smith, "taking the standpoint of women transformed how we thought and worked…almost every aspect of our lives…Women's experience of oppression, whatever its form and focus, was grounded in male control, use, domination of our bodies…When we begin with our experiences as women, however, we were always returning to ourselves and to each other as subjects *in our bodies*" (Smith, 1992, p. 89). Smith's efforts to craft and articulate a sociology for women was deeply connected to her identity as a feminist; she believed that women needed to recreate their relations with others and to re-establish women's experience as a legitimate form of knowledge that could contribute to alleviating women's oppression (Smith, 1987). Smith recognized sociology as a discipline created by and fostered in a man's world and concluded that the sociological methods, conceptual schemes, and theories that she was being taught during her training in sociology were based on and built up within the male social universe (Smith, 1974). Smith's writing has been significant for my own research and how I think about the production of inequities for women living with HIV as operating

through the domination and control of women's bodies that occurs in a male-dominated society. Smith's work has also provided me with a framework to think about how women's knowledges and embodied experiences can be responded to and women's oppression can be disrupted vis-à-vis how health and social services are delivered.

Women's Exclusion

Smith's extensive writing about the dominance of men and women's exclusion from the work of administration, government, and management (Smith, 1978) has given shape to my own research about women living with HIV. Smith's observations within academic spaces shaped her thinking about how women become positioned as marginal voices by having language and concepts imposed on them by men (Smith, 1974, 1987, 1990). Smith argues that women become conditioned to think about their world in these terms, and that we take for granted the language that justifies women's subordination, dependency, and governance by men and thereby live in a discourse not of our making (Smith, 1987). These are concerns that synergize with how I have come to know the experiences of women living with HIV, in particular the exclusion and subordination of pregnant women and mothers living with HIV in various health and social service spaces. As Smith asserts, not only have women been deprived of the means to participate in creating ways of knowing and thinking to express their own experience or to define and raise social consciousness about their situation and concerns (Smith,

1978), they have also been excluded from the making of ideology and culture that informs ruling organizations and discourses (Smith, 1987). I believe that this is the case for women living with HIV whereby the manufacturing of society and culture has occurred vis-à-vis men in positions of power and dominance, and in the absence, or silence, of many groups of people (Smith, 1978) resulting in routine, generalized and effective repression, including of women living with HIV (Smith, 1978, 1987).

It is Smith's writing about women's exclusion that has been particularly inspiring for me, and has given shape to my research. First, beginning an inquiry from the standpoint of women is something I strongly resonate with given my history of conducting research with women living with HIV and grounding my analysis and recommendations for practice in women's actualities (Smith, 1987). Second, the ontological orientation of women's exclusion provides a particular motivation and philosophical grounding to critically examine the silencing and objectification of women living with HIV who are navigating maternity care. The result of the silencing and objectification of women living with HIV is that they end up living in and navigating a discourse in which their local experiences, bodily realities, and knowledges do not become recognized or integrated. Third, I am interested to understand how the actions that women take to participate in their care occur as a result of the social organization of their maternity care. Importantly, Smith notes that the work that women do as part of institutional and social processes is essential to sustaining regimes of ruling and women's

repression (Smith, 1987), and an important aspect of my research is to uncover the nature of the inequities and disparities that women face. As Smith states, "the institutions which lock sociology into the structures occupied by men are the same institutions which lock women into the situations in which they find themselves oppressed" (Smith, 1974, p. 8). Through this study I attempt to disrupt the traditional sociological orientation and provide a counter narrative grounded in a sociology for women that illuminates how women's troubles and challenges are produced through institutional conditions.

Ruling Relations

An important orienting concept in Smith's sociology for people is ruling relations (Smith, 1974, 1978, 1990). Smith argues that women's exclusion from the creation of knowledge was born out of "ordinary social processes of socialization, education, work and communication" (Smith, 1987, p. 26). These processes are the socially organized activities that we enter into and participate in as part of the complex of organized practices that direct and regulate institutions and society (Smith, 1974, 1987, 1999). Smith asserts that the ruling relations are the discursive, managerial, and professional forms of governance and intelligentsia that organize society and our lives (Smith, 1987, 1990, 1999), and argues that we all participate in ruling relations as part of our work – as individuals, as employees within institutional and organizational settings, and as actors who engage with texts (Smith, 1999). Moreover, we all play a role in taking up ruling

concepts, discourses, and ideologies in our daily activities because we live in a knowledge-based society that relies on "authorized versions of knowledge" including knowledge routinely generated by sociologists, psychologists, and others in the intelligentsia (Campbell, 2003; Smith, 1978b). It is these ruling discourses and relations that I sought to explicate through this inquiry, in particular the ruling relations that organize the work of healthcare providers operating within HIV and maternity care services, and the work of women living with HIV as they interact with these services.

The Everyday World as Problematic and Institutional Ethnography

Institutional ethnography transforms Smith's sociology for women into a research strategy, and aims to explicate the connection between people's everyday worlds and how their lives are organized and coordinated by social relations that extend beyond them as individuals (Campbell & Gregor, 2008; McCoy, 2006; Smith, 1987, 1990, 1999). The inquiry is organized around an actual property of the everyday world as it arises for those who live it in their local contexts (Smith, 1987), for example, women living with HIV as they navigate care within specific clinical settings during pregnancy, childbirth, and early motherhood. The standpoint that forms the basis for an institutional ethnographic inquiry recognizes a disjuncture or tension between different ways of knowing and experiencing, for example, knowing from a ruling or experiential standpoint (Campbell & Gregor, 2008). The inquiry then focuses on how and why the troubles of the particular

individual or group are connected to and organized by institutional arrangements (Campbell & Gregor, 2008; Smith, 1987; Walby, 2007). Specificity is critical in an institutional ethnographic inquiry; an actual, material world is assumed and a single view or narrative of that world is rejected, recognizing that the everyday world looks different from different locations, standpoints, and ways of knowing (DeVault, 1999).

The Research Problematic

Moving from the everyday world of direct experience to the larger socially organized context in which that experience is embedded requires defining the research problematic. A problematic is not a problem that needs to be understood in the way that an individual study participant explains it (Campbell & Gregor, 2008). A research problematic is the conceptual apparatus that explicates an actual property or feature of the everyday world that has been lived and practiced (Campbell & Gregor, 2008; Smith, 1987). The research problematic directs attention to a "possible set of questions…or a set of puzzles…that are 'latent' in the actualities of the experienced world" that can become the focus of an ethnographic inquiry (Smith, 1987, p. 91). The research problematic is the starting place of an institutional ethnographic inquiry; it is a point of disjuncture in the relationship between the subject, and her embodied, lived experiences, and a "systematic knowledge of the social relations of her society," which are connected to power, organization, and regulation (Smith, 1987, p. 98). This disjuncture is the

anchor from which the ethnographer can uncover how certain conditions and experiences that occur within a local setting are produced and are connected to a broader context. Although an ethnographic inquiry begins from a place where social organization can be observed, the process to investigate how the practice and relations of this social organization actually work is open-ended and does not follow a particular sequence of activities or prescriptive approach (Campbell & Gregor, 2008; Smith, 1987). During the course of the investigation, the ethnographer keeps in view the standpoint of those who experienced the tension or challenge in their everyday world (Campbell & Gregor, 2008).

The Orienting Concept of "Work" in Institutional Ethnography

Institutional ethnography foregrounds the intentional, everyday work that people (for example, service users, service providers, administrators, policy makers, etc.) do that involves time, effort, skill, space, material conditions, and situational contexts (DeVault, 2006; Hussey, 2012; Smith, 2005). Smith encourages ethnographers to take a generous and expansive conceptualization of "work" to remain open to different forms and categories of work (Smith, 1987), including the various ways that women living with HIV interact with healthcare systems and providers, and are served, looked after, and worked on by people operating within healthcare institutions. Work is an orienting concept in institutional ethnography because the social "reality" of institutional ethnography is that people are actively involved in and cannot be detached from "actualities," which

includes their work, actions, and doings; and it is through an ethnographic inquiry that these "actualities" can be made visible (Smith, 2005). Importantly, institutional ethnography uncovers textually-mediated social organization (Campbell, 2003; DeVault & McCoy, 2006; Smith, 1987). Texts are an important "primary medium of power" (Smith, 1987, p.17) as they guide the organizational processes inherent within the ruling relations and uncover how work is coordinated and why people do the things they do within healthcare settings (Sinding, 2010; Smith, 1999). Texts are integral to people's work and explicating the work activities of people operating within institutional complexes; and Smith encourages us to think about texts as a component of someone's work and how they connect work activities through work-text-work and text-work-text sequences of action (Smith, 2005).

Aims and Possibilities with Institutional Ethnography for Health Services Research

Through its application in health services research, institutional ethnography can be employed to map the production of healthcare disparities (Sinding, 2010) and uncover the "multiple activities of individuals, organizations, professional associations, agencies and the discourses they produce and circulate – that are organized around a particular function such as healthcare" (Mykhalovskiy & McCoy, 2002, p. 19).

An institutional ethnographic inquiry does not test a pre-determined agenda or hypothesis, or advance pre-existing theoretical or ideological concepts (Campbell & Gregor, 2008; DeVault, 1999; G. Smith, 1990; Smith, 2005). For example, George Smith's inquiry into policing was not aimed at expanding theoretical understandings of policing, such as moral panic theory, but rather at making visible and problematizing how the policing of gay men actually works (G. Smith, 1988, 1990). George Smith's work demonstrated that addressing the "problem of police harassment" required legal reform to change the *Criminal Code*, which was the governing text that organized the work of police officers (Smith, 1988, p. 180).

George Smith reminds us that the capabilities of institutional ethnography extend well beyond the women's movement and that this approach can be employed by any individual or group positioned outside of the political, administrative and managerial regimes of ruling (G. Smith, 1990). Dorothy Smith's alternative sociology has evolved over time as Smith has acknowledged to not confine standpoint to a particular group or perspective (Smith, 2005). In fact, Smith and others have expanded a sociology for women and institutional ethnographic inquiry to include any subjects who "disappear" in objectified knowledges (Walby, 2007, p.1011). For example, sociologists employing institutional ethnography have begun their inquiries from multiple perspectives and places of knowing including various healthcare provider groups working on the frontlines of care delivery in a variety of institutional spaces (Campbell, 1998,

2001; Melon, White, & Rankin, 2013; Quinlan, 2009; Rankin, 2015; Rankin & Campbell, 2009). Importantly, institutional ethnography has been used extensively by researchers to explicate the ruling relations that organize the everyday worlds of people living with HIV (Bisaillon, 2011; Grace, 2015, 2019; G. Smith, 1990, 1995), including topics that are highly relevant to the present study such as their work to interact with doctors (Bresalier et al., 2002; McCoy, 2005) and take up biomedical treatments (McCoy, 2009; Mykhalovskiy, 2008; Mykhalovskiy, McCoy, & Bresalier, 2004).

Institutional ethnographers can begin from any local setting or particular event and arrive at a descriptive matrix of the generalized and generalizable text-mediated social relations that we are all caught up in (G. Smith, 1990). Institutional work processes are rarely critically examined in health services research; however, investigating regulatory structures of healthcare professionals is an important step to understand service user experiences, and determine how systems could be organized differently to enhance the end-user experience (Sinding, 2010), which is what this particular study sought to do as it relates to pregnant women and mothers living with HIV.

Contributions from Institutional Ethnographers

In addition to the work of Dorothy Smith, my doctoral research has been influenced by numerous scholars who have employed institutional ethnography to explicate the social organization of knowledge. Researchers who have utilized

institutional ethnography in projects that begin from the standpoint of people interacting with health and social services such as people living with HIV and women facing intimate partner violence have shaped my thinking about what kinds of socially organized knowledges can be explicated and problematized, as well as the practical utility of institutional ethnography to shift work practices.

Ellen Pence's research about the work of people operating within the criminal justice system was significant for my learning that institutional ethnography could offer concrete solutions to strengthen policies and practices. Pence's (2001) study showed how the organization of work within the institutional context of criminal justice produced accounts of women's experiences that erased the violence and intimidation they faced in their intimate relationships, and did not prioritize "victim" safety in existing documentation practices. The framework of the "safety audit" that arose from Pence's work to systematically investigate "problematic legal processes" has become a standard approach for examining domestic violence cases in multiple states across the United States (Pence, 2001, p. 226; Praxis International, n.d.).

Other researchers have analytically described and contributed to the study of illness experience (McCoy, 2005, 2009; Miller, 2005; Mykhalovskiy, 2008) and have made visible the ruling relations and discourses that operate and coordinate work within healthcare settings and other sectors in which people living with HIV interface (Bisaillon, 2011; Grace, 2015, 2019; Melon, White, & Rankin 2013; Mykhalovskiy, McCoy, Bresalier 2004; Rankin, 2015). These

institutional ethnographic inquiries have been important for me to see how this critical research strategy can reveal how disparities and inequities are produced for individuals through the routine organization of care.

I have also looked to institutional ethnographers to understand how this method of inquiry can offer pragmatic solutions for practice and policy. As George Smith stated, the "type of analysis [that's possible with institutional ethnography] is especially useful for providing a groundwork for grass-roots political action, not only because, as a matter of method, it begins from the standpoint of those outside ruling regimes, but because its analysis is directed at empirically determining how such regimes work" (G. Smith, 1995, p. 20). George Smith was highly influential in showing how institutional ethnographic inquiries could provide a scientific ground for political action; his political activist ethnography was instrumental in stimulating federal policy changes to the Emergency Drug Release Program to include new experimental treatments for HIV (G. Smith, 1995).

Eric Mykhalovskiy's work as part of the Making Care Visible project (Bresalier et al., 2002; Mykhalovskiy, McCoy, & Bresalier, 2004; Mykhalovskiy, 2008) is also directly relevant to my own research interests in women, HIV, and perinatal care, and highlights the mediating role of community-based HIV service organizations to bridge the gap between lay and medical knowledge. Mykhalovskiy (2008) describes the important role of community-based organizations to create space where medical and scientific knowledge can be

translated into accessible formats for people living with HIV, and where people living with HIV can meet to share their experiences related to their "healthwork" to engage in HIV care and to take HIV medications. In doing so, Mykhalovskiy "problematize[s] the institutional relations of biomedical knowledge" (Mykhalovskiy, 2008, p. 155) and offers important experiential accounts for health and social care providers to consider in relationship to their individual practices and institutional policies and procedures. As other scholars have highlighted, institutional ethnography has the potential to "guide action" by offering people operating in healthcare settings an "intellectually reliable way to 'talk back' to the objectified forms of health care knowledge being authorized by…[for example,] the evidence-based practice and 'outcome measures' through which hospital efficiency is managed" (Rankin & Campbell, 2009, p. 2). Just as George Smith's inquiry into policing revealed that legal reform was a key ingredient to solve the challenge of police harassment (G. Smith, 1988), institutional ethnographers have employed this strategy to identify "levers" or targets for activism, political engagement, and systems-level change (Campbell & Gregor, 2008; DeVault & McCoy, 2006; Hussey, 2012; Mykhalovskiy & McCoy, 2002). A unique feature of institutional ethnography is that it can provide "analytic help for activists in thinking about and *determining an effective direction for activism*" rather than activists using research as a way to "support a direction they are taking and to provide evidence favouring their side of an argument or struggle" (Campbell, 2006, p. 87). The explicative map or detailed

description of how an institutional complex actually works and how actors within the institution are connected through social relations can then be acted upon by those leading activist efforts (Campbell, 2003); at the heart of institutional ethnographic projects is to work towards a more socially just world and equitable society (Campbell, 2003; Campbell & Gregor, 2002; Grace, 2019).

My Standpoint and Defining Moments: Laying the Groundwork for this Inquiry

Through multiple conversations with Dorothy Smith and Susan Turner as part of institutional ethnography workshops at the Ontario Institute for Studies in Education (OISE), I have learned about the importance of reflecting upon my own location and positioning as an ethnographer. I acknowledge the ontological perspective and advocacy interests I bring to this research about women and HIV. I also recognize that my ontological stance has guided what I chose to focus on for this research, as well as what practice and policy recommendations I suggested related to the specific social relations that are operating in the everyday lives of women and are coordinating the work of healthcare providers. As I reflect upon Dorothy Smith's scholarship, the contributions of other institutional ethnographers, and what outcomes are possible with a research strategy such as institutional ethnography, I have come to appreciate how my personal trajectory of contributing to community-based HIV organizations and research have given shape to this doctoral research.

In discussing my journey in community development, my contributions to specific research projects, and defining moments that have catalyzed my interest to conduct an institutional ethnographic inquiry, I aim to situate myself in the research. I do this in order to demonstrate my historical connection to the present study in both biographical and epistemological terms. In keeping with the commitments of institutional ethnography, I also outline specific moments during my time with the HIV Mothering Study that facilitated my ontological and epistemological shift to understand social relations and the value of employing institutional ethnography to explicate the social organization of knowledge, and specifically the social organization of perinatal care for women living with HIV.

Finding a Foundation in HIV Community Development Work

HIV first came to my attention in high school as a biomedical issue. When I began my Bachelor of Science (BSc) degree at McGill University in 2001, I began to understand HIV as a health condition that had medical, social, psychological, and economic implications; and rather than learn about HIV solely through a textbook, I was interested to know more about how HIV actually affected people's lives. I chose to volunteer with the education department at an HIV service organization in Montreal and was involved in delivering workshops and presentations to youth about HIV transmission, prevention, general sexual health, and relationships. As an undergraduate student, I was also involved in advocacy to increase availability of generic HIV medications in resource-limited

countries. It was exhilarating to be a part of a mobilized student body and lobby for legislative change that had the potential to positively and significantly affect health and social outcomes. My BSc degree equipped me with scientific knowledge about HIV as a molecular, biological, and clinical phenomenon including how the virus is transmitted, affects people's immune systems, and is treated with medication. Through volunteering at the HIV service organization I came to hear directly from people living with and affected by HIV and the social and personal challenges they encountered because of their HIV-positive status.

After my BSc, I worked at non-profit health organizations including an HIV service organization in Waterloo Region. I was responsible for delivering educational workshops and awareness campaigns to increase knowledge and understanding about HIV in the surrounding community, and I partnered with people living with HIV and other community-based service providers to deliver these programs. One component of coordinating the community education program involved showcasing the unique experiences of women living with HIV including issues pertaining to pregnancy and motherhood, biological vulnerability to HIV infection, gender-based violence, and power and economic dependency in relationships. Throughout my BSc and as I began working in community-based organizations, I developed an appreciation for community development and how collaborative partnerships between different stakeholders can support and advance a cause. My tendency to act in the name of human rights was cemented during these formative years. During this time, I learned about some of the inequities that

people living with and affected by HIV face such as poverty, social exclusion, and discrimination, and how these experiences impacted their interactions within particular systems and institutions. Healthcare, social services, and the immigration system figured prominently as spaces where the marginalization of women living with HIV occurred, and this fueled my concern about the societal injustices that people living with HIV encounter in their daily lives. I was also inspired by the resilience and strength of the people living with HIV with whom I was working despite the struggles, challenges, and adversity they were facing. Because I was responsible for coordinating a program focused on women, advocating for the sexual and reproductive rights of women living with HIV became an important orienting philosophy for me as a community educator, and subsequently as a researcher.

These years of volunteering and working in community organizations were significant in my coming to know about the experiences of people living with HIV. It was through these experiences that I developed an appreciation for the value and importance of partnering with women living with HIV in community education initiatives, and grounding community work in the needs and priorities of women living with HIV. These experiences also reinforced my commitments to being an ally and advocate for women living with HIV as it relates to their access to healthcare, and identifying concrete strategies and approaches to ensure women have positive interactions with healthcare providers.

My Connection to Research about Women and HIV

The decision to complete a MSc was catalyzed by my work as a community educator and the expectation to evaluate the programs I was coordinating. Completing a Health Research Methodology program gave me the necessary knowledge and skills to conduct research. However, my orientation to conducting research and generating knowledge was grounded in a positivist paradigm and epistemology. My MSc program engrained a way of thinking about "evidence" and the role of literatures to understand "truth." I learned to conceptualize research from an abstract, theoretical place, and with a rationale grounded in specific literatures, rather than beginning a research inquiry from people's material actualities and everyday worlds.

Around the same time, I began working as a research coordinator in the Special Immunology Services (or SIS) clinic in the McMaster University Medical Centre (MUMC). The SIS clinic is a regional HIV clinic that serves a wide geographical catchment area in southwestern Ontario, and I was responsible for coordinating a community-based research study investigating a peer support program for women living with HIV. By this time I had formed relationships with people living with HIV and understood how an HIV diagnosis could influence someone's life in terms of their frequent and sometimes negative interactions with the healthcare system, their relationships with family members, seeking and receiving social support, engaging in their wider community, and their relationship with their own bodies. It was also at this time that my training in

positivist approaches to conceptualize and conduct research was challenged. Through my burgeoning involvement in community-based research, and working alongside community activists and community-based researchers, I began to link my background in community development with the tenets of participatory action research. I also began to see the important connections between the community movements of "nothing about us without us," and specifically the greater involvement of people living with HIV/AIDS (or GIPA), and feminist women's health social movements, and how research projects were imagined and realized. I came to believe that the involvement of people living with HIV in the research process was paramount, and I adopted the principles of community-based participatory research to engage in HIV research with and for people living with HIV.

I continued working as a research coordinator and in 2011 became involved in the HIV Mothering Study. I was responsible for implementing and facilitating this longitudinal mixed methods study in HIV and obstetrical health services across Ontario where women living with HIV accessed their care including the SIS clinic within the MUMC. The goal of the HIV Mothering Study was to develop a deeper understanding of the psychosocial experiences and needs of women living with HIV in Ontario during pregnancy and the first year of motherhood. During my involvement in this project, I became well-versed in literatures pertaining to HIV and motherhood. Importantly, I also learned directly from women themselves about the range of concerns, challenges, troubles, and

worries they faced and the multiple practicalities involved in participating in their care including traveling distances, taking time off work, and arranging childcare. The HIV Mothering Study team illuminated valuable insights into women's interactions within healthcare, child welfare, and legal systems, and identified important themes related to infant feeding, HIV-related stigma in medical settings, and how women respond to mothering under surveillance vis-à-vis acts of distancing, planning, resisting, and normalizing such surveillance (Greene et al., 2015b, 2017). These learnings formed the basis of many scholarly outputs (Greene et al., 2015a, 2015b, 2016, 2017; Ion et al., 2016; Khosla, Ion, & Greene, 2016) and were highly influential in developing my "knowing" as an HIV researcher and ally, and my subsequent doctoral research.

As earlier mentioned, I first became exposed to institutional ethnography around 2009 through the CHEPA seminar. Although I attribute my significant learning about institutional ethnography to my doctoral studies that began in 2014, and specifically my comprehensive exam and the OISE courses I completed with Dorothy and Susan, I began to appreciate the value and application of institutional ethnography as part of health services research while working as the HIV Mothering Study research coordinator. I gleaned important insights from the texts and studies I read during this time (Campbell, 1998; Grahame, 1998; McCoy, 2005; Sinding, 2010; Smith, 1987, 2005), which helped me to think about my own research interests and how I might employ institutional ethnography. It was also in reading these scholars that I began to shift my thinking. Rather than

take for granted the ways that I had come to "know" and understand HIV, I developed an appreciation for and learned to "see" how different and competing social relations influenced and organized my consciousness, and were built into my everyday world (Campbell, 2016; Smith, 1990).

Through my multiple interactions with mothers living with HIV and healthcare providers within MUMC as part of the HIV Mothering Study, I began to see a problem that warranted examination, that is, to describe how and why the conditions were created in which women living with HIV could experience troubles while interacting with and receiving maternity care. I thought that there would be tremendous benefit to explore how institutional arrangements were contributing to the kinds of experiences I was hearing about through the HIV Mothering Study and other research focused on women and HIV, and began to think about the possibilities for how institutional ethnography could be applied to conduct this investigation.

Defining Moments that Catalyzed My Interest to Conduct an Institutional Ethnography about the Social Organization of Perinatal Care of Women Living with HIV

During my time with the HIV Mothering Study, there were numerous moments that were particularly informative and helped to crystallize my interest to explore how women's experiences were connected to and organized by institutional arrangements such as the routinized practices within healthcare settings

(Campbell & Gregor, 2008; Smith, 1987; Walby, 2007). There were two factors in particular that shaped the development of this thesis including: i) noticing a disconnect between women's and healthcare provider's perceptions and ways of knowing about HIV; and iii) witnessing a scenario with one HIV Mothering Study participant and the emphasis on her HIV viral load to guide her care and shape her care trajectory.

Noticing Disconnections: Women and their Healthcare Providers "Know" HIV Infection Differently

As the HIV Mothering Study coordinator, I was responsible for collecting data where I met face-to-face with women as they attended routine clinic appointments in the SIS clinic, reviewed and extracted information from women's charts, and attended team meetings (or "rounds") at the end of each SIS clinic day to hear team assessments and issues for follow-through for each client who was seen. It was through these mechanisms that I observed the inner workings of the delivery of care to women living with HIV within the SIS clinic and became increasingly aware of how the regional hospital in which women received their HIV and maternity care was organized and coordinated. I witnessed the work practices of specific healthcare providers, and the technological and textual infrastructure that facilitated such work practices. I became intimately familiar with the systems of communication and electronic health records that were used to track, document, and advance both the care provided to women living with HIV and the work of

healthcare providers who were based within the SIS clinic. I also learned about, and was myself accountable to, regulatory and institutional frames that were operating in the hospital that employees were expected to follow, for example, related to research ethics, maintaining privacy and confidentiality of people receiving care within the SIS clinic, and being introduced to potential study participants vis-à-vis their clinical "circle of care." Exposure to these institutional elements not only opened my eyes to how people working in healthcare go about their work and how healthcare institutions operate, but also stimulated questions about what policies, routinized daily practices, and institutional arrangements may be creating the conditions for the types of experiences that women expressed during the HIV Mothering Study.

For example, meeting with study participants, I observed a disconnect between what women were sharing about their care "experiences" and how healthcare administrators, managers, and providers talked about HIV. There was a disjuncture between women living with HIV and those who provided healthcare to women whereby "HIV infection" was understood in different ways, and these different groups came from different places of knowing, experiencing, and understanding "HIV infection."

Working within the SIS clinic, I also began to see how women living with HIV were identified as part of institutional practices and texts, and how this representation was different from how women identified themselves and expressed their identities and experiences. For example, organizationally, an HIV

diagnosis is information that is used to hook women into the healthcare system by determining the type of healthcare they receive, the type of healthcare provider or specialist they interact with, and the health services for which they are "eligible." I learned that the particular system of services, healthcare providers, and physical spaces that pregnant women living with HIV interact with varies across geographic regions, is dependent on what services are available in the region, and what funding has been allocated to support HIV-specific services.

In my position within the SIS clinic I also learned about a routine process that became vitally important in my dissertation study: when women living with HIV become pregnant, they are automatically referred to the specialist "high-risk" obstetrical clinic within the MUMC known as the Maternal Fetal Medicine (or MFM) clinic. In the MFM clinic, obstetricians with training in "high-risk" pregnancies practice alongside a multidisciplinary team that also includes nurses and social workers. It is in this clinic where women living with HIV are seen for the duration of their pregnancies, and they plan to deliver their babies in the MUMC with the support of the specialist obstetricians who work in the MFM clinic. Referring pregnant women to the MFM clinic is a longstanding practice within the SIS clinic, and understanding the landscape of care that pregnant women and new mothers living with HIV interface has been a critical aspect of this inquiry. Importantly, what I have come to appreciate through this inquiry is that organizing care in this way has particular implications for women's

experiences of pregnancy, childbirth, and the early postpartum period, as is outlined in Chapter Five.

As I became familiar with the institutional complex in which women living with HIV receive care, I learned the medical jargon and institutional language used within these spaces and as part of the institutional processes to provide care to women. For example, clinicians in the SIS clinic often referred to people living with HIV as "patients" and were focused on medication "regimens," "adherence to antiretroviral therapy," viral load suppression, clinical "markers" of the CD4 count and HIV viral load, and the use of these clinical markers to determine "effectiveness" of HIV treatment. This language and jargon could be heard in team conversations and as part of dialogue between healthcare providers in the SIS clinic, and it is language I became accustomed to while navigating medical records and interacting with the SIS clinic team during rounds. I have subsequently learned through my orientation to institutional ethnography that I was gaining familiarity with discourses of the institutional complex (Smith, 2005). In these clinical spaces, research about specific treatments was often discussed, and the discourse of HIV as a chronic health condition if effectively treated with medications was regularly acknowledged in dialogue between clinic team members. "Patients" were understood as bodies using health services, and bodies supplying information to understand treatment effectiveness vis-à-vis blood tests and other biological markers. Bodies were also counted to justify funding to different health services, to ascertain which "populations" were

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receiving care within the institution, and to enable surveillance and monitoring of the SIS clinic population.

As part of my research coordination work, I learned how to navigate the medical record system, which includes an electronic and hard-copy "chart." In an institutional ethnographic framework, the medical record is a text that reveals how women's bodies and their HIV-positive status are known institutionally. For example, it is through notes dictated by their healthcare providers, through prescriptions and orders for specific treatments, and through blood tests, specifically their HIV viral loads and their CD4 cell counts, that women's bodies and their HIV-positive status are visible and become known. Requisitions are produced to order these blood tests and then clinical test results (in the electronic record and in hard-copy format) are generated to communicate the results to nurses, pharmacists, HIV specialists, and obstetricians. Test results, dictated notes, and prescriptions direct the activities of various healthcare providers operating within this regional hospital. For example, dictated notes recommended actionable next steps for the person to whom it was addressed, and prescriptions activated pharmacists to fill and dispense medications. Although I did not acquire this understanding until becoming more versed in institutional ethnography, it was clear that these institutional texts mediated relations between providers, and activated the work of various healthcare providers within this institutional setting.

Throughout the duration of my doctoral research, it has been important for me to reflect upon the language and jargon that I have come to know being based

within the SIS clinic and that I use as a researcher. Moreover, in developing an understanding of Dorothy Smith's scholarship and institutional ethnography, I have become more attuned to the language used by healthcare providers. I have garnered an appreciation for how language provides clues to determining how healthcare providers' work is connected organizationally to certain texts and the work activities of others based within the institutional setting. I have also become more attuned to people's language and jargon to make sense of and direct my attention towards what institutional discourses, and meta-level generalized and generalizing ideological discourses, may be operating within and coordinating their work practices (Smith, 2005).

Drawing together my experience working in the SIS clinic and reading institutional ethnography scholarship, I came to see how the routinized work practices of healthcare providers delivering care are based on objectified forms of knowledge where women's bodies are reduced to lab requisitions, medical charts, and notes that have been dictated by their healthcare providers. The healthcare providers who deliver care to women may practice with the best of intentions and do their best to meet the needs of women and their babies, however, the organization of healthcare is such that objectified and abstract forms of knowledge are what directs and coordinates care. The consequence of this is that women's bodies and experiences, and what matters to women in their everyday worlds, are rendered invisible (Smith, 1992). It is women's standpoints that I aim to amplify through this inquiry as a form of consciousness-raising and to reveal

the social matrices of women's experiences (Campbell, 2003; DeVault, 1999; Smith 1987).

Tanya's "Viral Load"

As noted at the beginning of this Methods chapter, novice institutional ethnographers can find it difficult to make the "ontological shift" to a sociology for people. In this section I offer an extended reflection about a situation involving an HIV Mothering Study participant that was significantly formative in my intellectual journey. I do this to show how informants' stories can become defining moments in understanding an institutional complex. The story of Tanya's viral load contributed to my "ontological shift" where I moved from a theorization and abstraction of the social to actually being able to "see" the everyday world as it is constituted in the actions and practices of individuals (G. Smith, 1990, p. 635). I describe how I drew on this new "seeing" to orient my dissertation study, and reflect on the significance of institutional ethnography in doing social justice-oriented projects.

For the HIV Mothering Study, our team relied on laboratory results, discharge summaries, and clinic notes dictated by multiple healthcare providers to obtain the data we were interested in, and to keep track of a women's clinical trajectory during pregnancy, at the time of childbirth, and early postpartum. While extracting information from women's charts I learned that any notes that healthcare providers dictate are automatically uploaded to the medical record

system following dictation. Laboratory results, on the other hand, take more time to be uploaded depending on the time it takes to process the person's blood work, run the laboratory test, and send the results back to the institution. For example, an HIV viral load test is conducted by a provincial laboratory and can take up to seven business days to appear in the chart after the blood has been drawn from the pregnant woman.

One day I was collecting information from the medical record of a participant given the pseudonym Tanya. A resident in obstetrics had dictated a discharge summary of the care Tanya received leading up to, during, and immediately following childbirth. The resident noted that Tanya had not gone to get her blood work done immediately prior to her delivery as there was no HIV viral load recorded in the chart at the time of dictation; the resident also implied that Tanya had not followed her physician's orders to complete her blood work, and as such information was missing from her chart to direct care for Tanya and her baby.

I discovered the information stated by the resident to be false. Tanya had gone for blood work, and an HIV viral load result had been uploaded into her medical record the day after her delivery, which was also the day after the resident dictated her note. Furthermore, Tanya had gone for blood work multiple times leading up to her delivery, and the multiple test results showed an undetectable HIV viral load coinciding with adhering to her treatment and reducing the likelihood of perinatal HIV transmission.

Importantly, the information in Tanya's chart had significant implications for her care at childbirth. The HIV viral load is an important marker of the effectiveness of HIV treatment, and the test result directs the decision-making of multiple members of a healthcare team at the time of childbirth including how the baby will be delivered (i.e. vaginal vs. Caesarian section delivery), what medications will be administered to the pregnant woman, and what medications will be administered to the infant postpartum. The laboratory result of an undetectable viral load means that a vaginal birth, not a C-section, is the recommended mode of delivery. I learned from Tanya, however, that she had an unplanned C-section and not the vaginal birth that was planned during her prenatal care. Tanya did not offer much explanation or information about why the C-section was performed, and we did not meet with her healthcare providers to hear their perspective about the rationale for the C-section. We cannot rule out, however, that the absence of a text (i.e. viral load result) and healthcare providers' participation in objectified forms of knowledge (i.e. medical chart) produced the conditions in which Tanya had a C-section.

At the time, I was struck by how the information that was recorded in the resident's dictated note pertaining to Tanya's blood work and HIV viral load result were false and misleading, and how this text harnessed much power to influence and produce particular circumstances - for Tanya, for her baby, and for the healthcare team providing care to Tanya and her baby. Later, reading and coming to know Dorothy Smith's scholarship, I came to appreciate how the

language and concepts that the resident articulated were constituted as "discrete phenomena in the institutional contexts of ruling" (Smith, 1990, p. 15), and that the expression of these terms and the production of a specific text (i.e. dictated note) could activate people's work and set into motion a particular care trajectory for Tanya and her baby. It was through this relationship between text and work in Tanya's case that I came to see how people can participate in objectified practices of knowing (Smith, 1990), and how this can have particular implications or consequences for people on the receiving end of these practices. It was objectified knowledge that came to be seen as "truth" in Tanya's chart and directed Tanya's care. The text that was produced through the resident's work activities was a property of institutional organization, and became a form of objectified knowledge that institutional actors engaged with and took cues from in order to subsequently direct their work activities (Smith, 1990).

Furthermore, Tanya's voice and experience as a woman and mother were absent and not represented in her medical records. The discharge summary was produced by someone who was involved in Tanya's care, and through the production of this institutional text, Tanya was objectified as a patient, a viral load, and a woman delivering a baby. During study visits with Tanya for the HIV Mothering Study, however, she shared her concerns about the health and well-being of her baby, and talked about her efforts to take her medication to keep an undetectable viral load to reduce the chance of perinatal HIV transmission. She also talked about her motivations to "cut down" smoking and to change the people

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she interacted with and the places she frequented to stay "clean and sober." The disjuncture between how I came to know Tanya's story and experiences in her own words versus how she was represented through her medical record was stark. Tanya's thoughts, intentions, desires, hopes, feelings, and actions were absent from her chart, and Tanya had become represented through texts constructed by others; this made it very difficult to contextualize her story, her history, and her experience (Smith, 1990). When I read Tanya's medical records, I thought about what her textual record meant *about* her – as a mother, as a woman, as someone interacting with perinatal health services, and as someone living with HIV. I also thought about how Tanya's textual representation in her medical record could have significant implications for how her life would be organized into the future.

Tanya's story highlights how we all participate in social processes and ruling relations that reach beyond the scope of our local, everyday worlds (Smith, 1987). These systems that we encounter can be in tension with our own ways of knowing and operating in the world because they are connected to discourses and ideological frames not of our making, nor that are relevant to our daily, local experiences (Campbell & Gregor, 2008; McCoy, 2006; Smith, 1987, 1990, 1999).

Tanya's story also highlights how we all participate in ruling discourses as part of our work - as individuals receiving healthcare, as employees within institutional and organizational settings, and as actors who engage with texts (Smith, 1999). Women like Tanya do not participate in the creation of these ruling discourses (Smith, 1987), however, and instead the social relations that women

like Tanya participate in overshadow her thoughts, experiences, actions, and dreams because perinatal care for women living with HIV, similar to medication "adherence," is "steeped in relevancies of medical power and social control" (McCoy, 2009, p. 129). Through regimes of ruling, women like Tanya have been repressed and stifled to assert her authority of knowledge, voice, and experience (Smith, 1978, 1987). Through institutional ethnography, however, we can illuminate the experiences of people who are objectified and ignored by ruling discourses, and expose relations of power that shape our worlds while preserving the doings of active individuals like Tanya (Grace, 2019).

Tanya's story also provides an example to observe and consider how discourses operate within healthcare settings; "discourse refers to trans-local relations coordinating the practices of definite individuals talking, writing, reading, and so forth, in particular local places at particular times" (Satka & Skehill, 2012, p. 195). Perhaps certain discourses and ideological framings, for example, related to "risk" or the "bad" or "difficult" "patient" were operating throughout the course of Tanya's interactions with perinatal care providers (G. Smith, 1990). I uncover and explicate discourses such as these in my doctoral research, and show how people "assimilate this ideological knowledge as a form of social consciousness received as an everyday feature of their lives" (G. Smith, 1995, p. 20).

Reflecting upon Tanya's story and learning about the challenges that women living with HIV can have when interacting with healthcare providers

motivated my interest to investigate how and why these circumstances occur in the first place. My involvement in the HIV Mothering Study was a formative experience that deepened my commitment to understand the specific services and procedures that women living with HIV are recommended to follow as pregnant women and mothers.

Through my dissertation inquiry I have been able to delve deeper to explore how institutional actors operating within healthcare organizations "know" HIV, to examine how this "knowing" translates into particular experiences of pregnancy and motherhood for women, and to uncover what forms of ruling and governance are operating in the organization of women's experiences.

While I was based in the SIS clinic, I was unaware of and had not yet developed the analytic framing to appreciate the social relations that organized my work as a research coordinator, the procedures and clinical processes that women interacted with in the hospital, and that maintained the system of perinatal care for women living with HIV. As I reflect back on these moments, and others, I now "see" the social relations that we're all caught up in, often without realizing it, and I recognize the ruling relations that coordinate our everyday worlds that Dorothy Smith and other institutional ethnographers articulate in their writing. These defining moments were pivotal in shaping my thinking and the questions I aimed to explore in this institutional ethnography.

Study Design and Methods

Sampling and Data Collection

This study began with the development of a research proposal, which outlined preliminary ideas for an institutional ethnographic inquiry focused on the social organization of perinatal care for women living with HIV. The proposal was first reviewed with clinicians and managers from both the Special Immunology Services (SIS) clinic and the Women's Health department (which includes the Maternal Fetal Medicine, or MFM, clinic) at the McMaster University Medical Centre (MUMC). Representatives from these clinics granted approval to recruit pregnant women living with HIV receiving care at the SIS clinic as participants, and to interview staff and physicians affiliated with both the SIS clinic and Women's Health department. Ethics approval was granted by the Hamilton Integrated Research Ethics Board. The data collection began with interviews with pregnant women living with HIV who were seen within the SIS clinic. I was introduced to women by a member of their healthcare team, for example, their HIV specialist, a clinic nurse, or social worker, as they attended routine HIV clinic appointments. From March 2016 to February 2017, five pregnant women were identified by SIS clinic staff to whom I was introduced; four agreed to participate in this research and gave written informed consent. I interviewed the women once during their 3rd trimester and again when their babies were three months old. The interviews were conducted outside of the HIV clinic in meeting rooms within the MUMC or the McMaster University campus to enhance participant comfort and anonymity. I asked each woman about the types,

frequency, and nature of appointments they attended during pregnancy, at childbirth, and postpartum for their HIV and maternity care; what types of providers and people they interacted with during the perinatal period within the hospital; what educational and textual resources they were given by any healthcare provider during the course of receiving care; and if they had identified any particular challenges, roadblocks, tensions, or concerns along the way. As women shared their experiences, I sought clarification to ensure I had obtained a comprehensive description of what they encountered while receiving perinatal care as pregnant women and mothers living with HIV. Women's accounts generated a wealth of concrete information about local practices (Smith, 1987) and enabled me to think not only about what they and the healthcare providers they interacted with were doing, but also how their actions connected to institutional relations (McCoy, 2006). These interviews were not about asking these women questions about their experience for their experience's sake, or for creating that experience as an object or "finding" of the research, but rather to collect clues and a direction to connect their experiences to healthcare providers' work practices and regimes of ruling.

The women I spoke with received their HIV and pregnancy care at the MUMC. Although all of the women were pregnant and living with HIV, they were not a homogeneous group. All participants had one to three children between the ages of 18 months and 19 years and had previous pregnancies following their HIV diagnosis. One woman was born in Canada and the other three had been

living in Canada for two to five years following immigration from their African

countries of origin. Two women were married with partners and two were not in a

relationship. Two women lived in Hamilton where the hospital is located whereas

the other two women lived about an hour drive from the hospital.

Once these interviews were completed, from November 2017 to April

2018, I met with 12 people working in the SIS clinic and the Women's Health

department including five physicians, three social workers, three nurses, and one

pharmacist. Following obtaining their written informed consent, I asked these

individuals about the day-to-day work that they do within the clinical setting to

deliver care to women living with HIV who are pregnant, giving birth, and/or are

new mothers; the setting where they work (e.g. what processes and structures

exist to deliver services to this particular population); their education and training

related to pregnancy, motherhood, and HIV; and what texts inform their work

such as clinical practice guidelines. I was often sitting with them at their

workstations such as an exam room or office located in a clinic or hospital ward

where they could demonstrate their tasks and activities, present texts used in their

work, and provide a detailed account of their work activities and the reasons

behind such practices. As the interview topics were discussed, I assumed the role

of an explorer to learn about healthcare providers' daily activities, as well as their

reflections of their work. These conversations revealed clues about how their

work was organized institutionally, and governed by institutional policies and

texts, but also where points of contention existed between written institutional

policies and their practices at the frontlines of care. Furthermore, the recruitment process was iterative; I did not begin my study with a plan to interview 12 healthcare providers of the various disciplines that ended up being represented. As the ethnographer, I made choices about what direction I wanted to take and what territory I was going to explore. As I learned about the institutional complex and the territory of which actors and processes were involved in the provision of perinatal care to women living with HIV, the direction of my study took shape and informed my decisions about who to reach out to and interview next. Importantly, my decisions and ethnographic process were informed by the experiences that women shared during the initial interviews, and throughout the inquiry I did not lose sight of the women from whom the inquiry began and the troubles with care they described. All interviews were audio-recorded and transcribed verbatim, and transcripts were cross-referenced with the recordings to ensure accuracy.

Analytic Process and Mapping

After each interview was completed with women and healthcare providers, I wrote a reflective account about what I was learning from them, what questions were emerging that could form the basis of my inquiry, and what possible directions the inquiry could take based on what information participants were sharing. These reflections occurred throughout the data collection process and were important to help me to "see" participant accounts "organizationally;" that

is, to read participant accounts as an institutional ethnographer by making connections between their "work" and institutional forms of ruling and governance, and to think about their accounts as clues about and providing a direction for explicating the social organization of perinatal care of women living with HIV. Reflecting upon the interviews in this way helped me think about the possible "threads" that were becoming visible and would become the content of my overall inquiry.

I then engaged in a reflexive writing process to conduct an analytic description of the interviews with women living with HIV. This involved writing out what I learned from the four women including who they interacted with as part of their HIV, pregnancy, childbirth, and postpartum care; what "work" they did to engage in this care including organizing their appointments alongside other daily commitments and responsibilities, taking their medications and following recommendations of their healthcare providers; and their overall experiences and reflections of their care – what was working well, what challenges they had encountered, and what moments and interactions left an impression on them. This reflexive writing process was helpful to understand the similarities and differences across the group of women. Reading and re-reading women's interviews highlighted the different viewpoints and experiences that women had related to a number of topics and issues. For example, women discussed: i) attending appointments – instituting measures to be able to attend and participate in their care such as organizing work shifts around the days of the week they had

HIV and prenatal clinic appointments, having a family member attend to help with translation and interpreting healthcare providers' recommendations, and organizing familial commitments, childcare and transportation; ii) people learning about their HIV-positive status – this is typically referred to as "HIV disclosure" in the HIV research community, and women discussed the sharing or disclosure of their HIV status within the healthcare system and as part of their wider social networks and communities. Women also discussed who in their lives they were and were not comfortable with learning about their HIV-positive status; and iii) taking HIV medications – for example, what women had been told by healthcare providers about their HIV medication in the context of pregnancy, what clinical procedures they were recommended to follow during pregnancy, childbirth, and postpartum, and their reflections of these biomedical interventions to prevent perinatal HIV transmission. As I wrote about women's viewpoints, experiences and concrete descriptions of their care, I was looking for possible chasms between women's experiential accounts and what might emerge in the institutional accounts of healthcare providers, specifically where there might be points of disjuncture between women's and healthcare providers' different ways of knowing and experiencing (Campbell & Gregor, 2008).

I then reviewed the interviews with healthcare providers and began to describe and organize the institutional work processes that they engaged in as part of delivering HIV and perinatal care to women living with HIV. As I read healthcare providers' interviews I paid close attention to their work practices, and

how texts such as care protocols, policies, and other text-based forms of

communication within the hospital setting were involved in their work. I looked

for references to texts that activated their work (for example, a referral, doctor's

order, or clinical test result) and that coordinated the work of others (for example,

a dictated note, prescription, or discharge orders). My goal was to map the work

sequences related to the provision of HIV and perinatal care to women living with

HIV within the SIS clinic, the MFM clinic, Labour & Delivery and the in-patient

ward (also known institutionally as the 4B and 4C units) at the MUMC in order to

create a comprehensive overview of care for this particular population within this

particular institutional complex.

I then engaged in a process to visually map the work-text-work sequences

of action of what was happening institutionally related to pregnancy, childbirth,

and postpartum care for mothers living with HIV. I learned about and was

encouraged to engage in a process developed by institutional ethnography scholar

Susan Turner (2006), and the identification, mapping, and analytic description of

such work sequences occurred during in-person meetings with Susan. I mapped

the work of various actors within the institutional setting including physicians,

nurses, and social workers to visually represent how their work was

interconnected and coordinated by texts. For example, see Appendices A, B, and

C of maps that were generated during this analytic process. This mapping process

gave me a macro, birds-eye-view of the various clinics and procedures involved in

delivering perinatal care to women living with HIV by healthcare providers within

the MUMC. As a way to refine and narrow my ethnographic inquiry, I then returned my analytic attention to the accounts of the four women living with HIV whom I interviewed to hook their particularly salient experiences into institutional work processes; that is, I drew connections between what women shared related to their encounters within the healthcare institution with the work processes and practices of healthcare providers operating within the healthcare institution. By returning to the lived realities of women from whom the inquiry began, I ensured that my inquiry, which intended to explicate the social organization of perinatal care for women living with HIV, was grounded in women's experiential accounts, and that connections were being made between women's experiences, day-to-day work practices of healthcare providers, and institutional forms of governance and ruling.

Conclusion

What follows are three manuscripts that outline three "threads" that form the basis of this dissertation. These "threads" begin from the standpoint of women living with HIV who were interviewed for this project, draw on the interviews with healthcare providers, and are a culmination of my process of reflexive writing, analytic description, visual mapping, and critically reviewing relevant literatures.

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Chapter Three: Keeping Secrets, Disclosing Health Information: An Institutional Ethnography of the Social Organisation of Perinatal Care for Women Living with HIV in Canada[1]

Abstract

This paper describes findings from an institutional ethnography that arose out of the concerns of women living with HIV in Ontario, Canada regarding the disclosure of their HIV status while accessing perinatal care. The enquiry traces the connections between women's experiences of perinatal care, the activities of healthcare providers delivering such care and the ruling relations that organise women's experiences and healthcare providers' activities. Focusing on HIV disclosure as a concern expressed by women, the findings make visible the day-to-day, routinised practices of healthcare providers working in perinatal care for women living with HIV, as well as the ideological discourses of 'fear of contagion' and 'AIDS hysteria' that contributed to producing the kinds of care experiences that were articulated by women. Opportunities to strengthen perinatal care policies and practices for women living with HIV are discussed.

Introduction

Disclosure of one's HIV-positive status to family, romantic partners and community is a phenomenon that has garnered much attention in scholarly literature (Adam et al. 2015; Vyavaharkar et al. 2011), community-based programming and public discourse. This paper outlines findings from an institutional ethnography that arose out of the concerns of women living with HIV in Ontario, Canada regarding the disclosure of their HIV-positive status while accessing health services during pregnancy and childbirth. Although the study focuses on perinatal care in one healthcare institution, it shines an important light on the ideological discourses that operate within health systems in Canada and other countries around the world.

Background

The evolution of HIV infection into a chronic condition has changed the landscape of health outcomes for people living with HIV around the world. Women living with HIV are increasingly having children in part because of treatment advances, which have dramatically prolonged life expectancy (Samji et al. 2013). Despite variable access to antiretroviral therapy and maternal and pediatric care, which maintain higher rates of vertical transmission in many parts of the world, with effective interventions during pregnancy, labour, delivery and breastfeeding, HIV transmission during the perinatal period can be significantly reduced globally (UNAIDS 2018).

Medical advances have reduced the vertical transmission of HIV (i.e. transmission during the perinatal period from pregnancy to early postpartum) to less than 1% in Canada where most women have access to maternity care and antiretroviral therapy (Forbes et al. 2012). HIV specialists play an important role in care, but the progression of HIV into a chronic condition has important implications for a range of other contexts including maternity care (Bradley-Springer, Stevens and Webb 2010). As such, it is imperative that healthcare providers and institutions keep in step with the shifting landscape of motherhood and HIV and respond to the needs and experiences of women living with HIV.

Through my work as an HIV researcher, educator and ally, I have learned about the unique needs and experiences of mothers living with HIV across Canada (Greene et al. 2015, 2016, 2017; Ion et al. 2016). In particular, HIV disclosure, or one's HIV status becoming known and shared by people in different circumstances, has been raised as a significant concern in previous work and in numerous studies conducted in other regions (George and Lambert 2015; Greene et al. 2015, 2016, 2017; Ion et al. 2016; Steenberg 2019). People living with HIV, community allies and researchers often note that sharing one's HIV status should be done with caution for fear of negative consequences such as rejection, the possibility of becoming the subject of gossip and ridicule and HIV-related discrimination (Bird, Eversman, and Voisin 2017; Gilbert and Walker 2010; Nachega et al. 2012). As such, women living with HIV often choose to keep their HIV status a secret.

While working in an HIV clinic within a regional hospital in Ontario, I witnessed how a woman's HIV-positive status connected her to a system of specialist care for pregnancy and childbirth. In this context, her HIV status informed the provision of care and the communication between healthcare providers involved in her care. I began to see a disjuncture between women's experiences, expressed as their challenges and worries and the activities of healthcare providers working within this regional healthcare institution. It was from this line of fault between women's and the institutional actualities that a research problematic came into focus and I sought to explicate 'the experience of those who are caught up in and subject to institutional forms of action' (Smith 2005, 187). This institutional ethnographic enquiry reveals how women's experiences pertaining to HIV disclosure are connected to the work of maternity care providers who respond to and account for women's concerns. In explicating the work of healthcare providers, I aim to make visible the ruling relations (Smith 2005) that organise healthcare providers' work and highlight the disjuncture between women's experiences of HIV status as a 'secret' to be kept and healthcare providers' work that is informed by HIV status as 'personal health information' that guides care practices.

Methods

Institutional ethnography as a method of enquiry

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This institutional ethnographic enquiry was informed by the scholarship of the sociologist Dorothy Smith (Smith 1987, 1999, 2005) and began from the experiences of women living with HIV as they navigate care during the perinatal period. Institutional ethnography is different from other ethnographic approaches because it focuses on uncovering social relations that are material and empirical and does not attempt to theorise everyday life (Campbell and Gregor 2008). Rather than categorise or theorise data in artificial ways, institutional ethnography is concerned with the actual connections that work to produce the experiences of individuals (Campbell and Gregor 2008).

The focus of this enquiry was the everyday work of women living with HIV and healthcare providers that involved time, effort, skill and material conditions (DeVault 2006; Smith 2005). By explicating work processes and paying attention to how this work is coordinated, I was interested to make visible the social relations that people are drawn into through their work (DeVault 2006; Smith 1987). The enquiry moved beyond the knowledge, concerns and everyday worlds of individuals to uncover the socially-organised exercise of power, or 'ruling relations,' that shape people's actions and their lives (Campbell and Gregor 2008; Smith 1987). Attention was paid to texts, which help to make sense of how work is coordinated and why people do the things they do within a healthcare setting (Smith 1999). Through this ethnographic process, concrete points in the system where practices or processes could be augmented to respond to the concerns of women living with HIV were identified.

Sampling and data collection

This research proposal was first reviewed with clinic directors within the regional

hospital and approval was granted to meet with staff and physicians affiliated with

the HIV and maternity services. Ethics approval was then granted by the Hamilton

Integrated Research Ethics Board, which reviews studies conducted within

Hamilton's healthcare organisations which are affiliated with McMaster

University. The data collection began with interviews with women living with

HIV. I was introduced to women by a member of their healthcare team as they

attended routine HIV clinic appointments. Five women were identified from

March 2016 to February 2017; four agreed to participate and gave written

informed consent. I interviewed the women once during their 3rd trimester and

when their baby was 3 months old. Interviews were conducted outside of the HIV

clinic in meeting rooms within the hospital or the university campus to enhance

participant comfort and anonymity. I asked about the types, frequency and nature

of appointments women attended for their HIV and maternity care; what types of

providers they interacted with; what educational and textual resources they

received; and any challenges or concerns they experienced. The women I spoke

with all received their HIV and perinatal care within the regional hospital where

the research was conducted. Although participants were pregnant and living with

HIV, they were not a homogeneous group. Participants ranged in age from 35 to

48 years. All participants had one to three children between the ages of 18 months

and 19 years and had experienced previous pregnancies as women living with

HIV. One woman was born in Canada and identified as Caucasian; the other three

identified as Black and had immigrated from African countries two to five years

prior. Two women were married with partners and two were not in a relationship.

Two women lived in the city where the hospital was located whereas the other

two women lived about an hour away from the hospital.

After these interviews, from November 2017 to April 2018, I met with 12

people working in the HIV and maternity care clinics including 5 physicians, 3

social workers, 3 nurses and 1 pharmacist. Following obtaining written informed

consent, I asked about the work they do to deliver care to pregnant women and

mothers living with HIV; the processes and structures that exist to deliver services

to this particular population; their HIV-specific education and training; and what

texts they use in their work such as practice guidelines. The recruitment process

was iterative; as I learned more about the institutional complex and who and what

was involved in caring for women living with HIV, I made decisions about who to

interview next.

Analytic process and mapping

All interviews were audio recorded, transcribed and used in an analytic process to

identify the people and processes involved in perinatal care for women living with

HIV (Smith 2005; Turner 2006). I first read through women's accounts, and gave

each woman a pseudonym to uphold their anonymity. Importantly, the women

were not the objects of the investigation, but rather it was 'the aspects of the institutions relevant to the people's experience, not the people themselves, that constitute the object of inquiry' (Smith 2005, 38). The concerns women raised related to disclosure of their HIV status were identified and became an entry point through which the work of healthcare providers related to disclosure could be explicated. Interviews with healthcare providers were used to identify their actions and the institutional processes related to HIV disclosure and how these actions were connected through texts such as notes in the woman's medical chart.

Concrete details about institutional processes as articulated by healthcare providers, who were also given a pseudonym, were then 'knitted' together to reveal the ideological processes that are constituents of the social relations that organise women's experiences and healthcare provider's work (Smith 1987). Importantly, it is these ideological processes that are discoverable through institutional ethnography and are transferable and have relevance beyond the four women from whom the enquiry began. Through this approach it is 'possible to go from particular events in local settings to a set of general, textually-mediated social relations because they have the same social form' (G. Smith 1990, 636).

The 'threads' connecting women's experiences, the doings of healthcare providers and the coordination of their doings through texts (Smith 1987, 2005; Turner 2006) were visually represented in a map, which was a visual aid to illuminate how women's experiences were connected to the activities of healthcare providers. What follows is an account of the social organisation of

perinatal care for women living with HIV with a focus on HIV disclosure that was revealed through this ethnographic process.

Results

HIV Disclosure: A concern shared by women living with HIV

All women raised disclosure, or their HIV status becoming known and shared by people working in the healthcare system, as a concern; women expressed a range of experiences related to HIV disclosure and the possible consequences of their HIV status being revealed. Women explained the things they did to conceal their HIV status or minimise the number of people in their lives who became aware. The women I spoke with all believed it was important for some people within the healthcare system to know about their HIV status because it would facilitate important referrals and obtaining appropriate treatment as pregnant women. Women also believed that minimising who knew would reduce the possibility of negative consequences. Women accepted healthcare providers finding out with whom they had a continuous relationship such as their family doctor and HIV specialist; women became more nervous when their HIV status became known by occasional staff who they believed did not need to know (e.g. part-time nurses, students).

Regardless of who was learning about their HIV status, women were concerned about assumptions being made about them if the person finding out had incorrect or outdated knowledge about HIV transmission and treatment. Tabitha

shared how she often declined being seen by trainees even though she receives care within an academic teaching hospital:

Very few people understand the way HIV is. Most of them just think it's deadly…contagious…most people have very little knowledge. And if you go about telling anybody else, it's like putting your own life at risk of stigma…you don't know what other people would say…I won't just go around and tell anybody because not everyone understands…how it's treated, how it's prevented, how it's transmitted.

Aisha expressed not wanting her status to become known because of concerns of judgement and being the focus of gossip: 'The HIV issue, some people just see it as like death…they think you're dying…that's why [I don't] want people from our community to know…also they think maybe your kids have it.'

Women talked about keeping their HIV status a secret as a measure they could take to mitigate rejection and negative experiences. As Jillian shared, hearing the negative information that was being taught in her nursing curriculum about HIV was the reason she stayed quiet amongst her peer group:

When I was in nursing [school], my sponsor said to me, 'Don't say anything to anybody about being an ex-drug addict because it's very misunderstood. And nobody needs to know that because its just causes them to fail you for whatever reason…it's very true…most of the classes we did talk about drug addicts and HIV, and the information that was being passed around was incorrect most of the time…So yeah, I didn't

share…I did end up sharing with my group of girls that I'm an ex-drug

addict and I'm sober or whatever. But I never told them I was positive

because the information they were getting was so negative.

Jillian recounted a conversation with her Alcoholics Anonymous sponsor, and her

decision to share her previous drug and alcohol use with women in her nursing

cohort, but to keep her HIV status concealed because of her discomfort with how

information about HIV was discussed in the classroom. The concerns about HIV

disclosure that women raised were known by the healthcare providers I spoke

with, and my enquiry revealed the extent to which healthcare providers shared and

responded to women's concerns.

Making 'HIV Disclosure' visible through institutional work practices

HIV disclosure was visible institutionally through the work of different healthcare

providers, including responding to and accounting for women's concerns about

HIV disclosure.

Responding to Women's Concerns about Confidentiality During Prenatal

Appointments

A woman's concern about HIV disclosure might be raised during an early

appointment in the high-risk prenatal clinic. As Nancy, a nurse, explained,

'They'll usually say, "Okay, I'm really worried about my stay in hospital…my

family doesn't know, or my in-laws don't know" … "I don't want anybody to

read the [chart].'" The woman's concern was documented in her chart 'care plan' so that other members of the healthcare team were aware including when she presented in labour for her delivery.

Nancy continued to explain the responsiveness of staff when HIV disclosure concerns were raised, and how their team had become increasingly aware of the importance of privacy and confidentiality when caring for women living with HIV:

> 'That's part of the education that we've given to the nursing staff around just confidentiality…you can't really disclose any personal health information in front of anybody else unless they agree to it…you don't want "Oh, here's the medication for the baby" when a visitor is there. "What's your baby getting?" It's not a good time, right?'

Nancy highlighted how members of the care team understood how a woman's HIV status could be disclosed, which would lead to questions by people who might not be aware of the mother's HIV status. Moreover, it was expressed that consent of the woman was a critical factor in determining what information would be shared by healthcare providers, and that engaging women in a conversation about their preferences related to their privacy and confidentiality was an important practice.

Disguising Medication During Childbirth

Once in labour, there were HIV-specific procedures to 'minimise the potential for neonatal complications' (Hamilton Health Sciences 2012, 1). Zidovudine (AZT) is a medication that is administered to women living with HIV as a protective measure during childbirth; its visibility and use could disclose a woman's HIV status or lead to questions from people visiting the mother in hospital who might not know about her HIV infection. People working in the delivery room had instituted practices to directly and indirectly prevent the disclosure of a woman's HIV status, for example, not saying the medication name out loud and disguising the medication label so it was not visible. As Rebecca, an obstetrician, explained:

> If a woman is labouring, and she's got her AZT running, and there's somebody there with her as a support, that you don't come in a say, "Oh, I've just got to change your AZT. It's not quite through yet.' And they'll go, "What?!" Right? ... What should we say? ... It's an antibiotic, or whatever. But we usually put a brown bag or something over it…to disguise the label…you don't just walk in and blurt something out. And don't assume that the man that's there is a partner. Because it could be anybody. So those sort of privacy things.

Assigning Women to a Private Room Postpartum

Within the regional hospital where this study was conducted, women living with HIV are assigned to a private room following childbirth. This practice is not reflected in a written policy but was an established practice that staff knew about

and reported following. A private room was not dependent on her health insurance or medical benefits; all women living with HIV were granted a private room. I asked staff responsible for organising this to elaborate, and a nurse named Catherine explained:

> We put all of our HIV positive women in private rooms. And it's not for isolation…it's just for confidentiality. So that if a physician has to go in and talk to them about, you know, their viral loads or what their follow-up is or whatever else, that's not necessarily something that their roommate needs to hear about, right? …There might be a stigma, or I don't want to room with somebody who's HIV positive right? ...There's sometimes some confusion, that people feel that they're isolated. Because, well, we have a private room, but we don't have a private bathroom. Well, they don't need a private bathroom, right? They just need a space where they can have a conversation with their healthcare team that isn't going to involve their roommate.

After hearing Catherine's account, I was reminded of a conversation I had had with a hospital employee while coordinating a previous study (HIV Mothering Study; see Greene et al. 2015, 2016, 2017 and Ion et al. 2016) where I learned that historically women living with HIV were assigned to a private room because of concerns related to their lochia, which is discharge from the uterus after childbirth. This historical explanation differed from what I heard from healthcare providers in the present study: namely, that assigning women to a

private room was about ensuring her HIV status was not discussed in front of

other patients or inadvertently disclosed to visitors. When I sought clarification

from Rebecca, an obstetrician who had provided perinatal care since the early

days of the HIV epidemic, she responded, 'I honestly still thought it was the

lochia…it's blood…And no other pregnant woman who's just delivered wants to

sit on somebody else's blood in the toilet. Which is a problem when they share a

bathroom…So a private bathroom. We have the same issue with…people that are

active viral carriers.'

Hearing the different accounts by healthcare providers who played a role

in assigning women to a private room revealed variation and subjectivity in the

organisational rationale for this practice. On the one hand, and historically, the

private room was assigned in response to concerns about infection control and

reducing other patients' exposure to HIV, which for some staff also necessitated a

private bathroom. The private room was also a mechanism staff used to protect

women living with HIV against HIV-related discrimination and negative reactions

when interacting with other patients. What is concerning about assigning a private

room for infection control purposes is the fact that there is no risk of acquiring

HIV when sharing a hospital room or public washroom, as was thoughtfully

explained by nurse Catherine:

> You'd have some nursing staff who say women with HIV and probably
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> hepatitis as well shouldn't share a bathroom… then you would get the kind
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> of argument – but you probably have used a public washroom after a

positive HIV woman countless times in your life, and you don't have HIV…that whole "you can't get HIV from a toilet seat," right? … and then the counterargument to that would go back to "but that patient isn't bleeding heavily after just having had a baby." Fair enough. Counter to that is yes, but they're not bleeding all over the toilet seat and then leaving it there. So we have wipes in the bathroom…and there are notices and you have discussions with your patient that the expectation is if you bleed on the toilet while you are going to the washroom, which inevitably is probably going to happen, then the expectation is that you will clean off the toilet seat with a wipe… so if the toilet has been cleaned and disinfected after the patient has used it, what's the risk?...[also] you're not sitting your perinea on a toilet seat. Your perineum or wherever else that you have had a tear is sitting over the bowl…. So theoretically the worse thing that's going to happen is there might be a tiny little bit of blood that was missed, and you're going to get it on your bum cheek. As far as my knowledge is, you're not going to get HIV.

Even with the availability of disinfectant wipes to remove blood from toilet seats, hospital employees had not reached consensus about the imperative for the private room practice and it was clear that concerns and questions lingered among staff. My conversations signalled the need to examine what discourses may be embedded within and legitimating institutional practices (Smith and Smith 1998). The different accounts from healthcare providers also made visible the

blurring of practices related to infection control and ensuring privacy and confidentiality, and how the practice of assigning a private room could be interpreted as serving both or either purposes. Hearing different interpretations from healthcare providers regarding the rationale for the routinised practice of assigning a private room without a clear directive or policy also illuminated how some actions that treat mothers living with HIV differently than other mothers receiving care on the same postpartum ward can be problematic.

The social organisation of healthcare providers' work

Throughout this enquiry I continued to question how it had come to be that women living with HIV and their healthcare providers shared similar concerns about HIV status being inadvertently disclosed. Healthcare providers were aware of women's disclosure concerns, and expressed a clear commitment, and had instituted practices, to keep women's HIV status private. This fact alerted me to investigate legislative texts, regulatory protocols and other 'ruling relations' that may be organising their practices, while at the same time, maintaining a state where women were concerned about the possibility of their HIV status being disclosed against their wishes.

I asked healthcare providers about how information about patients was communicated between people involved in caring for a mother living with HIV. Ann, an HIV specialist, explained the process of sharing dictated notes with providers working in other clinics, 'It's circle of care…and it's best practices.

Everybody who is taking care of you should know what's going on.' Nurse Nancy

expressed the importance of 'confidentiality' when caring for patients and sharing

their information amongst interprofessional team members, 'It's more around

confidentiality. I mean I think if you just practice good confidential information

practices, you're going to cover yourself, right?' Hearing healthcare providers use

terms such as 'circle of care' and 'confidentiality' signalled to me how

institutional language could be used to not only justify practices, but also to

coordinate people's thinking and activities (Campbell 2016).

While working in the HIV clinic, I had institutional permission to view

and extract information from patients' medical records and was also expected to

ensure 'confidential information practices' in how I was using the health

information of women living with HIV who attended the clinic. I learned through

this work that I, like the healthcare providers I spoke with, was a 'health

information custodian' and was regulated by Ontario's privacy legislation known

as the *Personal Health Information Protection Act* (OIPC, 2004). Consent,

disclosure and 'circle of care' are key constructs outlined in the Act, which directs

health information custodians to ensure the security and confidentiality of

'personal health information' including HIV status. 'Personal health information'

may only be disclosed if the person receiving care consents (OIPC, 2004);

however, the legislation also outlines broad circumstances in which disclosure is

permitted without the patient's consent (OIPC, 2004). As Cavoukian and Rossos

(2009) outline, the *Personal Health Information Protection Act* was 'specifically

designed so that it would not present a barrier to the disclosure of personal health information among healthcare providers' (7). As such, when individual practitioners or healthcare facilities are 'providing health care' or 'managing risks and error' (Beardwood and Kerr 2004), the disclosure of personal health information is permitted on the basis of implied consent (Cavoukian and Rossos 2009). In practice, however, the vague language and unspecified circumstances in the *Personal Health Information Protection Act* of when disclosure is permitted without explicit consent, along with the imperative to not create barriers to communication between healthcare providers, means that a woman's HIV status can be discussed openly between her care team. It is through this connection between the legislative text and the frontline work of healthcare providers that the conditions are produced for a woman's HIV status to be revealed to people working in the healthcare system who she doesn't feel need to know, and/or to people in her life who she does not want to find out.

In speaking with healthcare providers, it became clear that although they were organised by the broad provincial privacy legislation, there were not any specific institutional policies to clarify how to respond to women's specific concerns regarding HIV disclosure. Kristen, a pharmacist, explained:

> We did have a case where the patient didn't want us to tell her partner that she had [HIV] …I didn't know who the right person was to go to. This baby was receiving medication [because of HIV exposure], you know, as part of their standard care. And the father didn't know about it…Is it my

responsibility to tell him? Do I ask somebody else to tell him? ... But it

was just never put down on paper but everyone's sort of, "Okay, don't say

[HIV] in front of her partner" kind of thing…how do you handle those

situations?

Kristen's account illuminates an ethical tension between wanting to protect the

mother's rights to confidentiality alongside protecting the rights of the father to

know about the medical care being provided to his child. Moreover, Kristen was

unclear about what information should be kept private, and with whom. Employee

obligation to uphold privacy was muddied by an ethical quandary about under

what circumstances a person's HIV status should be shared, and how HIV status

can be indirectly disclosed simply by naming a medication the baby receives

postpartum.

The questions asked by Kristen are further complicated by the increasing

climate of HIV criminalisation in Canada (CATIE, n.d.). While Canadian law

outlines specific conditions under which people living with HIV are obligated to

disclose their HIV status before sexual encounters, a climate of surveillance has

crept into public health and social service arenas blurring the lines and creating

confusion regarding what disclosures are needed, by whom and in what

circumstances (Greene et al. 2015, 2017; Sanders 2014, 2015). In a healthcare

context, even if women living with HIV do not wish their HIV status to become

known, and/or healthcare providers wish to avoid unwanted disclosure of a

woman's HIV status, the legal obligation of people living with HIV to disclose to

sexual partners along with parental right to know about and consent to healthcare their child receives, create conditions where the disclosure of HIV may occur. Kristen was looking for guidance and direction about how to handle these ethical challenges:

> What we have so far is it's a protocol for AZT which is not really taking care of a patient with HIV, right? It's instructions for nurses… our hope was… to get rid of that … and then develop an actual policy which encompasses like all of the multidisciplinary aspects… something that takes care of the whole picture for everybody, not just a drug order…we would like to have sort of a well-rounded policy on all the different aspects of taking care of a mom living with HIV…what pieces are we missing maybe in taking care of this patient, and how do we bring everyone together to make them aware of that.

As Kristen highlights, privacy legislation governs the collection, use, and disclosure of personal health information, but it does not go far enough to provide concrete direction to account for the complexities and sociopolitical nuances of HIV disclosure. Even if women living with HIV and their healthcare providers want to keep her HIV status a 'secret,' vague laws and policies that permit such disclosure continue to organise the work of people operating within healthcare.

Discussion

This institutional ethnographic enquiry explored the social organisation of perinatal care beginning from women's concerns about HIV disclosure. Findings revealed some of the institutional practices that have been enacted by healthcare providers, and how practices and policies have created particular conditions for women living with HIV during the perinatal period.

Reflecting upon the fears that women shared about HIV disclosure, and the work of healthcare providers to account for and respond to women's concerns, broader sociohistorical discourses about HIV and AIDS, especially ideological perspectives reminiscent of the start of the HIV epidemic, became visible. As nurse Catherine stated, 'for people who have been in healthcare or nursing a lot longer, there's still that little bit of fear [that] never went away;' and this 'fear' of HIV was vividly felt by women themselves. Framing HIV as something to be 'feared' and kept 'secret' was embedded in the language of people operating within this system (G. Smith 1988). The ideological framing of HIV became visible in the day-to-day work practices of healthcare providers and contributed to the kinds of care experiences that women articulated. There is a sociohistorical context in which these discourses have come to be known and practised and have maintained the current state of care for mothers living with HIV in Canada and beyond.

When HIV and AIDS first emerged in the public sphere, mass media fueled moral panic and hysteria (Kinsella 1989; Lester 1992); 'information

released by the media [about HIV and AIDS] taught society how to think about this disease - regardless if the information was incorrect' (MacIsaac 2017, 1). The sentiments expressed in mass media were echoed in literature. Published articles focused on 'fear of contagion' and 'perceptions of risk' of nurses and other healthcare providers delivering care to people living with HIV (e.g., Gallop et al. 1992; Huerta and Oddi 1992). A survey conducted by Wallack (1989) demonstrated that healthcare providers were committed to caring for people living with HIV because of their helping role, but 26% 'feared they would become victims of AIDS if they continued their present work' (507). Although publications offered some clarification regarding HIV transmission and prevention and were framed with the goal to disrupt circulating misinformation, the very act of writing about and drawing attention to 'AIDS anxiety' and 'fear of contagion' helped to legitimate such perspectives into sociocultural norms that in turn organised the ways of knowing and practices within healthcare. Furthermore, although literature has documented medical and social advance as HIV has become a chronic condition and with social justice efforts to prevent discriminatory practices in healthcare (Bradley-Springer, Stevens and Webb 2010; Nyblade et al. 2009), 'fear of contagion' lingers as a discourse that organises institutional practices.

Fear of contagion is also embedded within healthcare provider education, which was highlighted by one participant completing a nursing diploma who commented on the negative and incorrect information being shared about HIV in

the classroom. Today's nursing curriculum in Canada lacks up-to-date, if any, information about HIV (Mill et al. 2014); HIV-specific education is also lacking in social work education (Natale et al. 2010). The absence of mandatory HIV education in nursing and social work curricula, continuing medical education and hospital staff training means that little has been done over time to systematically un-do and un-learn, let alone eradicate, lingering 'fears' and incorrect knowledge and perceptions about living with HIV. Furthermore, although guidelines have been developed to outline best practices when caring for people living with HIV (CANAC 2013; Money et al. 2014), challenges remain to operationalise these guidelines in local contexts and routinised work processes (Grol 2001).

This enquiry highlighted a number of tensions between institutional policies and unwritten work practices such as sharing patient information between interprofessional team members while interacting with patients and their families. Healthcare providers noted how regulatory policies can be subjectively interpreted as protecting privacy rights while also granting permission to share personal information when delivering care. Moreover, learning about the process to assign women to a private room postpartum revealed how the rationale for this routinised practice was understood differently across the healthcare providers who were interviewed. On the one hand, staff talked emotively about their 'confidentiality practices' to prevent women's HIV status being inadvertently disclosed, and protecting women living with HIV from possible negative attitudes of roommates and visitors. On the other hand, staff spoke confidently about historical and

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lingering concerns about infection control, and how the private room protected HIV-negative women from the bodily fluids of women living with HIV. An ethical dilemma about upholding a woman's secret versus not informing a father about his baby's treatment for HIV exposure was also shared.

As Kilty, Orsini and Balogh (2017) assert, the knowledge held by healthcare providers can affect how they balance their emotions with their professional duty to provide support, and this is further complicated in the ever-evolving medical, social and legal information about HIV. Emotions can shape the bioethical decision-making of workers in a variety of intersectional and sociocultural contexts (Kilty and Orsini 2017; Kilty, Orsini and Balogh 2017). Therefore, if the intentions behind unwritten, routinised practices remain unclear, this leaves room for interpretation and subjectivity, enabling discourses such as 'AIDS hysteria' and 'fear of contagion' to endure (G. Smith 1988; Smith and Smith 1998).

Although healthcare providers in this study were aware of women's concerns about HIV disclosure and were committed to protecting women from possible negative consequences including HIV-related discrimination, their work was still organised by ruling relations that maintain a fear of contagion discourse and permit health information custodians to discuss and share women's personal information. Furthermore, the fear of contagion discourse continued to operate and influence practices even though healthcare providers had correct knowledge about the negligible chance of HIV transmission in the context of sharing hospital

rooms and washrooms in the postpartum ward. Exposing these contradictions is critical to moving forward with possible practice and policy remedies. An opportunity exists to consider how women's concerns regarding HIV disclosure could be concretely folded into institutional policies to close the gap between broad legislative texts and healthcare provision on the frontlines of care.

Crafting a step-by-step protocol that is grounded in women's realities and orients healthcare providers involved in the care of women living with HIV would help to strengthen the knowledge and capacity of hospital staff. This protocol could include concrete tasks relevant to prenatal, labour and postpartum care. When planning a woman's birth plan, staff could be directed to ask about any concerns she has about keeping her HIV status concealed from hospital visitors. For the delivery, staff could be provided with suggestions about how to deliver care while maintaining privacy, for example, not naming HIV-specific medications in front of visitors and disguising medications administered during labour. Finally, assigning a private room for the purposes of ensuring a woman's privacy, not for concerns related to infection control, could be outlined in this protocol to dispel ambiguity amongst staff, and this rationale could be communicated to women during prenatal visits, so they too understand the institutional imperative for confidentiality. This protocol should be shared with all learners and new staff who are affiliated with the service, with a commitment to updating it in line with medical and social advances identified through the

leadership and meaningful involvement of women living with HIV (Carter et al. 2015).

Conclusions

This enquiry into the social organisation of perinatal care for women living with HIV in Canada illuminates opportunities to strengthen practices related to women's concerns about HIV disclosure while receiving healthcare. The insights and recommendations from this enquiry are significant and transferable to other health and social services accessed by people living with HIV in Canada and around the world. Confidentiality is paramount for people living with HIV given enduring HIV-related stigma; healthcare managers and decision-makers need to take notice and integrate people's concerns into their routinised work practices. By grounding the enquiry in the realities of women living with HIV and articulating the ruling relations that women and healthcare providers participated in when navigating, delivering, and managing healthcare, institutional ethnography affords decision-makers an opportunity to design services and enhance policies that directly respond to the needs and concerns of those who use the healthcare system.

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Chapter Four: Risk and Preventing Perinatal HIV Transmission: Uncovering the Social Organization of Prenatal Care for Women Living with HIV in Ontario, Canada[2]

Abstract

This paper presents an institutional ethnography that explored how risk discourse organized the experiences of pregnant women living with HIV, and was reproduced in the work of healthcare providers operating in a 'high risk' prenatal clinic in Ontario, Canada. This inquiry began from the standpoint of pregnant women living with HIV, and made connections between women's experiences, the work of healthcare providers delivering prenatal care, and the ruling relations that organized women's experiences and healthcare providers' activities. The study revealed how risk was an omnipresent discourse in women's lives and became visible through the treatments women were prescribed, the prenatal clinic appointment schedule women were expected to follow, and the application of medical interventions. The discourse of risk coordinated the work of healthcare providers and was inextricably linked to practices that prioritized fetal health. Women's daily realities and experiences were overshadowed by the healthcare providers' focus on the fetus and mitigating perinatal risks. As a result, the work women did to organize their lives to participate in care, and the physical and emotional costs they experienced when attending their appointments, taking their

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medicines, and following clinical procedures became invisible in a context where the primary goal was to reduce risks to their babies – even if women shared concerns and aspirations about preventing perinatal HIV transmission. Women's experiences reveal some important consequences regarding the current organization of prenatal care that emphasizes risk and possible ways to enhance prenatal care policies and practices.

Introduction

Medical advances over the two decades have reduced the likelihood of HIV transmission during pregnancy and childbirth, or the perinatal period, to less than 1% (CATIE, n.d.; Loutfy et al., 2018; Money et al., 2014). The success of HIV treatment means that parenthood is more common for women living with HIV in Canada (Loutfy et al., 2009; Salters et al., 2017) and around the world. These welcome and exciting developments have not eliminated the unique procedures that women living with HIV continue to face to prevent perinatal HIV transmission (Money et al., 2014).

In Canada, a number of interventions are recommended to prevent perinatal HIV transmission including maternal combination antiretroviral therapy (ART) for the duration of pregnancy, mode of delivery corresponding with maternal plasma HIV viral load, intravenous zidovudine for the mother during childbirth, ART for the newborn up to six weeks postpartum, infant serial HIV testing to 18 months, and breastfeeding avoidance (Loutfy et al., 2018; Money et

al., 2014). Although guidelines have been refined over time to reflect emerging scientific evidence, the procedures listed above have been consistently recommended since the advent of ART in the early 1990s; the primary goal of these interventions is to mitigate risks, specifically HIV infection, to the fetus.

The application of medical interventions on the pregnant bodies of women living with HIV with the goal to reduce HIV risk to the baby brings to mind Rothman (2014) who asks, 'is it even possible to talk about pregnancy and childbirth in language *other* than that of risk?' (p. 1). Rothman and other scholars assert that 'pregnancy and child birth have become important sites of risk in late modern societies' (Coxon, Scamell, & Alaszewski, 2012, p. 505) signaling how a risk discourse has become engrained in prenatal care practices where pregnancy and childbirth have historically been regarded as potentially 'dangerous' events (Cartwright & Thomas, 2001). This is exacerbated when pregnancy is combined with HIV infection where the risk discourse materializes and organizes care practices; in the pregnant bodies of women living with HIV, risk is something that *might* be happening, therefore, the '*perception* of threatening risks determines thought and action' (Beck, 2000, p. 3).

As a researcher whose work has focused on the experiences and needs of mothers living with HIV, I have witnessed what the application of medical interventions with a primary goal to prevent perinatal HIV transmission means in the context of women's everyday lives (Authors 2014a, 2014b, 2015a, 2015b, 2016a, 2016b, 2017a, 2017b). These observations have stimulated a desire to

critically examine conceptualizations of risk and how risk discourse materializes in the lives of women living with HIV. I agree with Coxon (2014) who argues that the current sociological literature on risk privileges individual lived sociocultural perspectives, ignores the structural inequalities that influence exposure to and experience of risk, and overlooks the development of a macro-theoretical risk analysis that is specific to pregnancy and birth. Therefore, while I acknowledge dominant risk theories (Beck, 1992; Lupton, 1999) and the theoretical conceptualization of risk as being influenced by sociocultural understandings (Coxon, 2014), I also have questions about what regulatory and structural forces may be operating and producing a particular kind of pregnancy experience for women living with HIV (Smith, 2005). I question how the risk discourse operates through regulatory texts including the clinical recommendations that pregnant women living with HIV are expected to follow. This paper explores the experiences of pregnant women living with HIV and the work of their prenatal care providers to understand how the discourse of risk operates in prenatal care for women living with HIV. Using institutional ethnography, this study aims to explicate the enactment of risk discourse vis-à-vis the application of clinical guidelines and medical interventions that prioritize the prevention of HIV transmission during pregnancy.

Theoretical Framework: Institutional Ethnography as Method of Inquiry

For this project, I wanted to investigate the conditions that produce the prenatal experiences of women living with HIV. Institutional ethnography (IE) was chosen as my method of inquiry because it enables an investigation into the relationship between local, lived experiences and the generalized social relations that organize such experiences (Smith, 1987). Rather than treat individuals as the object of inquiry and analysis, their experiences are the entry point to explicate the 'institutional relations of power in which people's lives are embedded' (MacKinnon & McCoy, 2006, p. 102); it is the participants' experiences, not the participants themselves, that constitute the object of inquiry (Smith, 2005). The analytic process uncovers the 'social and institutional forces that shape, limit and otherwise organize people's everyday/night worlds' (Mykhalovskiy & McCoy, 2002, p. 19). My study follows the tradition of other HIV researchers who have employed IE to explicate the ruling relations that organize the everyday worlds of people living with HIV (Grace, 2019). For example, Mykhalovskiy and colleagues (2002, 2008) explored the 'healthwork' of people living with HIV in Canada to highlight the wide range of health practices employed related to ART decision-making and interacting with healthcare providers. Grace and colleagues (2015) also showed how perinatal HIV transmission became criminalized in some African countries because of the standardization of 'best practice' model law, and the implications of this for community mobilization and advocacy.

Using an analytic process grounded in Dorothy Smith's scholarship

(Smith, 1987, 2005), I wanted to make visible how taken-for-granted conceptually

organized practices and ruling relations operate in the lives of women living with

HIV (Campbell, 2016; G. Smith, 1990; Smith, 1987, 1990, 1999, 2001).

Moreover, through IE I could highlight how the actions and experiences of people

in a local site, such as women living with HIV and their healthcare providers, are

connected to the actions of others across trans-local spaces, and are hooked into

broader social relations related to risk (Smith, 1999); these connections largely

occur through the mediating and organizing role of texts (Smith, 1987, 2005). In

revealing the social organization of prenatal care for women living with HIV in

Ontario, Canada, this study can increase awareness amongst women living with

HIV and people working within healthcare systems about how prenatal care is

organized, the implications of such organization on the care experiences of

women living with HIV, as well as the policy and practice enhancements that can

be made to optimize care on the frontlines.

Methods

Sampling and Data Collection

The study began with interviews with pregnant women living with HIV who I

recruited through an HIV clinic in Ontario, Canada. From March 2016 to

February 2017, I was introduced to five women by a member of their HIV care

team as they attended routine appointments. Four women agreed to participate

and gave written informed consent before being interviewed during their 3rd

trimester and at 3 months postpartum. These women were asked about the types

and frequency of appointments they attended during the perinatal period; who

they interacted with through HIV and maternity care services; what materials they

were provided; and if they had encountered any challenges throughout this

process. All participants received their HIV and maternity care within the regional

hospital where my research was conducted; all women had pregnancies following

their HIV diagnosis and had one to three children aged 18 months to 19 years. In

the previous two to five years, three women had immigrated from an African

country, and one woman was born in Canada. Two women were married with

partners and two were not in a relationship. Two women lived a short distance

from the hospital while the other two lived an hour drive away.

From November 2017 to April 2018, I interviewed 12 healthcare providers

working in the HIV and maternity care clinics including physicians, social

workers, nurses, and pharmacists. After obtaining written informed consent, the

healthcare providers told me about the work they do to deliver prenatal care to

women living with HIV; the processes and infrastructure that exist to deliver

services to this particular population; their education and training related to

pregnancy and HIV; and what texts inform their work such as clinical guidelines.

The recruitment process was iterative; as I learned about who and what was

involved to deliver prenatal care to women living with HIV, I made decisions

about who to contact next. The project was approved by the [insert Research

Ethics Board name] and I had institutional support from clinical managers within the hospital.

Analytic Process and Mapping

All interviews were recorded and transcribed. As I reflected upon the interviews with women and healthcare providers, I began to discover that risk as a discourse was visible in the interactions that women had during their prenatal care experiences, and that it informed the work practices of healthcare providers. I engaged in a process to map the prenatal care experiences, and institutional practices and processes related to reducing risk of HIV transmission (Smith, 2005; Turner, 2006). This process involved reading and re-reading all interviews, identifying the work of various actors within the institution, and tracing how their work was connected to the work of others through texts. The map became a visual aid to connect the dots in understanding how the experiences of women living with HIV and the actions of healthcare providers were interconnected and organized by ruling relations. I took an expansive conceptualization of work to remain open to different forms and categories of work (Smith, 1987), including the various ways that women living with HIV responded to recommendations by healthcare providers, and were served, looked after, worked on, etc. by healthcare providers. This process made visible a thread about risk that connected women's experiences during pregnancy, to the care they received as pregnant women, to how their care as pregnant women was organized by risk as a discourse (Smith,

1987, 2005). What follows is an explication of the social organization of prenatal care of women living with HIV in Ontario, Canada.

Findings

This inquiry revealed the various ways that risk in the context of HIV and pregnancy emerges and is attended to by both women living with HIV and healthcare providers. It became apparent that prenatal care for women living with HIV was connected to and organized by clinical practices that prioritize preventing perinatal HIV transmission. A focus on reducing the risk of HIV transmission to the fetus became visible vis-à-vis concerns regarding women's adherence to HIV treatment, expectations for women to follow a particular appointment schedule to facilitate monitoring of their pregnancies, and the application of medical interventions.

Reducing Risk through Adherence to HIV Medications

Maintaining adherence to HIV treatments emerged when speaking with both women living with HIV and their healthcare providers. Women told me about the work they do to receive, fill and take their prescriptions to achieve an undetectable HIV viral load during pregnancy, as one woman reflected, 'for a mother living with HIV and AIDS, you definitely have to take care of yourself… making sure that you abide to taking, you adhere to like taking the medications…to make sure that you don't give it to your baby.' Another woman

connected the work that she does to attend appointments and complete her blood work with the work she does to consistently take her HIV medication: '[HIV and pregnancy care providers] want me to do one more round of blood work two weeks before the delivery…Just to make sure my [HIV] viral load is good and I'm still undetectable.'

All of the women I spoke with talked about taking their HIV medications and the importance of having an undetectable viral load to prevent HIV transmission to their babies, as one woman told me:

> My [HIV specialist] advised me…this baby, as long as you keep yourself good, is going to be good. Take this medicine, never miss it. I was doing what my doctor was telling me always…you're a good mom because you did what we're always telling you… the medicine is going to save the baby…it is not easy to take the medicine…I'm taking for life. And why I'm doing that…I want to make my kids to be safe.

This woman's perspective aligns with all the women I spoke with who expressed a deep desire to protect their babies from acquiring HIV. At the same time, not only had women learned to speak the language of medication 'adherence' through interactions with their healthcare providers, as this woman points out, these interactions also highlighted the relationship between women's HIV treatment adherence and engagement in care and being viewed as a 'good mother' by those providing care.

Although women expressed the importance of taking their HIV medications to do all that they could to prevent perinatal HIV transmission, their work to fill prescriptions and take their medications was also about adhering to and maintaining compliance with the recommendations set out by their healthcare providers. Women understood that taking their medication, albeit difficult, and completing their blood work, were important; their blood could produce a test result that would serve as evidence to their healthcare team that they were following doctor's orders and minimizing risk to their baby. This became visible when learning about the work of HIV specialists who prescribe medications and monitor women's HIV viral loads. Although the evolution of HIV into a chronic condition where viral suppression is possible due to the success of HIV medication was acknowledged by many of the healthcare providers I spoke with, the process of monitoring women's blood work continued to be a focus for healthcare providers during pregnancy. Monitoring blood tests corresponded with a frequent prenatal appointment schedule that women were expected to follow, in addition to the focus on compliance with medication regimens, as one HIV specialist explained:

> I want to see that the viral load is undetectable sort of not quite on a weekly basis but very regularly… what I'm really wanting to do is have confidence that she's undetectable right up until the stage of delivery…that generally means monthly viral loads, particularly after

about the 7th month…and so it's just making sure that that gets done on a

regular basis.

All people living with HIV can expect therapeutic benefit from HIV medications

and achieve an undetectable viral load if they consistently take the medication as

prescribed (Bansberg et al., 2000; Mykhalovskiy, McCoy, & Bresalier, 2004;

Paterson et al., 2000). Importantly, having an 'undetectable' viral load is an

identity that people living with HIV around the world are increasingly associating

with in broader public discourses as a risk management strategy to signal their

negligible risk to others in sexual encounters (Grace et al., 2015). The goal of

viral suppression in this study, however, was increasingly emphasized in the

context of pregnancy and was framed by HIV specialists as a key prenatal

outcome given that viral suppression would greatly contribute to reducing

perinatal HIV transmission.

Reducing Risk through Regular Appointment Attendance

I learned from women and healthcare providers that a referral to the 'high-risk'

obstetrical clinic occurred at 12 weeks gestation, and it was in this clinic that

women would be seen for their prenatal care. Following the referral, women noted

an increase in frequency of their HIV specialist appointments; women typically

saw their HIV specialist every four to six months, and this increased to every one

to two months as their pregnancy progressed. Increasing HIV specialist

appointments coincided with increased obstetrical appointments, however, the

schedule of prenatal appointments was similar to what all pregnant women would expect, as one obstetrician explained:

> We try and aim to do a first visit somewhere at the end of the first trimester. And then we aim to do regular prenatal care from that point until the very end of pregnancy. Assuming that the pregnancy otherwise is uncomplicated, we don't generally see [women living with HIV] more frequently than otherwise women would be seen during pregnancy.

Prenatal care was important to all the women I spoke with because it helped them understand how their pregnancies were progressing and feel assured about the steps they were taking to 'keep their baby healthy.' For the most part, women felt supported by their healthcare providers. Three women who had recently emigrated to Canada commented on the close attention they received from their maternity care team. These women valued their interactions with healthcare providers, and compared their experiences to their encounters with healthcare providers in their country of origin. As one woman noted,

> Back home they can just give you like one [prenatal] appointment and then the next time you just come when you feel the labour. And when you get there, you're the one who has to tell them that you have a problem…you have HIV…But here they have all the information before you come. So you don't have to say anything…they know you really well…you don't feel alone…[and that's] very good.

When comparing her two pregnancies, another woman reflected on the possible reasons she had more frequent visits with her HIV specialist and obstetrician throughout her first pregnancy, in particular at the start, which was shortly after she arrived in Canada, as she explained:

> [For my second pregnancy, visits are] not as frequent as it used to be…[For my first pregnancy visits were] more frequent because it was like giving out the information, my past record, like the history of…my medical situation…My first pregnancy, I was only like months in Canada…I was coming from a different country… they had to make sure that everything was like recorded, everything was put in their records here…everything had to be like made sure that they follow-up everything and they're also up-to-date according to their own like local things here compared to how I was being treated in my own country.

This woman believed that her visits were increased during her first pregnancy so that her healthcare providers could understand her medical history and ensure she had appropriate treatments; as she identifies, her medical record was an important text that connected members of her healthcare team. Furthermore, similar to the other participants who were new to Canada, this woman understood and appreciated the increased monitoring and visits during pregnancy, and had positive interactions with her healthcare providers.

One woman who was born and raised in Canada also experienced increased visits during pregnancy, but expressed frustration with the rigidity of

the appointment schedule, and a lack of clarity from her healthcare team as to why she had to attend a specific clinic for procedures that she felt could be completed closer to home:

> A nurse called me a few times and said, "You've got to come in. We haven't seen you [in a month]… the [prenatal clinic] wants me to be here every four weeks at least…They never gave me an explanation, "Because you're HIV positive"… "You have to come here. We need to see you"… I have little kids at home and I'm a single mom. I don't drive…it's an hour drive to get there, and a lot of finagling…[and] it's a long day to bring [young children] for five hours. Cab rides there and back, food, you know, diapers, all this stuff you have to bring.

I asked this woman what she thought about the nurse insisting that she comply with the appointment schedule, and she responded:

> My assumption and how I felt she was talking to me was, "You're HIV positive. You're irresponsible. You're an ex-drug addict. You're not taking care"…It was like she was looking for something wrong…Because I'm HIV…The first pregnancy, I was more than happy with the care because I was just as much in fear as is drilled to you in the world, right?...This is my third pregnancy [as a woman living with HIV]…I'm their lowest "high risk" patient…I'm on my meds. I don't use drugs and alcohol. I'm perfectly healthy…I'm not doing anything that would put my baby at risk.

This woman valued the assurances of her HIV specialist and obstetrician during her first pregnancy, which helped mitigate her fears about HIV transmission. Her perspective began to shift during her third pregnancy, however, when she questioned why her pregnancy was viewed as 'high risk' given her experience and knowledge as a mother living with HIV and the work she was doing to prevent transmission. This woman questioned how a rigid prenatal appointment schedule would further contribute to achieving the goal of preventing perinatal HIV transmission, and felt that the rigidity of her healthcare team was partly fueled by their discriminatory beliefs about people living with HIV as irresponsible. This woman's interpretation highlights how institutional expectations regarding appointment frequency can be experienced in positive and negative ways. How women participate in prenatal care as its currently organized may vary depending on their social positioning and past experiences. Furthermore, this woman's suggestion that being monitored also served a purpose to find 'something wrong' became a clue to look closer at institutional practices.

The rationale of the 'high risk' obstetricians to increase prenatal visits over time was grounded on the assumption that all pregnant bodies, regardless of HIV status, should be monitored to respond to any emerging complication and to ensure minimal risk to the baby, as one obstetrician explained:

We start escalating visits toward the end of pregnancy…on a week to week basis, there is a higher and higher probability of something being different…the fluid starting to decrease because the placenta doesn't work

as well, the blood pressure starts to go up, or some other complication that

happens.

Another nurse highlighted the importance of all women attending prenatal

appointments in the 'high-risk' clinic to ensure a 'healthy pregnancy,' and to give

women options in the event of a complication emerging:

> There are different things that happen at different times in pregnancy…If
>
> we miss that boat, and they say, "Well, I can't come, can't come, can't
>
> come," then at 24 weeks, they have anatomy ultrasound, baby has a big
>
> bad heart. We're no longer in that window of time for a termination, if that
>
> is what they wanted… there's risks to everything, right… pregnancy is a
>
> time-limited event…And we don't see them for the first 3 months…until
>
> 12 weeks. So we only have that 6 months of time to care for them and
>
> potentially impact or make sure that, you know, the pregnancy is as
>
> healthy as possible.

Various healthcare providers recognized the difficulty some women have with

attending appointments, but admitted the system was not always flexible to

correspond with women's realities, as one obstetrician explained:

> By the time of the third phone call from the clinic saying, you know, you
>
> haven't made your appointment… what I do is say okay, just ask her what
>
> day of the week she can come. Because we're too rigid. Your ultrasound is
>
> at 7:30 in the morning. Well, they can't get there…And then all of a
>
> sudden they don't show. Well, of course they don't show because it's not

convenient. Ask her when she can come, and work backwards…But our

nurses are saying, "No, but as part of your care, the standard is that you be

seen every 2 weeks," or 4 weeks, whatever it is. And if we fail to do that

then we're potentially missing out on a complication…They still can get

high blood pressure. They can still get every other complication. So we

need some interval…we've got to have a little bit of flexibility around

that…if we could work around it, we could accommodate it. The clinic

system isn't that flexible…where they can just arrive and have an

ultrasound.

This provider revealed how the availability and scheduling of appointments was

influenced by the organization of hospital care and prenatal care guidelines. When

combined, these factors create particular conditions that pregnant women who are

deemed 'high risk' are expected to comply with, even if their social circumstances

make it difficult to do so.

Reducing Risk through Medical Interventions

Women and their healthcare providers discussed other mechanisms through which

risks to the fetus could be mitigated in the context of HIV and pregnancy,

including the application of medical interventions.

Breastfeeding avoidance is currently recommended for mothers living

with HIV in Canada since the risk of transmission through the consumption of

breast milk is not zero, and, in a Canadian context, the benefits to the infant of

formula feeding outweigh the risks associated with breastfeeding (Money et al., 2014; WHO, 2016a). The recommendation to formula feed is communicated to women living with HIV as part of routine prenatal care where, for the most part, pregnant women are encouraged to breastfeed, as one nurse explained, 'We encourage breastfeeding for all our moms, except where it's contraindicated. Which would include any medications that they're taking or HIV, right? Because it's safe for most other infectious diseases. Like Hep C, Hep B, we encourage breastfeeding. But HIV's the one *no*.'

All of the women I spoke with had already come to terms with this recommendation, and did not question or raise formula feeding as a personal concern; similar to taking their HIV medications, women felt it was something they could – and should - do to protect their babies from HIV. This perspective rang true for a social worker who reflected upon their experience getting women access to formula, which is freely available to mothers living with HIV across Ontario: 'Most often it's the second, third pregnancy, and it's sort of like business as usual…the woman will often say, "When are we going to do the…application for the formula? I'm late for my [next] appointment. Can we hurry up, I've got to get to the lab" …and off she goes.'

Healthcare providers varied in how much time they spent explaining infant feeding guidelines with women, and how comfortable they were discussing the current state of global infant feeding practices in the context of HIV, based on their discipline and scope of practice. The one thing that healthcare providers did

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consistently was reinforce the recommendation to formula feed. One HIV specialist, who spent considerable time with women during prenatal visits, described her interactions:

> I talk [with women] about feeding, in that we don't recommend breastfeeding and that there is fully funded formula. And talk about how that's difficult. And increasingly, starting to talk a little bit about emotions of how you feel about that…and how are they going to explain that they're not breastfeeding, particularly if they come from a culture where breastfeeding is really the norm [for mothers living with HIV] … also talking about the emotion of being on [the inpatient ward] … we are a very pro-breastfeeding culture in general. So saying that you're going to see posters promoting breastfeeding, and that may be quite difficult for you to deal with…We're saying you can't breastfeed. But you can have skin to skin with the baby's head on your shoulder…as long as they're not going to suckle at your breast.

This healthcare provider acknowledged the complexity of the recommendation to formula feed for women living with HIV in Canada, especially since in other parts of the world women living with HIV are recommended to breastfeed. Despite her openness to discuss this issue with women prenatally, the recommendation to formula feed was firm; there was no possibility of discussing choices, or breastfeeding, because of the current guidelines (Money et al., 2014; WHO, 2016a). Although tensions remain in the ways that women living with HIV,

healthcare providers, and advocates around the world apply research evidence to make recommendations about infant feeding in the context of HIV (ICASO, 2018; CATIE, 2018; WHAI, 2017), these discussions are always grounded in a risk discourse that prioritizes reducing risks to the baby regardless of women's infant feeding preferences.

The mode of delivery (vaginal or caesarean section) was another clinical intervention that was discussed with women prenatally. For healthcare providers, the recommended mode of delivery coincided with the goal to reduce risk and was based on available research evidence, as was explained by a nurse:

> As soon as we offered the antiretrovirals…we saw that transmission decreased significantly. So you have to follow those guidelines…And then offering vaginal deliveries. Because it used to be caesarean section regardless. And now depending on the patient, their viral load, how they've done in their pregnancy, then we talk about vaginal births…Which is…much better for the patient, as long as we're not harming the baby.

The women I spoke with had a similar goal to reduce harm to their babies during childbirth, as was expressed by one woman who reflected upon her decision to have a caesarian section (C-section):

> I got to pick whether I wanted to have a C-section or a regular birth…that was a big deal because everybody I had ever talked to prior to having my first baby was like, "Oh, you're going to have to have a C-section because you can't have a [vaginal] delivery" …and so I did opt for a C-section

with all my babies because I feel for myself there's more control over the

amount of blood they're in.

This woman wanted to do everything she could to protect her children, and even

though she had an undetectable viral load and was told by her healthcare

providers that she could have a vaginal delivery, she went ahead with having a C-

section. This same woman told me about the fear that had been 'drilled' in to her

about reducing risk; she repeated adamantly that she was taking her medication

and 'not doing anything that would put my baby at risk.' Although her

explanation suggests that she had full control and choice over her mode of

delivery, the risk discourse that prioritizes preventing perinatal transmission

underpinned her decisions. The risk discourse also coordinated the actions of the

healthcare providers who supported her decision, who approved the C-section to

go ahead, and who organized all of the institutional resources that were needed in

the operating room and on the postpartum ward. As this woman suggests, risk is

what organizes women's decisions, even if they are given information about the

safety and benefits of a vaginal delivery. The broad and active 'social presence'

(Mykhalovskiy, McCoy, & Bresalier, 2004) of the risk discourse in women's

daily lives means that the emphasis of care, as was noted by a nurse, is 'not

harming the baby,' even if it means more risk and difficulty for the mother

following a C-section or providing formula regardless of her infant feeding beliefs

and preferences.

Discussion

This study revealed how the prevention of perinatal HIV transmission permeated the experiences of pregnant women living with HIV, and was reproduced in the work of healthcare providers operating in a 'high risk' prenatal clinic in Ontario, Canada. Echoing Mykhalovskiy and colleagues (2004), risk was a 'complex social technology' and omnipresent discourse in the lives of women living with HIV that intersected 'across a variety of interlocking sites' (p. 328) including the treatment regimens they were prescribed and expected to adhere to, attending prenatal clinic appointments, and the application of medical interventions. Healthcare providers' work was also organized by a dominant discourse that centers on reducing risk and ensuring pregnant women are compliant with medical recommendations. The risk discourse that women encountered and that coordinated the work of healthcare providers is central to the sociohistorical organization of prenatal health practices and pre-dates HIV; these practices prioritize fetal health by reducing risks to the baby generally, and preventing perinatal HIV infection specifically.

     'Risk-based' prenatal care is the normative care model that focuses on identifying and targeting 'high risk' individuals in order to decrease risk to the fetus (Weir, 2004); this model emerged in the early twentieth century when the monitoring of pregnancies became the norm, and the 'patient's body became a site for continuous data collection' (Weir, 2004, p.58). This dehumanized, mechanistic approach to pregnancy and childbirth is a result of the rise of

technological interventions and protocol-based care (Coxon, Sandall, & Fulop, 2014). As the women in this study articulated, their medication adherence and HIV viral loads were technological markers used to monitor their pregnant bodies. Practices such as these gave rise to surveillance medicine in the early twentieth century (Armstong, 1995; Rothman, 2014), which refers to the application of surveillance and diagnostic technologies to individuals and populations (Foucault, 1973), as well as epidemiological and statistical models to create probabilistic understandings and actuarial calculations of health risks (Bauer & Olsén, 2009; Murphy, 2000). Not only were these practices applied to the practice of caring for individual women; 'risk factor' epidemiology paved the way for widespread population surveillance, and health and social services increasingly targeted their programmes and services towards 'at risk' pregnant women, mothers, and their babies, and continue to do so today (Zadoroznyi, Benoit, & Berry, 2012). These actuarial practices are also disciplinary practices because they fuse statistical norms with moral claims; risk takes on moral connotations whereby the moral 'good' is about minimizing risk and harm to the baby (Ruhl, 1999).

Preventing perinatal HIV transmission has been the focus of health professionals, policy makers, and the public at large not only in Canada, but around the world for decades (Moland & Blystad, 2009; WHO, 2010, 2016b). Significant funding allocations, policy decisions, and the organization of health services have centered around the scale and spread of services known as 'preventing mother-to-child transmission,' or PMTCT (Mutabazi, Zarowsky, &

Trottier, 2017). PMTCT programmes are credited for reducing HIV infections among children by 52% from 2001 to 2012 and being an important mechanism to completely eliminate perinatal HIV transmission (Mutabazi, Zarowsky, & Trottier, 2017; WHO & UNICEF, 2007).

While women living with HIV strongly desire preventing perinatal HIV transmission, the PMTCT discourse is problematic because it maintains a direction of blame of mothers giving HIV *to* their infants. In Canada, language continues to evolve and, for the most part, 'perinatal transmission' has been adopted by clinicians and in published guidelines (Loutfy et al., 2018; Money et al., 2014). At the same time, the taken-for-granted language of PMTCT remains in literature and public consciousness (Mutabazi, Zarowsky, & Trottier, 2017; WHO & UNICEF, 2007), and coordinates people's ideological perspectives (Smith, 2005). Moreover, 'adherence' and 'compliance' were terminologies used frequently by women and healthcare providers. Mykhalovskiy and colleagues (2004) argue that the term adherence has been 'popularized within biomedicine as a less paternalistic alternative to compliance' (p. 317); however, it was interesting to note how women living with HIV in this study utilized the term adherence while healthcare providers continued to speak about appointment and treatment compliance. Perinatal care decision-makers and clinicians are encouraged to think critically about how language, for example, appointment 'compliance,' treatment 'adherence,' and breastfeeding 'avoidance,' can have certain connotations, can influence how people think and act (Campbell, 2016), and can set in motion

institutional courses of action (Smith & Smith, 1998). Furthermore, women living with HIV have become conditioned to think about their bodies and their worlds through the lens of these terminologies; they have had language imposed on them, and have been consigned to live in a discourse not of their making (Smith, 1974, 1987, 1990). We all need to account for our language as coordinating our consciousness (Smith, 2005), and shift the discourse of PMTCT to not continue to position women living with HIV as vectors of HIV infection.

The underlying ideology of programmes aimed at preventing perinatal HIV transmission is a 'risk rationality that links health behavior to concrete manifestations of good or ill health' (Moland & Blystad, 2009, p. 470); and it is this rationality that links a mother's behaviour to the health observed in her fetus and infant. As Murphy (2000) asserts, the 'discourse on risk and responsibility is particularly heightened where it intersects with the ideology of motherhood' (p. 320). Moreover, in PMTCT programmes, the goal is to ensure 'HIV-negative' children, however, 'the health and survival of the mother is not an issue that the program addresses, even though the program's success is critically dependent on her efforts as a mother, carrying and nurturing her child' (Moland & Blystad, 2009, p. 448). When considering the accounts of women in this study alongside the policies and practices underpinning PMTCT programmes, the significant chasm between the top-down aims and organization of PMTCT services and the social circumstances of women living with HIV (Moland & Blystad, 2009) becomes visible.

This study also expands the conceptualization of 'healthwork' of people living with HIV put forward by Mykhalovskiy and colleagues (2002, 2008) demonstrating how women living with HIV go to great lengths to juggle numerous pressures and responsibilities in order to fully participate in their care and achieve the recommendations of their healthcare providers. Women 'learn that they may avoid infecting their infants if they take certain precautions and carefully observe instructions' (Moland & Blystad, 2009, p. 447); they do this by enduring clinical procedures and practices that have physical, social, and emotional effects on their bodies, relationships, and their daily lives. Women's efforts, and their specific needs and experiences as they navigate perinatal care, become overshadowed by the goals to prevent perinatal HIV transmission. Although women very much want to prevent HIV transmission in their infants, more attention could be paid to their needs and realities as pregnant women and mothers.

By virtue of their HIV-positive status, the pregnancies of women living with HIV are institutionally categorized as 'high risk,' but the present study revealed how the risk discourse has also crept into women's everyday worlds. Risk is also about what women do day-to-day. This became particularly visible by the participant who felt under surveillance when corresponding with a nurse regarding her appointment attendance, and believed she was being labelled as 'irresponsible' because of her HIV-positive status and addiction history. As is evidenced in the institutionalized practices of 'risk factor' epidemiology

(Zadoroznyi, Benoit, & Berry, 2012) and the social relations of risk and compliance, scrutiny and suspicion of health and social care providers may fall disproportionately on women who are perceived to pose a greater risk to their infants (Mykhalovskiy, McCoy, & Bresalier, 2004) resulting in heightened prenatal surveillance and monitoring. This leaves women living with HIV in a position to monitor their own bodies and present themselves as 'responsible, effective "risk managers"' (Coxon, Sandall, & Fulop, 2014, p. 54). In particular, women are expected to be 'extremely attentive in monitoring their bodies to ensure the health of their babies is not threatened in any way,' as well as be 'vigilant in their attendance at antenatal appointments and undergo all medical tests and examinations suggested by their healthcare professionals' (McDonald, Amir, & Davey, 2011, p. 2).

Healthcare providers that women interact with focus on producing institutional accounts regarding women's treatment adherence and undetectable viral loads, appointment attendance, and the clinical procedures performed on them; accounts of this nature minimize women's daily realities, feelings, and experiences. As Pence (2001) asserts, the frame that organizes institutional reporting prioritizes the work of healthcare providers. The full story of how women organize their lives and overcome personal challenges to attend medical appointments, as well as their desires as pregnant women and mothers, and the physical and emotional effects of the procedures that are expected of them because of their HIV-positive status become obscured as the specialist

practitioners overseeing their pregnant bodies focus on specific processes and outcomes (Pence, 2001). The result is that practitioners develop a 'very narrow definition of what it means to accomplish their task and what it means to do so in a fair manner' and, most importantly, the medical records that officially document the procedures and interactions throughout a woman's entire prenatal trajectory are 'about the woman, but not from her' (Pence, 2001, p. 220). Healthcare providers must shift their language and consciousness away from positioning women living with HIV as the *source* of risk for their babies; this standpoint perpetuates the direction of blame from mother to child and maintains harmful ideologies. Those involved in the provision and management of perinatal care for women living with HIV must acknowledge that these women are doing what they can do to ensure the health of their babies, regardless of their social circumstances. Women's actions and efforts should be valued and commended, and their experiences should be celebrated by their healthcare providers and reflected in institutional textual accounts.

Conclusion

Through institutional ethnography, some of the consequences for women living with HIV regarding the current organization of prenatal care that emphasizes risk were revealed. This study suggests some ways to shift language practices to optimize the prenatal care experiences of pregnant women living with HIV in Canada and beyond.

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Chapter Five: Time, Travel, Risk and Safety: A Critical Examination of the Organization of "High-Risk" Maternity Care for Women Living with HIV in Canada[3]

Abstract:

In Canada, the pregnancies of women living with HIV are classified as "high-risk" and are typically overseen by obstetricians who practice in regional, academic teaching hospitals within large urban centres. This institutional ethnographic inquiry explicates how the organization of maternity care for women living with HIV has particular implications for women's pregnancy and motherhood experiences. Beginning from the standpoint of mothers living with HIV in Ontario, Canada, this study reveals how the discourses of "risk" and "safety" are differently known and operationalized by women and their healthcare providers, and calls into question the classification of women's pregnancies as "high-risk."

Introduction

Risk in pregnancy is predominantly assessed from a biomedical perspective whereby one's past obstetric and medical history is evaluated alongside epidemiological and population-level data (Bachman & Lind, 1997; Gupton, Heaman, & Cheung, 2001). The classification of a woman's pregnancy as "low" or "high-risk" can predict the obstetrical care trajectory that she will follow including care related to risk prevention and management (MacKinnon & McIntyre, 2006). In Canada, the care of pregnant women who have been categorized with "high-risk" pregnancies is typically overseen by obstetricians. Although many hospitals have specialized clinics for "high-risk" pregnancies, these services tend to be located in major urban centres (CIHI, 2004).

In Canada, the pregnancies of women living with HIV are classified as "high-risk" due to the increased chance of maternal or fetal medical complications developing (CIHI, 2004; Vanier Institute, 2017; van Teijlingen 2005). "Risk" in this context includes the mother's medical conditions including HIV infection. Women living with HIV are recommended to be monitored by an HIV and maternal fetal medicine specialist during pregnancy (Money et al., 2014); these specialists are predominantly located in tertiary, regional academic teaching hospitals where women typically deliver their babies (PCMCH, 2013).

Categorizing the pregnancies of women living with HIV as "high-risk" from a biomedical perspective and situating women's care in specialist clinics in regional hospitals means that women will make logistical arrangements related to

employment, transportation, and/or childcare responsibilities to attend

appointments and complete recommended procedures (CIHI, 2013). Locating care

in regional hospitals is particularly problematic for women who live a

considerable distance away. For women who rely on public transportation, have

precarious employment and/or have limited income, the act of travelling to

appointments and leaving behind local responsibilities can introduce troubles and

worries that can complicate women's experiences of pregnancy and motherhood.

Moreover, the current organization of maternity care for women living with HIV

means that women may not be afforded the same flexibility and choice of

healthcare provider as women who are not HIV-positive (e.g. midwives, family

physicians, and community obstetricians). Instead, pregnant women living with

HIV are expected to comply with the recommendations and care protocols that

exist within a particular system of specialist and centralized care (Money et al.,

2014).

As a researcher who has contributed to projects focused on HIV and

motherhood (Authors et al. 2015a, 2015b, 2016a, 2016b, 2017) and who has

learned about the current organization of maternity care for women living with

HIV in Ontario, I became interested in exploring how women navigated care

during the perinatal period. I sought to elucidate how the coordination of this

specialized system of maternity care produced particular pregnancy and childbirth

experiences for women living with HIV. For example, I have questioned how the

system of care that women encounter creates conditions in which women living

with HIV need to reorganize their daily lives and responsibilities to participate in their care – both for their own sakes, and to satisfy expectations of their healthcare team. "Healthwork" refers to the physical, emotional, and psychological activities that people do to take care of themselves both within and outside of formal healthcare spaces including medication practices, interacting with healthcare providers, and learning about their health conditions and treatments (Abraham et al., 2017; McCoy, 2009; Mykhalovskiy, 2008; Mykhalovskiy & McCoy, 2002). "Healthwork" has served as an important orienting concept in this study regarding how and under what circumstances women encounter HIV and maternity care.

Method of Inquiry: Institutional Ethnography

Institutional ethnography has been used extensively to explicate diverse health, public health, and HIV-specific issues (e.g. Bisaillon, 2011; Grace, 2015; Grace, Egan, & Lock, 2016; Mykhalovskiy, 2008) and is the critical research strategy that was employed in this study. Developed by Canadian sociologist Dorothy Smith (Smith, 1987, 1999, 2005, 2006), IE starts from people's lived experiences by making connections between their local realities and the socially-organized "ruling relations" that shape people's actions and their lives (Campbell & Gregor, 2008; Smith, 1987). The analytic focus in IE is people's intentional work that involves time, effort, and skills (Hussey, 2012; Smith, 2005). By engaging in an iterative investigation, the ethnographer aims to uncover the trans-local social processes that organize and produce situations, and reach beyond the scope of any

one individual and their local, everyday world (Smith, 1987). IE is particularly useful to examine complex social processes across multiple local sites including healthcare institutions, community organizations, and government entities (Grace, Egan, & Lock, 2016). Furthermore, the ethnographer explores the actions of multiple people within an institutional setting to trace how people's work is coordinated and why people do the things they do within a particular setting such as healthcare (Sinding, 2010; Smith, 1999). A detailed description of how everyday experiences are inextricably bound to social and institutional forces of dominance and subordination is created through this process (Miller, 2005; Mykhalovskiy & McCoy, 2002).

Data Collection

This project was approved by [Research Ethics Board] and began with interviews with pregnant women living with HIV who received their HIV and prenatal care within a regional hospital in Ontario, Canada. Participants were recruited at an HIV clinic as they attended routine appointments with their HIV specialist. Five women were identified through this process from March 2016 to February 2017; four women agreed to participate, gave written informed consent, and were given a pseudonym to protect their identities. I interviewed the women once during their third trimester and again when their babies were three months old. I asked about who, how often, and for what purpose they attended medical appointments during pregnancy, at childbirth, and postpartum; what textual resources they were given

by any healthcare provider during this time; if they encountered any challenges along the way, and how they were affected by those challenges. Participants ranged in age from 35 to 48 years. They all had one to three children between the ages of 18 months and 19 years and had experienced previous pregnancies as women living with HIV. One woman was born in Canada and identified as Caucasian; the other three identified as Black and had immigrated from African countries in the previous two to five years. Two women were married with partners and two were not in a relationship. Two women lived in the city where the hospital was located and two women lived an hour drive away.

After completing these interviews, between November 2017 and April 2018, I interviewed 12 people working in the HIV clinic, prenatal clinic, Labour & Delivery and the postpartum in-patient ward including five physicians, three social workers, three nurses, and one pharmacist, all of whom were given pseudonyms. I asked about their day-to-day work to deliver care to pregnant women and/or mothers living with HIV; their HIV-specific training; and texts that guided their practices. Recruitment of healthcare providers was iterative; as I learned about the challenges that women faced and about the institutional complex women navigated for HIV and maternity care, I made decisions about which healthcare providers to reach out to and interview next. I asked healthcare providers about their roles and work activities as a way to shed light on and find possible explanations for the experiences that women described. All interviews were audio-recorded and transcribed verbatim.

Analytic Process

I began my analytic process from the standpoint of women living with HIV. I first reviewed women's accounts to understand what "work" was involved to participate in their care. Reading women's interviews in this way helped me begin to "see" their accounts "organizationally," that is, to make connections between their activities and institutional forms of ruling and governance.

I then reviewed the healthcare provider interviews to understand their work activities and make connections between their routine practices and women's experiences. As I read women's and healthcare providers' accounts, I was paying attention to the social relations that organized their actions. Importantly, women living with HIV and their healthcare providers were not the objects of the investigation, but rather, "it [was] the aspects of the institutions relevant to the people's experience, not the people themselves, that constitute[d] the object of inquiry" (Smith, 2005, p. 38). Through this analytic process, it became apparent that the delivery of perinatal care to women living with HIV by specialists within regional hospitals in large urban centres created certain conditions in which women living with HIV had particular experiences of pregnancy and childbirth. Furthermore, this process also illuminated how the current system of care may create different experiences depending on where women lived and the specific nature of their employment, childcare, and other familial responsibilities. What follows is a description of the "work" that women living with HIV do to interact with and navigate perinatal health services, the

current organization of "high-risk" maternity care for women living with HIV, and how the current system of care creates troubles for women, especially women who live a considerable distance from the hospital and/or find it challenging to balance responsibilities at home alongside healthcare engagement because of their social circumstances.

Findings

Women's Accounts of Navigating Appointments During Pregnancy

All four women talked about troubles they faced with regard to scheduling and attending their appointments during pregnancy, and the measures they instituted as a result. Place figured prominently in women's troubles, and vicinity to healthcare was something women considered when discussing their experiences navigating prenatal care. Tabitha, pregnant for the second time following her HIV diagnosis, explained how she travelled one hour each way to the regional hospital where her HIV and maternity care specialists practiced, even though she had a family doctor in her community who she saw regularly for her general health. Tabitha identified some challenges she associated with traveling to her prenatal appointments:

> It's a big deal because you have other things that you have to leave behind…mostly work…I've learned to schedule [my appointments] on the days that I want to take a day off…[and] just to avoid the frequency of travelling…I feel like it's a burden to always ask for time change from

friends or give up work just because I have to come [to my appointments]…There's laundry to be done, there's cleaning to be done, there's the baby's stuff to put together. And just my time to relax…being pregnant now, I'm getting tired. I need that time to sit and relax.

I asked Tabitha what she meant by leaving things "behind:"

I wait for a long time, but we see doctors for just like maybe five minutes…But look at the time that you're losing for wait, right? It's an 8-hour shift. That's money….[I arrived at] 7:30am this morning…I'll be going home, maybe it will be like 3:00 or 4:00 depending on the weather. That's like a full shift…The longer I wait here, I get tired. And the following day, I have to go back to work.

Although Tabitha valued the specialist care she received, attending her appointments was not without consequence. Tabitha did a considerable amount of work to synchronize her appointments with her employment schedule and physically travel to the hospital. She equated the time and energy spent waiting for her healthcare providers and organizing her life around her appointments as "lost" time. Tabitha was aware how her multiple appointments had implications on her various responsibilities including her family and employment, and she associated allocating time towards these appointments with losses pertaining to her income and physical health.

Noelle also expressed frustration with the time she spent waiting, which was partly caused by her reliance on a taxi for transportation. Her frustration was

exacerbated by the distance she lived from the hospital, and her desire to prioritize her children's routines of school, naptime, and meals. She explained her frustration that resulted from relying on a taxi and feeling a lack of control over her appointments:

> I'm also on somebody else's time…I've had to wait an hour or two for my return [taxi] …if [my child] is in school, I have to be back [home] for [a certain time]…we have a life here…The nurse I had a problem with…She kept booking my [prenatal] appointments for 1:00. And I kept saying I can't come…I'm not bringing my kids after school or take them out of school or whatever at 1:00 when no one's napped and it's insane. And then we're going to have to have dinner [near the hospital]. And we're not coming back [home] until after probably 6:00, 7:00. Then bedtime's missed…I'm not doing it. And then [the nurse] was giving me crap, "You need to get to your appointments. We haven't seen you in 6 weeks."…8:30 in the morning, book me for that time. Because then I'd just pile everybody in, we go, and then I'm back generally by noon or 1:00 so I can nap everybody. Lunch and nap. And then it's more of a sane day…It makes no sense to go all the way up there with my kids, or for anybody to sit an hour, maybe 2, for the doctor, for the nurse to come in, take your blood pressure, check your urine, and you go on with your day…Why am I here for this long? You know, it doesn't make any sense. It's an hour's drive there and back."

Tabitha and Noelle's accounts highlighted a number of organizational clues for further exploration including the amount of time they spent waiting for and seeing their HIV specialists and obstetricians, the frequency of their prenatal visits and the rigidity of their appointments in terms of how often their healthcare providers expected them to attend and when appointment times were available. Noelle's questioning of "why am I here for this long?" also raised questions about why some aspects of her care, such as checking her blood pressure, testing her urine and completing an ultrasound, could not be completed closer to home by another healthcare provider rather than a pregnancy "specialist." I turned to healthcare providers to uncover some answers.

The Organization of "High-Risk" Maternity Care

The healthcare providers I spoke with described their work to deliver care to mothers living with HIV, and some of the rationale for locating this care within regional hospitals. Women living with HIV were referred to a specific hospital for their HIV and maternity care because it was located in the provincial health district in which they resided (LHIN, 2007). This particular hospital, as one obstetrician pointed out, was the "level 3 referral centre" in which high-risk obstetricians practiced and were responsible for a particular "catchment area;" the distance women had to travel to receive care was an outcome of where the hospital was located relative to their home.

Meredith, a high-risk obstetrician, explained what procedures women living with HIV could expect as part of their prenatal clinic visits:

> For practical reasons we tend to do most of their prenatal care [in the hospital], even for the times when it seems like it's not, you know, sort of a high-risk appointment…They're not seeing other specialists, they're not necessarily getting specialized tests here. Just to avoid either the duplication or the incomplete prenatal care…We try and aim to do a first visit somewhere at the end of the first trimester. And then we aim to do regular prenatal care from that point until the very end of pregnancy. Assuming that the pregnancy otherwise is uncomplicated, we don't generally see patients more frequently than otherwise women would be seen during pregnancy…What we do is offer again normal prenatal care. We make sure that people have their normal blood work that every pregnant person is supposed to have done…We go through how we think that her HIV is going to be impacted by the pregnancy. Which usually we're not expecting…Usually the pregnancy care itself doesn't change very much. But around the time of labour and delivery, there's certain precautions…For follow-up visits…a nurse will do routine things like check their blood pressure, listen to the baby, measure their tummy. And then… a question period of…tell me how things have been going since your last appointment.

Meredith explained that women living with HIV received "normal" prenatal care within the "high-risk" obstetrical clinic, for example, their visits occurred at the

same frequency and they would have similar screening bloodwork to women without HIV; her explanation calls attention to the contradictory nature of locating the "normal" prenatal care of women living with HIV within a "high-risk" clinic. Rather than attend a "high-risk" prenatal clinic because of medical "risks," Meredith explained that women's prenatal care occurred within the regional hospital "for practical reasons" and to avoid duplicating care or result in women having incomplete prenatal care. Meredith's explanation raised questions about for whom the clinic organization and care delivery was "practical." Returning attention to Tabitha and Noelle's accounts, seeing their HIV specialist during pregnancy in a separate clinical setting coupled with the need to travel and coordinate their lives to attend appointments illuminates the disjuncture between healthcare providers' and women's perspectives, and the fact that the current system of prenatal care was not "practical" for many women.

I asked another obstetrician named Rebecca about the rationale for the frequency of prenatal visits. In contrast to Meredith, Rebecca openly questioned the schedule of appointments that women were expected to follow; she acknowledged that the visit frequency was not based on a particular clinical guideline or body of research evidence when she stated "our nurses are saying, 'as part of your care, the standard is that you be seen every 2 weeks,' or 4 weeks, whatever it is. And if we fail to do that then we're potentially missing out on a complication…So we need some interval. The made-up sequence of visits for Ontario, the way we do it, the 13 visits, is stupid. It's just made up. So we've got

to have a little bit of flexibility around that." Rebecca acknowledged that some flexibility in women's visits may be possible to better respond to women's realities. Our discussion continued with Rebecca describing the origins of centralizing pregnancy care for women living with HIV; in response to Tabitha and Noelle's challenges of getting to the hospital, I inquired if prenatal care could be shared with other providers such as midwives and community obstetricians who practiced closer to where women lived. Rebecca explained that concerns related to HIV-related stigma at the start of the HIV epidemic along with the specific procedures that are recommended during the perinatal period contributed to the establishment of services for this patient population under the umbrella of the "high-risk" prenatal clinic: As Rebecca stated:

> Historically, part of the reason for [the clinic] was the other supports that we can give in real-time…they can see social work at the same time, if that's convenient, and save umpteen trips…Often it means long-ish visits but we try and do it like same day as [HIV clinic] …so that everything can be one time… And then it became, okay, well, there was lack of familiarity with the condition. So then that evolved…And the whole stigmatization. Which is also what we felt that we do well here…Our nurses are very sensitive about that…so we felt we had something to offer…it's not that our midwife colleagues can't see somebody who's totally suppressed on their meds and do the delivery. That's not the point…it's the organization of all the rest of it…There are some things

that I do think that we do well…And those things include stuff around privacy, stuff around not being judgemental…there's a whole lot of stuff that places do well if you see something repeated. Whereas if it is a one-off or the first time, then it's like how do we do this? And then it becomes people feel like they're special, but not in a good way.

Rebecca's account highlights how the providers were committed to creating a clinic where women could receive non-stigmatizing care that reflected best practice in the field and have access to numerous supports in one setting including obstetrics and social work. At the same time, Rebecca's explanation was at odds with women's accounts of the inconveniences they associated with traveling and waiting for care they believed could be provided in less time, and perhaps closer to home. Rebecca also argued that her team "had something to offer." Not only did the "high-risk" team have the clinical expertise and familiarity with HIV in the context of pregnancy to ensure women received the care required to prevent perinatal HIV transmission, they could also offer some assurances – to themselves, to women living with HIV and to regulatory bodies funding and monitoring "high-risk" pregnancy care – that the care they provided ensured the safety of women living with HIV and their newborns. "Safety," as Rebecca highlights, was not only about the medical procedures that healthcare providers instituted to prevent transmission, such as HIV-specific medications at the time of delivery and access to formula postpartum, but also encompassed ensuring women's safety as it relates to her privacy and delivering non-judgemental care.

In this context, the discourses of "risk" and "safety" became visible in Meredith and Rebecca's arguments for ensuring "complete" prenatal care, their descriptions of their work to monitor women's pregnancies, and through the institutional establishment of services for this specific population.

Rebecca's account aligned with other healthcare providers who endorsed centralizing perinatal care for women living with HIV as a mechanism through which women could be assured "safe" care for themselves and their babies. Healthcare providers explained that part of their work was to coordinate care and ensure women and their newborns received HIV treatments. Meredith shared:

It's not that there's necessarily a lot of active complicated issues…most women with HIV are [now] otherwise healthy. They take their medications. And their pregnancies unfold [in a] pretty straightforward fashion. Some of it's more just the coordinating with the pediatrics team to make sure that babies get on treatment after delivery. And it's coordinating with the social work team to make sure that they're getting access to formula. And some general obstetricians in the community just don't know those links and how to facilitate those links. So that's the role of [the high-risk team]…it's not necessarily that we're doing much different on a day-to-day visit-to-visit basis but just that we have those links with the different specialists and other groups that these patients need links with…we try and make sure that we're minimizing risk for transmission.

Meredith's view on ensuring care continuity and patient safety, especially to facilitate HIV prevention, was echoed by a nurse, Nancy:

> It's anticipating risk, it's dealing with the medical issues and how they impact the pregnancy… a community hospital cannot care for [some patients]. I mean could they in a pinch? Yes. But is it the safest place for [those patients]? Probably not…She's [likely] going to have absolutely a normal delivery. But if she doesn't, she needs to be in a centre that can care for her…Mom and baby may not be discharged with the appropriate medications…we have it in-house…Mom can go down to the pharmacy…and go home without thinking, 'I have to call it in. Are they going to have it there? Do they have to order it in?'

Both Meredith and Nancy articulated that much of the "specialized" care that women received occurred at the time of delivery, and that prenatal care was similar to what other pregnant women – categorized as "high-risk" or not – would receive. While describing their work, these healthcare providers noted that the pregnancies of women living with HIV would likely proceed similarly to other pregnant women because of the effectiveness of antiretroviral therapy (ART) and the evolution of HIV infection into a chronic health condition. Meredith and Nancy also made arguments for why women living with HIV would benefit from delivering their babies in the regional hospital with the support of maternity "specialists." The team with specialized training in "high-risk" pregnancies were equipped to actively respond if complications emerged thus enhancing "safety"

for women and their babies. Moreover, access to ART for the infant postpartum was noted as a critical component of care coordination. Concern was raised by Meredith and Nancy about a lack of expertise in community hospitals to facilitate this treatment, and how this could have detrimental effects on the safety and health outcomes of women and their babies.

Examining "Safety:" From Whose Standpoint and Under What Conditions?

Healthcare providers' descriptions of their work to mitigate "risks" and ensure the "safety" of women and their babies further emphasized the disjuncture between women's and healthcare providers' standpoints. "Risk" and "safety" took on a different meaning when understood from the perspective of women living with HIV. As Tabitha and Noelle remarked, they had to travel one hour each way to attend prenatal appointments. Noelle was especially frustrated with relying on taxis and shared: "I was just sick of using a cab because…my kids are in the car, [the drivers] drive like maniacs on the highway. So I'm all worked up in this car ride with my…kids crying…it just adds to the chaos…There's already enough with three kids, right?" For Noelle, the very act of travelling to her appointments was experienced as "unsafe" and added "chaos" to her life, even though her healthcare providers perceived care provided in the "high-risk" clinic as "practical" and important to ensure women's "safety."

Tabitha also problematized the notion of "safety" when we met to discuss her childbirth. Although she planned to have a Caesarian section (C-section) at the

regional hospital, Tabitha ended up going into labour early. Consequently,

Tabitha had to seek emergency care at her community hospital because of

concerns about how long it would take to travel to the regional hospital. Tabitha

expressed feeling unhappy with the care she received from the healthcare team

who did not know her history:

> The way that things were handled…I wasn't so happy…When we were
>
> discharged, like [the baby's antiretroviral] medication…the [community
>
> hospital] didn't know the procedure…After we were discharged, we had to
>
> keep going there to get [the baby's] medication. [The baby] used to take
>
> the medication at 6am and 6pm, but we'd go in [to the nursery at the
>
> hospital] every time to get the medication…that happened for a
>
> week…[With my first baby], we had the whole bottle right away…Once
>
> discharged, [the hospital has] to consult the company that brings in the
>
> same medication. And that wasn't done…I think they really didn't know
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> the procedure…[The community hospital] just gave us the prescription. So
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> we went to the pharmacy to get that medicine. But they don't just issue
>
> that medicine…And it was a weekend too…There's nothing the pharmacy
>
> can do unless the hospital where [the baby] was born communicates with
>
> the [company] that releases the medicine…Because I had the [C-section]
>
> operation…I couldn't get up and down. So [my husband] was doing much
>
> of it…[Then] the [specialist] communicated…[and] my husband had to
>
> come to [the regional hospital]…to get the medicine…you can imagine the

> inconvenience…this is a big hospital…they have doctors… They deal
> with different emergencies…They're supposed to know their procedures, I
> would think…And things are supposed to be made easy for us.

At the time of discharge, Tabitha and her husband were handed a written
prescription for zidovudine, but discovered that their community pharmacy could
not fill the prescription. Tabitha already had one baby following her HIV
diagnosis, which she delivered at the regional hospital, so knew that her baby
would receive zidovudine every 12 hours for six weeks, and that there was a
specific process to obtain the medication. As I also learned from the pharmacist in
the regional hospital, access to this medication is facilitated by the in-patient
healthcare team because it is distributed by and paid for through a provincial
government program. Although the community hospital had zidovudine in their
in-patient pharmacy to give Tabitha's baby while in hospital, from Tabitha's
perspective, the team was not aware of the procedure to provide women with a
home supply at the time of discharge. This resulted in Tabitha's husband making
multiple trips to obtain the medicine, and Tabitha and her husband
communicating with her specialists about their challenges. One week postpartum,
and with the assistance of her specialists, Tabitha received a home supply of
zidovudine; but the time that Tabitha and her husband spent waiting and traveling
to the hospital caused much stress and worry for their family – not only because
of the inconvenience, but also with regard to preventing HIV transmission.

Tabitha's difficulties to obtain zidovudine revealed how community hospitals are not organized to facilitate this important aspect of women's perinatal care. Tabitha's story also raises important questions about the rationale to locate women's maternity care in regional hospitals. Even if women are seen prenatally in a "high-risk" clinic and plan to deliver under the care of specialists, her childbirth may not proceed as planned, and she may need to seek care elsewhere. Moreover, although healthcare providers operating in the regional hospital described their role to coordinate perinatal procedures recommended to reduce HIV risk, these practices are irrelevant if women cannot physically access these centres to deliver their babies and they need to rely on other healthcare institutions. As Noelle and Tabitha's circumstances highlight, the "safety" of women and their babies could be compromised if "high-risk" maternity services located in regional hospitals are the only services that are organized to provide women with the tools to prevent perinatal HIV transmission.

Discussion

This institutional ethnographic inquiry explicates how the organization of maternity care for women living with HIV under the care of specialists within regional hospitals has particular implications for women's motherhood experiences (CIHI, 2004; PCMCH, 2013; Vanier, 2017; van Teijlingen, 2005). Even though women had access to obstetrical specialists, this access did not necessarily equate to more positive care experiences or improved healthcare

outcomes (Lewis, Willis, & Collyer 2018). Rather, women questioned the extent to which "risk" was reduced and "safety" was enhanced by specialist care given the troubles they faced. Women's standpoints ran counter to healthcare providers' who argued that the current system was organized as it was to ensure "risk" reduction and patient "safety." Women's social circumstances of traveling distances and leaving behind local responsibilities to attend appointments shaped their view of "place" of care as producing their healthcare experiences (Davidson, Mitchell, & Hunt, 2008). As Winchester and King (2018) highlight, distance is one aspect of healthcare access; it is a "material feature of landscape, yet experienced through the social lens of infrastructure, transport availability, individual resources, choice, and perceived burdens" (p. 201), and these social constructs were definitely salient in women's accounts.

Although this study was conducted in Ontario, Canada, the disjuncture between women's and healthcare providers' perspectives is translatable to other contexts where the pregnancies of women living with HIV are categorized as "high-risk." Because of this designation, women and their families enact practices to follow a rigid, albeit arbitrary, prenatal schedule and manage costs associated with accessing centralized care. The realities of women living with HIV are also translatable to other settings where there exist similar models of centralized and specialist care including cancer care (Arcury et al., 2005; Maddison, Asada, & Urquart 2011; Sinding, Warren, Fitzpatrick-Lewis, & Sussman, 2014).

Examining the troubles that women face during the perinatal period alongside healthcare providers' work calls into question the designation of women's pregnancies as "high-risk" and the centralizing of maternity care within regional hospitals. As noted by healthcare providers, the prenatal care that women receive within "high-risk" clinics is similar to the "routine" procedures that women who do not have HIV would expect. Care becomes more focused on the mother's HIV infection at and following childbirth when she receives zidovudine during labour, the baby receives zidovudine postpartum, and access to formula is facilitated (Money et al., 2014). Importantly, women living with HIV who become pregnant are typically already aware of their HIV-positive status, are taking medications, and are connected to an HIV specialist who is monitoring their treatment (Bitnun et al., 2018; Loutfy et al., 2012). Furthermore, accessing formula through Ontario's government-funded program is not onerous nor does it require a referral from a healthcare provider based in a "high-risk" clinic; women can be referred by any service provider who can verify their HIV-positive status. Women can also self-refer if they received formula for another child and are registered with the administering organization. The interventions to prevent perinatal HIV transmission are also being employed in a context where HIV infection continues to evolve from a medically complex illness with a grim prognosis to a chronic health condition that can be effectively managed with ART, which prolongs lives and has created conditions in which women living with HIV are considering their reproductive options and choosing to become

pregnant (Money et al., 2014). Given these medical and social advances, it is imperative to question the "high-risk" categorization of women's pregnancies, especially when women encounter so many challenges, and often have to bear costs and burdens, when navigating the "high-risk" system.

Canadian guidelines for the perinatal care of women living with HIV recommend that the "provision of pregnancy and reproductive health care…should involve collaboration with individuals experienced in the management of high-risk pregnancy and HIV care of women and infants" (Money et al., 2014, pg. S4). As women and healthcare providers illuminate, however, it is not clear that locating care within regional hospitals is essential to achieving "safe" perinatal care. Women invested significant time and effort to attend their appointments and mitigate social consequences related to employment and familial commitments to participate in care that healthcare providers framed as "safe" and "practical." Following childbirth, Tabitha's account also illuminated how centralizing care introduced concerns related to her baby's "risk" of perinatal HIV transmission, and impracticalities related to accessing zidovudine.

This study makes visible how the discourses of "risk" and "safety" show up differently in the activities and perspectives of women living with HIV in contrast with their healthcare providers. Healthcare providers are organized to implement standardized, routine prenatal care practices and HIV-specific checklists that center around reducing "risks" to the infant (Rankin & Campbell, 2009). Conversely, the women's accounts evidenced a different interpretation of

"risk" and "safety." By following the tradition of other institutional ethnographers who have contributed to the study of illness experience (Miller, 2005; McCoy 2005, 2009; Mykhalovskiy, 2008) and who have explicated the discourses operating within healthcare settings (Melon, White, & Rankin 2013; Mykhalovskiy, McCoy, Bresalier 2004; Rankin 2015), this study amplifies the activities that women living with HIV enact to manage and participate in their perinatal care.

This inquiry revealed how the perspectives of mothers living with HIV were overshadowed by maternity specialists who have secured hegemonic control over perinatal care, have positioned themselves as the authoritative knowledge of pregnancy and childbirth, and whose practices have become cemented within regional hospitals (Benoit et al., 2010; Jordan, 1997). As Rankin and Campbell (2009) assert, "different knowledge expresses different standpoints, and in any institution not all standpoints are equal" (p. 2). Healthcare providers' and women's "knowing" of "risk" and "safety" were found to be not only socially organized, but also influenced by unequal positions of power within the institutional complex (Campbell & Rankin, 2017). Consequently, women's "healthwork" (Mykhalovskiy, 2008) to mitigate "risks" and ensure "safety" for their babies remained invisible organizationally. Instead the "patient and family centered care" that healthcare providers' endorsed actually became an "idealized abstraction" that differed from women's lived realities (Rankin, 2015, p. 533).

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Chapter Six: Conclusion

This institutional ethnographic inquiry into the social organization of perinatal care for women living with HIV began from the standpoint of pregnant women and mothers who received their HIV and maternity care within a regional hospital in Hamilton, Ontario, Canada. The experiences of the women who participated in this study and were navigating and interacting with health services during pregnancy, at the time of childbirth, and early postpartum became an entry point to conduct an analytic description of how such experiences were produced by routine practices and institutional arrangements at the McMaster University Medical Centre. The stories of the women who participated in this research revealed clues for further investigation into how ruling relations and social controls work to organize multiple facets of women's everyday worlds, and particularly their experiences of perinatal care (Smith, 1987). In my analysis, I showed how participants' experiences were connected to routinized institutional work practices that were guided and organized by ruling relations and ideological discourses.

The inquiry followed three investigative and analytic "threads" that are explored within this dissertation. In my first paper (Chapter Three), I examined women's concerns related to HIV disclosure, and healthcare providers' practices that were enacted in response. This paper uncovered how the ideological discourses of "fear of contagion" and "AIDS hysteria" contributed to producing the kinds of care experiences that women articulated. In my second paper

(Chapter Four), I illustrated how "risk" was an omnipresent discourse in women's lives and became visible through the treatments women were prescribed, the prenatal clinic appointment schedule women were expected to follow, and the application of medical interventions. This paper revealed how the discourse of "risk" coordinated the work of healthcare providers and was inextricably linked to practices that prioritized fetal health. The third paper (Chapter Five) presented a critical examination of the classification of women's pregnancies as "high-risk" and the location of their "high-risk" maternity care in regional, academic teaching hospitals. This paper illustrated how the organization of maternity care for women living with HIV in regional, centralized hospitals has particular implications for women's pregnancy and motherhood experiences, and revealed how the discourses of "risk" and "safety" are differently known by women and their healthcare providers.

After reflecting upon the scope of this inquiry, it became apparent that there were two ideological discourses operating across all three areas of analysis: the notion "HIV exceptionalism," which positions HIV as unique from other infectious and communicable diseases, and the contrary idea of "HIV normalization" that positions HIV as a chronic health condition that should be viewed like other chronic, manageable health conditions. In discovering the social organization of perinatal care for women living with HIV, I came to view HIV exceptionalism as an important and dominant discourse that was reflected in women's and healthcare providers' actions. I began to observe what happens

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when HIV exceptionalism is interpreted and enacted in variable ways in different settings, and operates in the context of the discourse of HIV normalization. In this final section of my thesis I consider how these discourses play out in specific maternity care practices that both benefit and have negative implications for women living with HIV.

The stories that women shared in this study illuminated the tensions between practices that treat HIV as exceptional versus practices that position HIV infection as normalized. On the one hand, there are unique medical procedures that women living with HIV encounter during pregnancy, at the time of childbirth, and early postpartum that are specific to preventing perinatal HIV transmission. Women appreciate and value the availability of these interventions, which are generally believed to guarantee that their babies will not be born with HIV. On the other hand, women living with HIV do not want to be treated differently because of their HIV status, and view their pregnancy and motherhood experiences as similar to women living with other chronic health conditions. Women highlighted the tensions between HIV exceptionalism and HIV normalization when they asked questions about how much risk their HIV infection posed to their babies and why they needed to have such frequent monitoring by specialist obstetricians given that they were engaged in HIV care, were on HIV treatment, and had sustained undetectable HIV viral loads.

While institutionalized procedures related to risk reduction can be viewed as common sense because they essentially ensure the baby will not be born with

HIV, in my study I came to see that they are also partly organized by the discourses of "fear of contagion" and "AIDS hysteria" (Gallop et al., 1992). These discourses were revealed through my inquiry and serve to regulate and coordinate the practices of people working in clinical settings where women living with HIV receive perinatal care.

The tension that women experience between the ideological discourses of HIV exceptionalism and HIV normalization is also connected to a wider tension; the "exceptional" treatment that women living with HIV receive reflects how pregnancy and childbirth have come to be known, and how medical technologies have been applied as a result of such ways of knowing. As Cartwright and Thomas (2001) note, the obstetrical "dangers" of pregnancy and childbirth became institutionalized and transformed into "biomedically constructed and sanctioned notions of risk" (Cartwright & Thomas, 2001, pg. 218). Perinatal care of women living with HIV is a space where we see different discourses related to HIV, pregnancy, and motherhood collide and play out in women's daily lives and in the work practices of the healthcare providers who look after women during this period of time.

In this concluding chapter, I present a critical review of literatures about HIV exceptionalism and HIV normalization. I then discuss how HIV exceptionalism and HIV normalization emerged in the healthcare practices to which women living with HIV were exposed and responded. I also explore the tensions that were visible between HIV exceptionalism and HIV normalization in

the context of perinatal care for women living with HIV. I conclude this chapter

with a discussion about some implications and lingering questions about

healthcare practices and the organization of maternity care for women living with

HIV in Canada.

HIV Exceptionalism: A Dominant and Organizing Discourse

HIV exceptionalism is a term that was coined by Bayer (1991, 1999) and is an

academic concept that reflects the differential approaches that were taken to

manage and fund HIV in the early days of the epidemic (Philbin, 2014). As an

academic discourse, HIV exceptionalism positions HIV as so unique from other

communicable diseases that it needs to be treated as such by public health

authorities and governing bodies (Bayer 1991, 1999; Gagnon & Holmes, 2008).

HIV-related stigma and discrimination related to one's mode of acquiring HIV

(e.g. injection drug use, sexual transmission), discrimination towards people

living with HIV, disproportionate representation of marginalized individuals

including racial and sexual minorities in the populations affected, and the absence

of HIV treatment were factors that concerned activists in the late 1980s who

viewed HIV infection as unique compared to other communicable diseases

(Bayer, 1999; Philbin, 2014). As such, public health administrators, government

officials, clinicians, and people living with HIV mobilized to determine whether

public health strategies that were historically developed to control other sexually

transmitted infections and communicable diseases should be applied to HIV, and

what would justify the application of such strategies (Oppenheimer & Bayer, 2009). The public health strategies that were debated and had been utilized historically included mandatory examination and screening of the infection, breaching the confidentiality of a person who had been diagnosed with the "dangerous disease" by reporting them to public health, imposing treatment, and in rare circumstances, implementing mandatory isolation and quarantine (Bayer, 1991, p. 1500).

Because of the efforts of community activists, civil libertarians, clinicians, and public health representatives, HIV exceptionalism was adopted as an organizing discourse in the public health practices that were promoted and implemented early in the epidemic (Bayer, 1991). The exceptional measures that were adopted ran counter to the more forceful public health strategies listed above that were implemented historically for other infectious diseases (Oppenheimer & Bayer, 2009). The adoption of exceptional measures was directly attributed to the advocacy of HIV activists and public health allies who were responding to the prevailing fear and anxiety about HIV, and who fought for policies that would protect the rights of people at risk for and living with HIV (Oppenheimer & Bayer, 2009). For example, consensus was established regarding HIV testing that it should only be done in voluntary circumstances with people's informed and explicit consent (Bayer, 1999). Rather than implementing mandatory testing that could be conducted under coercive circumstances, community advocates rallied to fight for voluntary testing that incorporated pre-test counseling and written

informed consent because of concerns about discrimination and the psychological burden if people learned about their HIV-positive status at a time when effective therapies were not available (Oppenheimer & Bayer, 2009). While these exceptional measures were adopted to respect the privacy and human rights of people at risk for HIV, it was also believed that they would protect broader public health and help to prevent the epidemic from going underground (Bayer, 1999; Gagnon & Holmes, 2008).

From HIV Exceptionalism to HIV Normalization

Although HIV infection was viewed by many early on with significant fear and worry, the availability and efficacy of treatments that emerged in the 1990s shifted many people's perceptions about the public health threat that HIV posed, and contributed to decreasing acceptance of HIV exceptionalism as an organizing discourse (Bayer, 1991). The waning of HIV exceptionalism began as clinicians increased their competence to manage HIV infection vis-à-vis the introduction and increasing availability of antiretroviral therapies. At that time, clinicians began to challenge the exceptional restrictions that were imposed related to HIV testing and the need for pre-test counselling and written informed consent. In particular, pediatricians began arguing that infants had a right to testing that superseded their mothers' rights to privacy because of the availability of treatments that infants could have access to for HIV prevention and treatment if transmission occurred (Oppenheimer & Bayer, 2009). These arguments

contributed to the implementation of mandated HIV testing in newborns in certain U.S. states in the 1990s followed by recommendations for mandatory HIV testing of pregnant women (Oppenheimer & Bayer, 2009). Calls for mandated HIV testing were based on clinical trial evidence that demonstrated the efficacy of zidovudine to protect infants when administered intravenously to a labouring mother during childbirth and orally to an HIV-exposed infant postpartum (Connor et al., 1994). Clinical research along with advocacy from governing healthcare bodies such as the American Medical Association, the Centers for Disease Control, and the Institute of Medicine ushered in new provisions whereby, in many jurisdictions, clinicians were mandated to offer HIV testing or conduct routine testing with an opt-out provision (Oppenheimer & Bayer, 2009). HIV exceptionalism was challenged by the dissenting voices of clinicians and government officials whose arguments were likely motivated by multiple discourses. Pediatricians' advocacy to conduct infant HIV testing was grounded in their disciplinary mandate to reduce perinatal morbidity, conserve fetal and neonatal health, and protect "vulnerable" infants from risk and harm (Gupton, Heaman, & Cheung, 2001; Verschoor et al., 2007; Weir, 2004). Gagnon and Holmes (2008) also argue that advocacy against public health practices that treated HIV as exceptional were rooted in motivations and preferences to implement biosecurity and surveillance efforts of HIV as an infectious disease, even if people's, specifically mothers', human rights were suspended. In other words, with advancing medical technologies to prevent and treat HIV infection,

clinicians asserted their duty to protect infants and prevent perinatal transmission at the cost of prioritizing women's privacy and confidentiality, and achieving these goals required strategies for population surveillance and monitoring.

The policies that emerged in the 1980s and 1990s that treated HIV as exceptional have been challenged over time as treatment options for people living with HIV have continued to improve (Bayer, 1999). As Bayer (1991) notes, "as AIDS has become less threatening, the claims of those who argued that the exceptional threat would require exceptional policies have begun to lose their force" (p. 1503). Scholars argue that HIV exceptionalism is no longer reasonable where public health strategies have been implemented to identify people living with HIV through testing and public health surveillance, to prevent HIV transmission, to systematically treat and manage people living with HIV through HIV clinical services, and to conduct population-based monitoring (Bayer & Fairchild, 2006; Gagnon & Holmes, 2008; Wynia, 2006).

Public health strategies and medical advancements that have contributed to the waning of HIV exceptionalism and the transformation of HIV into a less threatening and chronic health condition have also supported what many believe to be is a normalizing or "mainstreaming" of HIV in society and public consciousness. HIV "normalization" can be viewed as a competing, ruling discourse regarding how HIV is known and practiced. Persson (2013) reflects on the mainstreaming of HIV as a repositioning of people living with HIV as "ordinary, non-infectious bod[ies]" from earlier framings of such bodies as

"dangerously contagious" (p. 1075). A number of stakeholders support the normalization of HIV and do so from a number of viewpoints, as well as goals for social change and healthcare improvements. For example, HIV activists working to eliminate HIV-related stigma, healthcare providers advocating for the equitable treatment of people living with HIV, healthcare administrators pushing to integrate HIV care into existing programs and generalized clinical settings, and public health policymakers promoting efforts to scale-up HIV testing and treatment have all been organized by the idea that HIV is similar to other chronic health conditions (Moyer & Hardon, 2014; Philbin, 2014).

The drive to treat HIV as similar to other chronic health conditions contrasts with efforts at the beginning of the HIV epidemic when clinicians, activists, and public health representatives lobbied for policies and practices that would treat HIV as exceptional from other infectious diseases in order to protect the privacy rights of people living with HIV, particularly at the time of HIV testing. It should also be noted, however, that while the discourses of HIV exceptionalism and HIV normalization contrast in terms of how HIV is known and understood, there exist important parallels in the advocacy initiatives in which these discourses have been taken up. HIV activists and clinicians have enacted both HIV exceptionalism and HIV normalization in efforts to reduce HIV-related stigma and discrimination, ensure equitable treatment, and protect the human rights of people living at risk for and living with HIV (Bayer, 1999; Gagnon & Holmes, 2008; Moyer & Hardon, 2014; Philbin, 2014)

Examining the Tensions between HIV Exceptionalism and HIV Normalization

With increasing attention to normalizing HIV in the context of available medical treatments, tensions emerge between the view of HIV as exceptional versus the view of HIV as a normalized health condition. On the one hand, HIV exceptionalism was adopted as an organizing discourse to respond to the needs, experiences, worries, and rights of people living with HIV at a time when no HIV treatments were available. On the other hand, exceptional measures were implemented to also respond to wider public health concerns about HIV testing and preventing transmission. Over time as treatments became available, perspectives shifted and resulted in practices that did not always prioritize the rights of people living with HIV (Oppenheimer & Bayer, 2009). For example, pediatricians asserted the rights of infants over the privacy of their HIV-positive mothers in the name of preventing perinatal HIV transmission stating that "what had once been justified as protecting the rights of individuals could now be viewed as clinical negligence and an impediment to HIV prevention" (Oppenheimer & Bayer, 2009, p. 990).

Many argue that despite treatment advances, the availability of HIV-specific healthcare, and improved life expectancy comparable to the general population, the complex and distinguishing features of HIV infection hamper its normalization and acceptance as a chronic health condition (Jelliman &

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Porcellato, 2017; Moyer & Hardon, 2014). Smith and Whiteside (2010) assert that the immunological impact of HIV on the body, as well as its long-term social, economic, and political effects, distinguish HIV from other public health issues. In their study with HIV care providers, Jelliman and Porcellato (2017) also noted the complexities that providers experienced as part of HIV care management because of the medical *and* psychosocial issues that were faced by people living with HIV; it was these complexities that HIV care providers believed differentiated HIV from other long-term health conditions. Similarly, Cain and Todd (2009) discovered how the increasing availability of HIV treatments has shifted social service delivery to people living with HIV in Ontario, Canada. Care management previously focused on acute health concerns and issues related to death and dying. In light of medical advances, care management within HIV service organizations is increasingly focused on chronic social issues that are compounded in the context of HIV such as poverty, precarious housing, and access to services for concurrent health issues including mental health and substance use challenges (Cain & Todd, 2009).

HIV-related stigma has been noted as one of the key characteristics of living with HIV that contributes to people experiencing poverty, lack of access to health and social services, concerns related to privacy and confidentiality, and challenges related to HIV disclosure (Jelliman & Porcellato, 2017). The criminalization of HIV non-disclosure that now exists in many countries has also been cited as a significant issue that is unique to living with HIV (Jelliman &

Porcellato, 2017). Specific to pregnancy and motherhood, research has noted the communicable nature of HIV compared to other chronic health conditions, and how the chance of transmission produces anxieties for women during the perinatal period (Jelliman & Porcellato, 2017; Sandelowski & Barroso, 2003).

In relation to the specific focus and approach of my study, the tension between HIV exceptionalism and normalization is apparent at the disjuncture between institutional ways of knowing and people's experiences of living with HIV. Moyer and Hardon (2014) argue that efforts to normalize HIV as a chronic health condition conflicts with people's embodied realities. HIV is still "experienced as exceptional" (Moyer & Hardon, 2014, p. 264) because of the affiliated social and economic stressors, concerns related to HIV disclosure and stigma, and threats of criminalization, which endure in all parts of the world. Even though clinical advancements have produced indisputable evidence that people living with HIV who are on treatment and have a suppressed viral load are sexually non-infectious (Rodger et al., 2016, 2019; Vernazza 2009), people living with HIV are hesitant to identify as "non-infectious" and continually face material realities that maintain their HIV-positive status as exceptional including regimented treatments and viral load monitoring (Persson, 2013). Philbin (2014) also highlights the complexity of labelling HIV as a chronic health condition; when HIV is viewed in the same light as, for example, diabetes or hypertension, assumptions are made that HIV can be cured with treatment, and that the experience of living with HIV is comparable to other chronic health conditions.

Moreover, Moyer and Hardon (2014) argue that "while the treatment of HIV in clinical settings may have become normalized, 'normal' conditions outside the clinic continue as before, resulting in the continued exceptionality of HIV" (Moyer & Hardon, 2014, p. 264). Importantly, the research that was conducted for this dissertation raised questions about the extent to which HIV has become normalized in the clinical settings that women living with HIV interact with during the perinatal period.

The different ways that HIV is known, understood, and practiced through the discourses of HIV exceptionalism and HIV normalization has endured throughout the epidemic, and certainly emerged in this research. HIV exceptionalism continues to operate as a ruling and organizing discourse in the system of perinatal care that women living with HIV interface, and HIV normalization emerges as a competing discourse in terms of how women question and experience their care, and how healthcare providers' work is organized.

While HIV exceptionalism is discussed in literatures as an academic concept, it can also serve as a device through which the variable ways that HIV is known and interpreted can be observed in the actions, practices, and material realities of women living with HIV and the work activities of their healthcare providers. In other words, by examining the tensions between HIV exceptionalism and HIV normalization as competing, ruling discourses in the social organization of perinatal care for women living with HIV, we can better perceive and

understand how the conditions of women's experiences – both positive and difficult experiences – are produced.

This institutional ethnography contributes to the discussion about HIV exceptionalism and HIV normalization, and the tensions that emerge in perinatal care practices of women living with HIV and their healthcare providers. What follows is an overview of the practices and tensions related to HIV exceptionalism and HIV normalization that were visible throughout the perinatal period and manifested in this inquiry related to HIV disclosure (Chapter Three), the organization of women's prenatal care (Chapter Five), and the application of risk prevention practices during childbirth and early postpartum (Chapter Four).

Making Visible the Tensions between HIV Exceptionalism and HIV Normalization in Women's and Healthcare Providers' Activities During the Perinatal Period

HIV Exceptionalism and Normalization in the Context of HIV Disclosure

As I outline in Chapter Three, the women living with HIV who participated in this study were concerned about their HIV-positive status becoming known by people who they did not want to find out including family members, friends, and strangers within healthcare settings. Women were particularly concerned about healthcare providers talking about their HIV-positive status in front of family members or friends as they received care during childbirth and following the birth of their baby while on the postpartum ward. Women had developed a number of

measures to conceal their HIV status and minimize the number of people who found out including people in their social networks, and healthcare providers and trainees they interacted with for different aspects of their health. Women were worried that if it came to be known that they were HIV-positive, and the person learning this had incorrect or outdated knowledge about HIV, assumptions would be made about them and they would become the subject of gossip, ridicule, and discrimination. The concerns women raised about HIV disclosure were echoed and responded to by healthcare providers who had implemented work practices to mitigate the disclosure of HIV. For example, women's concerns about privacy were articulated in prenatal care plans so that all healthcare team members would be aware and could respond accordingly, medications were disguised at the time of childbirth or discussed privately with the woman when others were not present, and women were assigned a private room postpartum. It was revealed through this study that these actions were implemented in response to women's concerns about their HIV status being disclosed against their wishes, and that healthcare providers felt a sense of responsibility to protect women's privacy. Interestingly, the healthcare providers I spoke with also shared the view that it was important to keep one's HIV status a secret, and that if someone's HIV status became known by people who held negative views or assumptions about HIV, this could result in women being judged, rejected, ridiculed, or discriminated against.

Herein lies a tension related to treating HIV as an exception vis-à-vis healthcare providers' actions related to HIV disclosure. On the one hand, one

intention behind healthcare providers' practices was to protect women living with HIV from negative experiences and to ensure their privacy and confidentiality. Healthcare providers acted in response to concerns that women raised, in a sense normalizing women's concerns as part of healthcare work practices, and the women in this study appreciated the care and consideration that healthcare providers exhibited related to their desire for privacy.

On the other hand, healthcare providers' work practices maintained the idea that HIV infection is a unique issue that requires unique actions on the part of those delivering care to women; these actions were not taken with other patient groups, and were underpinned by sentiments that HIV *should* be kept a secret. An important message that emerged from healthcare providers' explanations about their work practices was that women's concerns related to HIV disclosure should be attended to as part of institutional work practices because of lingering societal "fear" of HIV, and the discourses of "fear of contagion" and "AIDS hysteria." This "fear" of HIV was vividly felt by the women themselves, and framing HIV as something to be "feared" and kept "secret" was embedded in women's embodied experiences. Echoing the work of George Smith, the framing of HIV as a "secret" by women and their healthcare providers demonstrated how ideologies are activated and coordinated through language (G. Smith, 1988); it was the framing of HIV as a secret that organized the actions and speech of women and their healthcare providers within the space that perinatal care was delivered.

The possibility of interpreting HIV exceptionalism in variable ways was also revealed in this example. The women's HIV-positive status was framed negatively – as something exceptional to be kept secret, as something exceptional that could result in discrimination and judgement. Although the healthcare providers in this situation responded in a way that reflected the original intention of HIV exceptionalism – to protect the rights and privacy of people living with HIV – the contrary framing of HIV as negatively "exceptional" was also operating, for both women and their healthcare providers.

Another tension related to HIV exceptionalism vis-à-vis healthcare providers' practices related to HIV disclosure emerged in assigning women to a private hospital room following childbirth. As discussed in Chapter Three, I learned that this practice was done historically on the postpartum ward in response to concerns about infection control and reducing other patients' exposure to HIV through blood and bodily fluids. Healthcare providers articulated different viewpoints for why a private room was assigned, and how the rationale for this practice blurred lines between ensuring infection control and enhancing women's privacy and confidentiality. Through healthcare provider accounts it was discovered that the practice for assigning the private room could serve both infection control *and/or* privacy purposes. That is, on the one hand, assigning a private room would help to protect the woman's privacy and confidentiality and mitigate unwanted HIV disclosure while discussing medical procedures and treatments with her thereby facilitating the normalization of her childbirth and

postpartum experience. On the other hand, the private room could also be used as a strategy to protect public health by preventing people without HIV from being exposed to the bodily fluids of women living with HIV. Hearing different understandings from healthcare providers regarding the rationale for the routinized practice of assigning a private room without a clear written directive or policy illuminated how some actions that treat mothers living with HIV differently than other mothers receiving care on the same postpartum ward could be problematic. How women are assigned to a private room in terms of the care and explanation they receive from their healthcare providers matters. The exceptional practice of the private room may be motivated by perceptions about HIV as "contagion" and concerns about infection control, even if these perceptions are not founded on scientific evidence about HIV transmission. At the same time, women may find this practice necessary and welcome because of their concerns about HIV disclosure, and may experience the exceptional practice as important and critical as mothers living with HIV.

HIV Exceptionalism and Normalization in the Organization of Women's Prenatal Care

Prenatal care for women living with HIV is currently organized such that it is overseen by "high-risk" obstetricians and is located within regional hospitals; women will see maternity care specialists for the duration of their pregnancies and plan to deliver within the regional hospital. HIV is not the only medical condition

that classifies a woman's pregnancy as high-risk; numerous maternal and fetal medical complications will result in a woman being referred to specialist obstetrical services for monitoring. What the women who participated in this study questioned, however, was the exceptional nature of their prenatal care being located within a high-risk obstetrical setting given the negligible likelihood of HIV transmission with the use of antiretroviral therapy. Women questioned the degree to which their HIV-positive status posed a risk to their fetuses given their long-term, consistent use of antiretroviral therapy, their previous experiences of pregnancy and childbirth as women living with HIV, and their undetectable viral loads. Moreover, the centralization of women's prenatal care within high-risk obstetrical services had material implications for women's local commitments including familial and employment responsibilities. As a result, women had to invest much time and effort to attend their prenatal appointments, and encountered numerous challenges when doing so. For example, women faced numerous difficulties to participate in their prenatal care within the regional hospital because of barriers related to transportation, employment, childcare, and other social, structural, economic, and life circumstances.

Crucially, as described in Chapter Five, when one participant found herself unexpectedly going into early labour, she had to give birth in her local community hospital rather than at the regional hospital. Consequently, the specialist care and HIV-specific procedures she required were unavailable because of the lack of integration between specialist care and the community

hospital, and the limited capacity of the community hospital to facilitate care for women living with HIV in labour and early postpartum. Herein lies a tension related to treating HIV as an exception vis-à-vis the organization of women's prenatal care, and the implications of such organization on women's childbirth experiences. Because the discourse of HIV exceptionalism in part organizes the prenatal care of women living with HIV, the specialist care that women living with HIV are recommended to receive during the perinatal period is isolated in a regional hospital. Because prenatal, childbirth, and postpartum procedures that are recommended for women living with HIV have not become normalized or integrated within community and primary care settings outside of these specialist practices, women may encounter prenatal and childbirth experiences that cannot be handled in local hospitals, and that produce conditions in which women have negative and challenging perinatal care experiences.

Importantly, healthcare providers acknowledged that women received "normal" prenatal care within the high-risk clinic that was similar to what women without HIV would receive including screening bloodwork, visit frequency, and maternity care milestones. Multiple healthcare providers also noted that the pregnancies of women living with HIV would likely proceed in a similar fashion to other pregnant women because of the effectiveness of antiretroviral therapy. Despite this tension between delivering "normal" prenatal care within a "high-risk" clinical setting, healthcare providers made arguments in support of the current organization of maternity care citing their clinical expertise and familiarity

with HIV in the context of pregnancy as critical to ensuring that women and their babies received the care necessary to prevent HIV transmission at the time of childbirth and early postpartum. As was discussed in Chapter Five, healthcare providers viewed locating women's prenatal care within high-risk obstetrical clinics as "practical." This view contradicted women's experiences of care; women viewed the location of their prenatal care within regional hospitals as impractical because of the difficulties they faced attending and participating in such care. Similarly, healthcare providers prioritized the prevention of HIV transmission to infants even if it meant that women would face material challenges and have to make significant arrangements in their daily lives in order to keep up with the expected appointment schedule and recommended procedures. Even though women shared with providers the goal to prevent HIV transmission to their babies, the exceptional nature of HIV as a risk to the fetus prevailed over women's lived realities, needs, and experiences during the prenatal period.

HIV Exceptionalism and Normalization in the Context of Risk Prevention Practices During Childbirth and Postpartum

HIV exceptionalism became visible in the practices focused on reducing the risk of HIV transmission to the fetus, and in the ways that women were expected to follow the HIV-specific medical interventions that make prevention possible. Tensions related to treating HIV as an exception emerged when the procedures to

reduce risk were applied, in particular during childbirth related to the mode of delivery and postpartum related to infant feeding.

Method of childbirth was an important example when HIV exceptionalism was revealed through healthcare practices and the current organization of maternity care for women living with HIV. Canadian clinical guidelines outline the normative childbirth practices, which include vaginal deliveries and the avoidance of elective C-sections (SOGC, 2019). It became apparent in this study, however, that maternal HIV infection was an exception to the recommendation to avoid elective C-sections. Not only were women's pregnancies categorized as "high-risk" organizationally, but the institutional priority to reduce risk and prevent perinatal transmission underpinned women's and healthcare providers' decisions and actions. As outlined in Chapter Four, one participant elected to have a C-section even though her undetectable viral load meant that a vaginal birth was the normative practice based on HIV-specific clinical guidelines (Money et al., 2014). This woman viewed her HIV-positive status as an exceptional circumstance, and out of concern and worry, wanted to do everything she could to prevent HIV transmission during childbirth. Her healthcare team supported her decision, approved the elective C-section to go ahead, and organized the institutional resources required to make the C-section surgery possible. Numerous studies have examined the short- and long-term negative outcomes of C-sections for women and children compared to vaginal deliveries (Keag, Norman, & Stock, 2018; Liu et al., 2007), hence the reason for recommending vaginal birth and not

recommending elective C-sections within clinical guidelines (SOGC, 2019). Despite the clinical evidence pertaining to C-sections, HIV exceptionalism was operating here, especially when contrasting this scenario with the response that a woman without HIV may have received if she expressed a desire to have an elective C-section.

As previously mentioned, the woman's utilization of antiretroviral therapy and maintaining an undetectable viral load meant that, scientifically and based on clinical guidelines, the exceptional application of C-section as mode of delivery was not substantiated. A tension emerges when considering the rationale for such practice and how HIV as "exception" may have been interpreted. Was the C-section approved in order to support the mother and be responsive to her individual needs and worries? Or, was the C-section approved because of institutional concerns about risk to the fetus and the enactment of views of HIV as "contagion"? It cannot be ruled out that the mainstream and dominant view of HIV as a unique communicable disease that needs to be treated accordingly was a contributing factor in the response of the healthcare providers. These healthcare providers may have prioritized the health and safety of the fetus over the woman's childbirth experience, even if she would have encountered difficulties postpartum following her C-section surgery.

The exceptional nature of HIV was also visible in postpartum care practices with regard to infant feeding and the recommendation to avoid breastfeeding in the context of maternal HIV infection. Women were subjected to

interventions that ran counter to the routine and "normal" procedures that are typically recommended for pregnant women and mothers who do not have HIV such as receiving counselling to formula feed their babies. Formula feeding is a common practice because of the risk of HIV transmission through the consumption of breast milk. As was discussed in Chapter Four, maternal HIV infection is one of the only circumstances in Canada where breastfeeding is contraindicated, and healthcare providers' typical practice to encourage breastfeeding is disrupted. The healthcare providers I spoke with acknowledged the exceptional nature of this recommendation given the breastfeeding norms and expectations that exist in Canadian society (Health Canada, 2013a, 2013b). The normative maternity care practice is to support women to breastfeed. In maternity care for women living with HIV in Canada, however, healthcare providers support women to formula feed. The procedures that are conducted in this exceptional circumstance revolve around ensuring that she has access to formula on the hospital ward postpartum, connecting her to the provincial formula program so she has access to formula upon hospital discharge, supporting her around the use of formula, and supporting her around her emotions, worries, and joys about formula feeding, especially if she had a preference and desire to breastfeed her children. Formula feeding for women living with HIV is supported by scientific evidence regarding the transmission of HIV through breast milk, global clinical practice guidelines about infant feeding in the context of maternal HIV infection

(WHO, 2016a), and the implementation of free formula programs in Ontario and other provinces by governing health ministries.

However, another layer of tension is present given the "pro-breastfeeding" culture that exists within wider society and specifically within hospitals. The dominant "breast is best" view (Wall, 2001) was acknowledged by healthcare providers in this study including through a discussion about the Baby Friendly initiatives that have been implemented in hospitals around the world and encourage all maternity care centers to become centers of breastfeeding support (UNICEF, 2005). As I note in Chapter Four, one healthcare provider acknowledged how women may feel different from the other mothers giving birth on the hospital ward because of the visibility of breastfeeding in hospital literature, breastfeeding images on the hospital walls, and in the practices of healthcare providers who discuss, promote, and physically assist women to breastfeed. At the same time, the exceptional nature of formula feeding babies exposed to HIV is rooted in scientific evidence, and it matters how this recommendation plays out for women in the postpartum period. Formula feeding may be an exceptional practice in the grand scheme of maternity care for all women that highlights the exceptional nature of maternal HIV infection, but it's "normal" for women living with HIV and their babies.

Final Reflections Regarding the Tensions between HIV Exceptionalism and HIV Normalization

This inquiry explicated a number of ways that HIV exceptionalism structures and justifies the organization of maternity care for women living with HIV in regional, centralized hospitals.

As was revealed through the practices of healthcare providers, the discourses of "AIDS hysteria," "fear of contagion," and maternal HIV infection necessitating "high-risk" maternity care continue to operate within the healthcare settings where women living with HIV receive perinatal care. It was the discourses of "AIDS hysteria," "fear of contagion," and risk that prevailed when the epidemic first began, catalyzing a sense of urgency and HIV exceptionalism (Smith & Whiteside, 2010). These discourses continue to operate in healthcare practices today, as was shown through this research. Furthermore, it is through the institutional arrangements and rote practices of people operating within healthcare that these discourses are perpetuated, even though public health experts, clinicians, and activists hypothesized that the increasing biomedicalization through available treatments and medical advancements would depoliticize and normalize HIV (Moyer & Hardon, 2014).

The findings of this inquiry also focus attention to the consequences of HIV exceptionalism and HIV normalization as dominant and ruling discourses within maternity care for women living with HIV. While practices that treat HIV as exceptional may be carried out in order to respond to women's individual concerns and needs, organizing care along the lines of HIV exceptionalism may also work to create experiences for women that are negative, challenging, or result

in discrimination. Similarly, while normalizing HIV may come with benefits for women who do not wish to be treated differently than other mothers, organizing care along the lines of HIV normalization may result in women not having access to HIV-specific procedures or care that responds to their unique circumstances as women living with HIV. The tension that lies between HIV exceptionalism and HIV normalization, and the various ways that these discourses can be enacted, is important to consider in the organization of health services that women living with HIV utilize, including maternity care, and in the distribution of tasks and responsibilities of the healthcare providers who deliver care to pregnant women and mothers living with HIV.

What must also be considered and kept in view in the organization of maternity care for women living with HIV is how the everyday practices of exceptionalism can also serve to ignore the challenges and tensions that women experience as a result of these practices. When healthcare practices are organized to prioritize the reduction of risks to the fetus and infant and facilitate ease for specialist providers, thereby maintaining HIV exceptionalism, these practices can serve to undermine and ignore women's practical challenges, needs, desires, and rights throughout the perinatal period.

Implications for Maternity Care for Women Living With HIV

This institutional ethnographic inquiry offers numerous insights for the delivery of maternity care to women living with HIV. The study findings alert clinicians,

healthcare administrators, policymakers, and HIV researchers to how the actions of women living with HIV and their healthcare providers frame HIV as an exceptional illness in some ways and, in other ways, as a "normalized" chronic condition. When HIV exceptionalism is operating in healthcare practices, it can produce the conditions where women receive the HIV-specific care that they need and want to ensure a healthy pregnancy and to achieve the shared goal of preventing HIV transmission to their infant. However, HIV exceptionalism can also operate in ways that result in women feeling and being exceptional in negative ways such as depriving them of their desired prenatal care and childbirth experiences; it is in these circumstances when women express desire for and raise questions about the normalization of their pregnancies and being handled in a similar fashion to pregnant women and mothers without HIV.

The tensions between HIV exceptionalism and HIV normalization that have been described herein behoove healthcare administrators to examine the benefits and consequences of centralizing women's prenatal, childbirth, and postpartum care within high-risk, specialist, regional hospitals. Although there were HIV-specific procedures that women highly valued and had access to through their high-risk healthcare team, women encountered challenges when trying to access these services. Perhaps there are opportunities to introduce different disciplines and roles to facilitate meeting women's unique needs throughout the perinatal period while also integrating care with other health and

social care providers who can contribute to the normalization of pregnancy and motherhood in the context of HIV.

For example, in the early years of the HIV epidemic, specialists were critical to managing an illness that had limited treatment options and prospects of a cure (Deeks, Lewin, & Havlir, 2013). With time, many people living with HIV have become accustomed to the system of specialist HIV care that has been widely implemented across Canada, and have expressed concerns about trust and stigma if accessing HIV care through generalists (Perry et al., 2013). It is important to carefully consider the concerns expressed by people living with HIV before making changes to the current organization of healthcare. However, scholars have suggested an increasing role of generalist health and social providers including primary care providers, nurses, and social workers in the care of people living with HIV (Jelliman & Porcellato, 2017). Washington, Meyer-Adams and Anaya (2009) specifically position social workers as key players to eradicating perinatal HIV transmission because of their capacities to provide education and support to women of childbearing age within a comprehensive model of care. Importantly, because HIV infection has not reached universal recognition as a "normal" and manageable long-term health condition, Jelliman and Porcellato (2017) assert that reducing the availability and input of HIV specialists in the care of people living with HIV would be detrimental, and that specialists should continue to be involved in an education and support role, as well as "advocates of normalization" (Jelliman & Porcellato, 2017, p. 171). It

should be noted that healthcare institutions are increasingly introducing policies

and programs that directly respond to the tensions between generalist versus

specialist care, as well as the tensions between HIV exceptionalism and HIV

normalization. As Moyer and Hardon (2014) point out, "practices once considered

exceptional to HIV – such as patient-friendly health care, the involvement of

volunteer 'expert patients' in care, interdepartmental cooperation within clinics,

and linkages with community-based organizations – have become normalized

within institutions and health policies" (Moyer & Hardon, 2014, p. 267). It is

these kinds of services that women are asking for as a way to ensure they receive

the HIV-specific healthcare they and their babies need, along with ensuring that

care is accessible and integrated in such a way to normalize their experiences as

mothers living with HIV.

A number of Canadian scholars have called for the establishment of

women-specific and women-centered HIV/AIDS services because of concerns

that women's experiences of HIV infection are unique (Carter et al., 2013; Loutfy,

Khosla, & Narasimhan, 2015; O'Brien et al., 2017). These researchers argue that

tailored, specially designed programs are needed to meet women's health and

social care needs and improve health outcomes including HIV treatment

adherence and engagement in care similar to what has been outlined in the HIV

treatment cascade (Carter et al., 2013; Loutfy, Khosla, & Narasimhan, 2015;

O'Brien et al., 2017). These scholars outline a women-centered HIV care

approach that includes recommendations for healthcare services to embed basic

care competencies and components of "patient-centered care" alongside elements of women-centered HIV care (O'Brien et al., 2017). The authors define women-centered HIV care as: i) coordinated and integrated services that are designed to address both HIV and women's healthcare priorities and prevent exclusion from or discrimination during care due to HIV-related stigma; ii) care that acknowledges and responds to structural barriers to care (violence, poverty, motherhood in the context of HIV, HIV-related stigma, and challenges to safe disclosure); and iii) care that fosters involvement of women living with HIV as peer support and peer leadership in its design and delivery as a means to overcome isolation, cater to the diversity of women's experiences, and prioritize women's ownership over key decisions that affect their lives (O'Brien et al., 2017, p. 725-726). These elements of women-centered HIV care are echoed in Carter et al. (2013) and Loutfy, Khosla, and Narasimhan (2015) who also advocate that women's reproductive health and human rights are central to the delivery of comprehensive care for women living with HIV.

The research about women-centered HIV care cited above is important and strongly aligns with the findings of the current study in terms of focusing on the healthcare experiences of women living with HIV in Canada and examining how healthcare services could be organized to respond to women's needs. At the same time, it is critical to also consider how this body of literature may perpetuate HIV exceptionalism with less of an emphasis on accounting for women's concerns and healthcare providers' activities related to HIV normalization. For

example, it was revealed in this dissertation research that even though women valued their access to obstetrical specialists because of the HIV-specific procedures they received during childbirth, this access did not necessarily equate to more positive care experiences overall. Healthcare administrators should account for the scholarship about women-centered HIV care when reviewing the organization and delivery of maternity care for women living with HIV. Administrators and policymakers should also acknowledge, however, how the adoption of HIV-specific approaches may produce the conditions in which women living with HIV continue to experience their HIV-positive status as exceptional, but in ways that are less desirable and that enact negative views of HIV, for example, HIV as "contagion."

The findings from this study along with scholarship focused on women-centered HIV care parallel calls from global health experts to decentralize maternity care for women living with HIV to ensure women have access to services close to home, and to address inequities that may create barriers for women to access care (UNAIDS, 2014). As suggested by UNAIDS, "broader health service integration that is family-centred, covering maternal and child health, sexual and reproductive health and HIV services, would help to ensure that women and children receive the care they need when they need it" (UNAIDS, 2014, p. 11). This global position has been echoed by Canadian experts in high-risk obstetrics, and may contribute to reconciling some of the tension between HIV exceptionalism and HIV normalization. Canadian guidelines recommend

"coordination and communication between HIV specialists and obstetrical providers" and recognize that "if, for geographic reasons, a woman is unable to attend for specialist consultations, these can be provided virtually through effective communications between care providers in remote settings and urban sub-specialists" (Money et al., 2014, p. S6). A key component of successful integration of care coordination and communication between providers is a "non-hierarchical structure in which all participants work together with equal power and responsibility" (Rogers, 2003, p. 195).

Most importantly, collaboration must place women living with HIV at the center, and this recommendation has been supported by numerous HIV and women's health scholars in Canada (Carter et al., 2013, 2015; Loutfy, Khosla, & Narasimhan, 2015). As this inquiry revealed, women are left doing a significant amount of work to access care without much power to participate in healthcare on their own terms (Griffith & Smith, 2005). As a result, the current system accommodates those *delivering* the high-risk maternity care while ignoring the experiences of women *receiving* this care whose bodies have been labelled organizationally as high-risk. Women's voices should be elevated, and women should be positioned as leaders to facilitate care continuity to ensure meaningful pregnancy and motherhood experiences. Efforts should made to strengthen peer support programs, and meaningfully engage women living with HIV in the development and evaluation of maternity care services (Carter et al., 2015; UNAIDS, 2014). These efforts could bolster communication and collaboration

between those involved in care, which are integral to positive pregnancy experiences (WHO, 2016b).

Lingering Questions and Final Thoughts

Questions remain about the future of perinatal care for women living with HIV in Canada. For example, could models of care that position specialists working with generalists be implemented as a way to mitigate some of the concerns and challenging experiences that women expressed in this study? How would obstetrical specialists respond to the redesign of maternity care for women living with HIV if certain elements or procedures are decentralized out of regional hospitals and integrated into generalist, community health services? Could the reorganization of perinatal care with increasing involvement of generalist and community providers re-ignite concerns about the capacity of generalist healthcare providers located outside of regional hospitals to ensure women get the HIV-specific care that they need to prevent HIV transmission at the time of childbirth and postpartum?

Despite these important questions, opportunities exist to reimagine and optimize perinatal care for mothers living with HIV in Canada by attending to the exceptional care that women require while normalizing their experiences of pregnancy and motherhood. Integrated care approaches could be explored as a mechanism to strengthen care linkages, experiences, and outcomes for all pregnant women and mothers living with HIV in Canada and around the world

(UNAIDS, 2014; WHO, 2017). These non-hierarchical and equitable care approaches can ground care in a human-rights approach that respects women's dignity, elevates their participation in decisions affecting their reproductive health, and promotes their health and well-being (WHO, 2016).

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Women's Health Department

Community providers
Family Physicians
Public Health Department
Public Health Lab
(Viral load testing)

SIS Clinic	**MFM Clinic**	**Labour + Delivery**	**4C In-Patient Ward**

SIS Clinic

- HIV Care
- HIV Medications & prescriptions
- Woman's order set at delivery

HIV Specialists
Social Work
Nursing
Pediatrician
Pharmacist

Referral & order

MFM Clinic

- 1st appointment at 12 weeks gestation
- Prenatal care
- High risk pregnancy
- Tertiary care & teaching hospital

Nurse Practitioner
Obstetricians
Social Work
Residents

Labour + Delivery

- Order sets
- Infection control
- 1:1 nursing
- Shift Work

Nursing
Residents
Obstetricians
Pharmacist

4C In-Patient Ward

- Postpartum floor
- Private room
- Order sets
- In-rooming with baby
- Discharge planning (formula, medications for baby, follow-up at SIS and family doctor).

Nursing Residents
Pharmacist

Clinical Charts & Electronic Health Records (Meditech, Sovera, Clinical Connect)

Viral Load   **Pregnant Body Viral Load**   **Infant = patient**

Mapping work processes & text-work-text sequences of action

Direct connection — ————

Numbered steps — ◯

Texts that are produced in action / product of previous work & physically present — ▢ (blue box)

Texts that are activated (e.g. legislation, policy, sections of official plans, etc.) — ▢ (dashed box)

Activity performed — ⬭ (yellow ellipse)

From Turner (2006)

SIS Clinic | Women's Health at MUMC

SIS Clinic | MFM Clinic (4B1) | L & D | | 4C (In-Patient)

- Woman calls SIS to report pregnancy
- Pregnancy test at SIS
- Consult form with gestation ultrasound & HIV treatment (referral to MFM)
- Chart — Includes Care Plan
- IV AZT (Woman)
- Call for Private Room
- NEO-HIV At-Risk Infant Protocol
- Bathe Baby
- Order Set (Woman)
- Order Set (Baby)
- Patient Binder
- Consent for Baby HIV Test
- HIV Testing
- AZT to Baby
- PPE
- Lab Requisition
- Viral Load
- BORN Database Questions
- ODDP Registration Form
- Referral to Teresa Group (Formula Program)
- Dictated note
- Meditech EMR
- Call Teresa Group re: Formula
- Schedule SIS Follow-up for Baby

Appendix C:

Healthcare Practices related to HIV Disclosure
& Maintaining Women's Privacy

SIS Clinic Work

HIV specialist & pediatrician dictate note →
- Meditech EMR
- Faxed to family doctor

SIS SW verbal consents re: sharing info with MFM SW → SIS SW contacts MFM SW

SIS SW discusses Teresa Group Formula program with woman → Teresa Group referral form → SW explains disclosure to pharmacy

Pre-existing notes in SIS chart → SIS SW reviews with parameters (no snooping)

SIS pediatrician discusses woman's disclosure concerns by bringing up in prenatal appointment → Handwritten note → SIS pediatrician dictates → Note in Meditech EMR

- HIV diagnosis directs work at SIS clinic – no way of getting around that "this is part of what I'm Doing…HIV is their first Diagnosis…it's just so much part of the norm"
- "circle of care" (social work & pediatrician)

4B1 High-Risk Obstetrical Clinic (MFM) Work

Woman identifies concerns related to disclosure at MFM visit → Note in MFM chart re: woman's concerns & how workers will respond re: communication & care plan →

MFM staff confirms woman's contact information → Contact information sheet (e.g. leave message?)

- Label: SIS = HIV
- "confidential information practices" (MFM nurse practitioner)

L / D & 4C In-Patient Unit Work

L&D nurse identifies concerns via MFM chart or when speaking with woman → Hide AZT with label or paper bag

L&D nurse communicates & provides care with disclosure concerns in mind → 4C nurse reviews concerns with woman

L&D nurse gives verbal report to 4C bedside nurse re: delivery → Birth record (Labour summary) → 4C nurse charts → Nursery Binder (all baby's information, e.g. document high viral load of mother)

"transfer of accountability" from L&D to 4C unit (not always written down, "things like that can get missed")

Right after delivery

OB prepares postpartum orders → Order → L&D nurse calls 4C for private room for "medical reasons" → Woman assigned to private room on 4C through Meditech for billing purposes

- "Best practices" - "everybody who is taking care of you should know what's going on" (SIS pediatrician & MFM social work)
- Use of chart & orders/ order sets to direct work & communicate across team members ➜ automatic sharing through EMR & within "circle of care"
- Private room for "privacy" not infection control practices

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