PUBLIC HEALTH'S RESPONSE TO HIV/AIDS IN ONTARIO:
A CRITICAL ETHNOGRAPHY OF CASE MANAGEMENT NURSING

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There is a systematic and compulsory policy of ‘screening,’ of tracking down disease in the population, a process which does not answer any patient demands.

What governs society are not legal codes but the perpetual distinction between normal and abnormal, a perpetual enterprise of restoring the system of normality.

Michel Foucault

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Abstract

HIV/AIDS is now widely recognized as a medically manageable condition. However, more than 2,000 new HIV infections are reported across Canada each year. A pressing issue in the public health response to HIV is how to better engage people at risk and living with the virus in testing, treatment, and support services. For this study, a critical ethnography was undertaken with 22 public health nurses involved in HIV case management in 14 public health units across Ontario. The objectives were to describe the experiences of case management nurses involved in the follow-up of people who test positive for HIV in public health units across Ontario and identify how public health policies shape the boundaries of nursing care and client outcomes in the response to HIV. A poststructuralist, feminist and critical geographical lens was employed to understand how different discourses determine the social and spatial organization of case management and structure the possibilities in nurses' follow-up at the point-of-care. The main finding is evidence of two different sets of goals and measures in the public health response to HIV in Ontario: (1) a medical-epidemiological discourse tied to a biosecurity approach and goal of disease containment; and (2) a nursing discourse linked to a relational approach aimed at promoting meaningful engagement and ensuring people with HIV "feel supported." The thesis of this study is that the hegemony of a biosecurity approach and singular biomedical indicator of success (an undetectable viral load) are contributing to the relegation of relational work and nurses' efforts to support people who are unable or unwilling to engage in risk reduction measures to the margins of care. Strengthening the capacity of case management nurses to develop a relational approach and account for the diversity of emotional and social issues impacting the ability of people to live with HIV may be an important starting point for improving the outcomes of the public health response. The findings have implications for future research, policy, and practice in the areas of governmentality, public health nursing and efforts to end the "War on HIV."

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INTRODUCTION

The management of modern pandemics are commonly framed in the media and public health using references to war: “The War on Ebola” (The Economist, Oct. 2014); “The War on SARS” (Ong, 2004); “The War on AIDS” (Worldpress, Nov. 2005). The term “frontline nurse” has become normalized in the language used to describe nursing’s position in the global public health response to outbreaks of infectious diseases. Both are examples of a largely unquestioned acceptance of a biosecurity framework in infectious diseases management, and its pervasiveness in our public and professional imaginations. The purpose of this study is to explore how equating the management of infectious diseases with war shapes public policy, public health practices, and the experiences of people with HIV. A critical reflection on the public health response to HIV/AIDS was proposed for this study as a means of examining the meaning of “engagement” in HIV care and limitations of the current approach to HIV follow-up. The overall goal is to identify strategies to better engage people at risk and living with the virus in testing, treatment and support services. This research stems from a belief in the need to better understand and account for the combined power of government and science in the establishment of the parameters of public health care, and a commitment as a nurse researcher and former public health practitioner to “hold ourselves to the highest ethical standards, never stop monitoring our progress, and always be open to public scrutiny, and willing to admit our mistakes” (Inscription, Tuskegee Human & Civil Rights Multicultural Center, 2015).

Public policies and public health strategies have come under scrutiny in the latest outbreaks of Ebola (Evans, 2019; Wintour, 2019), Measles (Miller, 2019), Syphilis (Howard, 2018; Payne, 2019; Subramarian, 2017; “STIs,” 2018), and Tuberculosis (Lewis, 2017) both globally and locally. Relational and social issues such as failure to gain the trust and engage people in available medical care appear to be important drivers of new infections that appear to be rooted, in part, in the values, beliefs and measures common

in the management of infectious diseases (Botehlo, 2014; "Ebola crisis," 2014; Farmer & Panjabi, 2014; Hammond, Holmes & Mercier, 2016; McKirdy, 2014; Minder, 2014; O'Manique, 2018; Panetta, 2014). For example, following a two-day visit to the center of the Ebola crisis in the Democratic Republic of the Congo in 2019, the U.K.'s International Development Secretary, Rory Stewart, reported that the shortcomings of the United Nations' emergency response could be traced to problems accounting for the social concerns of different stakeholders and gaining the community's confidence in public health care: "In medical terms it is a no-brainer, but there is a very major community problem…People are very suspicious of the vaccine" and "we're constantly seeking messengers to build trust among local people" (Wintour, 2019). The results of Stephen Lewis' (2017) fact-finding mission to understand the reasons for the persistence of high rates of Tuberculosis (TB) among Inuit in the Arctic reported similar difficulties in understanding and addressing the community's needs: "There is a TB crisis in Nunavut at this very moment…and this is my personal shame…I did not realize TB was inextricably tied—if I may take a phrase from the Truth and Reconciliation Commission—to a form of cultural genocide" (para. 22). Lewis (2017), the co-director of AIDS-free World and former United Nations' special envoy on HIV/AIDS, concluded that improving the outcomes of TB in Canada would not simply be a matter of scaling up testing and treatment, but "a matter of reconciliation" to renew public trust in government responses to TB following the history of forced medical evacuations to sanatoriums in the 1940s-50s (see for e.g. Selway, 2016). According to *Médecins Sans Frontières*, one of the main organizations involved in efforts to manage infectious diseases globally, "prevention strategies…seem to have more political than medical implications" (McKirdy, 2014, p. 1).

In his analysis of the HIV/AIDS pandemic, Stephen Elbe (2009) argues from an international relations perspective that framing an outbreak of an infectious disease as a political issue—as a matter of biosecurity--may help mobilize economic and public support

for government efforts to fight a disease, but it also makes it easier for state institutions to respond by imposing harsh measures, and overriding the human rights of people living with infections such as HIV/AIDS in the name of protecting the population. Elbe adds: "Moreover, it risks pushing the debate on HIV/AIDS in the direction of a knee-jerk, 'panic politics' response to the pandemic that may ultimately fail to come to terms with its underlying causes and may therefore not deliver a sustainable response to the disease" (2009, p. 35). Physician and anthropologist, Paul Farmer, issued a similar warning (Farmer, 1999; Farmer, Kim, Kleinman & Basilico, 2013). Farmer's (1999) comparison of the patterns of responses and outcomes in global outbreaks of Ebola, HIV/AIDS, and Tuberculosis pandemics in the last three decades, resulted in a call for a global re-examination of approaches used to manage infectious diseases.

Farmer, along with others, advocate for the integration of a social justice perspective and critical theory into current medical and epidemiological frameworks for practice, policy, and research in infectious disease management (Benatar, 1998; Gilson, Doherty, Loewenson, & Francis, 2007; Elbe, 2009; Gagnon, 2012; Kim, Farmer, & Porter, 2013; Mill, Ogilvie, Astle & Opare, 2005; Nixon, 2006; O'Byrne, 2019; Orsini, Hindmarch & Gagnon, 2018; Petersen & Lupton, 2000; Ruger, 2012). In his seminal work, *Infections and Inequalities: The Modern Plagues*, Farmer explains: "Critical perspectives on emerging infections must ask how large-scale social forces come to have their effects on unequally positioned individuals in increasingly interconnected populations; a critical epistemology needs to ask what features of disease emergence are obscured by dominant analytic frameworks" (1999, p. 5). Therefore, this study involves a critical reflection on the policy frameworks dominating the public health response to HIV/AIDS in Canada.

In a summary of Canadian public policy related to the HIV/AIDS response, Orsini et al. (2018) claim:

> Social policy responses to HIV have largely failed to address the ultimate

> drivers of the epidemic: poverty, racism, homophobia, and other complex, intersecting forms of social exclusion and structural inequities that make some people more vulnerable to HIV. Consequently, some populations—mainly ethno-racial and sexual minorities—continue to be disproportionately affected by HIV and to experience significant challenges in accessing appropriate services and supports. (p. 5)

The province of Ontario consistently reports the highest number of new HIV infections in Canada annually (Haddad, Li, Totten & McGuier, 2018). Subsequently, this study uses a poststructuralist theoretical perspective and critical ethnographic design to explore the rationalities and strategies used by public health nurses for the case management of people with HIV/AIDS in Ontario, and examine how the discourses circulating in and through public policies and public health units determine the social and physical boundaries of case management practice and nurses' ability to engage with people who test positive for the virus. Foucault (1980) defines *rationalities* as systematic ways of reasoning and responding to a problem drawing on bodies of knowledge or expertise (Dean, 2010), and *discourses* as "statements" (p. 59), spoken or written words that represent bodies of knowledge (McHoul & Grace, 2002). Working at the interface of public health policies and client concerns, case management nurses are situated between different discourses about "best" practices for the follow-up of people newly diagnosed with HIV (O'Byrne, Holmes & Roy, 2014). This research helps illustrate how nurses navigate competing priorities at the point-of-care through efforts to balance the spread of infectious diseases in the population with strategies to ensure that the goals and needs of individuals affected by HIV/AIDS are accounted for in the public health response.

In particular, nurses' experiences are examined in light of theoretical concerns that some rationalities and strategies influencing the organization and practice of case management, even those based on an ethic of care and intentions to "do no harm," can be detrimental to clients at risk and living with HIV in case management when implemented with little attention to the social context of care or a concern with social justice (Edwards

& MacLean Davison, 2008, Gagnon, 2012; Mykhalovskiy, 2012; O'Byrne, Holmes & Roy, 2014). It is argued in this thesis from a critical theory lens that the current "War on HIV/AIDS" can be viewed as a "battle for truth." It represents a hegemony over the discourses circulating as truth in the management of infectious diseases--an unequal positioning in the media, the public's imagination, and in public health policies and practices of biomedical concerns and a biosecurity discourse in comparison to the knowledge, concerns and disease experiences expressed by nurses and the people at risk or living with HIV/AIDS at the point-of-care--about the priorities for HIV care. In this light, the management of infectious diseases can be understood as a form of governmentality, a process tied to a 'governmental rationality' that prioritizes biosecurity over efforts to understand and address the emotional and social impact of living with HIV, in which case management nurses are integrally involved. It is in this context that nurses' abilities to lead the development of a more integrated approach to the management of infectious diseases is described, starting with an analysis of how power/knowledge, economics, assumptions about gender, and the organization of institutional space may be impacting nurses' potential to contribute practice and policy ideas capable of addressing the power imbalance shaping case management policy and practice priorities in Ontario.

In Chapter one, evidence is reviewed that suggests public health's progress in managing the HIV epidemic in Canada is stalled, and there are a number of different discourses about the direction needed for a more effective HIV response. In Chapter 2, the literature about nurses' experiences in the management of HIV/AIDS is examined. A review of the literature reveals ambiguities in how case management is currently defined and practiced, divergent approaches in the follow-up of people who test positive for HIV, and tensions among public health nurses related to a perceived lack of autonomy in determining the direction of care. In Chapters 3 and 4, the theoretical framework and methodological considerations for this research are described. The relevance of Michel

Foucault's (1972-2008) writings on governmentality, Chris Weedon's (1999; 2008) analysis of gender, identity and experience in patriarchal societies, and David Sibley's (2007) work on geographies of exclusion for helping explore and articulate the links between the discourses, practices, and position of case management nurses within the public health response to HIV/AIDS is outlined. A critical ethnographic design was proposed for its congruency with the theoretical framework, ability to help elicit information about the variety of rationalities and strategies influencing case management policies and practices, and potential for identifying dominant discourses and power relations that contextualize the decision-making process in nurses' care. In Chapter 5, the results of the study are presented, and in Chapter 6, their implications for nursing research, policy and practice are discussed.

CHAPTER 1: RESEARCH PROBLEM

HIV/AIDS is now widely recognized as a medically manageable condition. Yet, worldwide, many people living with the virus remain undiagnosed and untreated, and HIV continues to spread (UNAIDS, 2016). This is true even in countries like Canada, where testing and follow-up with a specialist are free and treatment is readily available. The Public Health Agency of Canada (PHACa, 2018) estimates that among the 63,110 people living with HIV/AIDS in Canada, 14% (*n* = 9,090) are unaware of their HIV positive status. Among those diagnosed with HIV, 30% *(n* = 19,430) are not receiving treatment (PHACa, 2018). Knowledge of a positive HIV status, access to treatment, and social support are important for preventing the spread of HIV (UNAIDS, 2016; O'Byrne, 2012). Highly Active Anti-Retroviral Therapy (HAART), a medical breakthrough in treatment capable of suppressing the virus and helping prevent transmission, became available in 1996 in Canada (Canadian AIDS Treatment Information Exchange, 2014; Gusafson, Montaner, & Sibbald, 2012). However, more than 2,000 new infections are reported across the country each year (Haddad, Li, Totten & McGuier, 2018). A pressing issue in the "War on HIV/AIDS" is how to better engage people at risk or living with the virus in testing, treatment, and support services.

HIV prevention and linkage of people to testing, treatment and support fall under the domain of public health in Canada (PHAC, 2012). *Public health* can be defined as "the art and science of preventing disease, prolonging life and promoting health through the organized efforts of society" (Acheson, 1988 in WHO, 2019). In most provinces, public health nurses involved in the c*ase management* of sexually transmitted infections (STIs) are responsible for providing HIV care, including follow-up counselling with every client newly diagnosed with HIV, and their contacts (Provincial Infectious Diseases Advisory Committee [PIDAC], 2009). The Public Health Agency of Canada (2014) defines *HIV care* as a continuum of engagement with clients designed to "ensure reasonable access to

diagnosis, treatment, support and rehabilitation, as well as prevention services to reduce ongoing infection" (p. 1).

There appear to be competing discourses over the direction of HIV care in Canada. The people most affected by HIV/AIDS are from communities with a history of marginalization: gay, bisexual and other men who have sex with men (gbMSM) (51.9%); people who use injection drugs (IDU) (17.4%); newcomers to Canada primarily from sub-Saharan Africa and the Caribbean (15%); Indigenous people (9.6%); and at-risk women including trans women and women who are sexual partners or drug-using partners of people with HIV (23%) (Canadian HIV/AIDS Information Treatment Exchange [CATIE], 2018). *Marginalized communities* are groups of people who are disproportionately affected by stigma and discrimination (Provincial Infectious Diseases Advisory Committee, 2009). HIV guidelines issued from within these communities commonly recommend that greater attention be given to establishing trust, confidentiality, cultural sensitivity, addressing quality of life issues, and ensuring community involvement when designing and implementing HIV/AIDS policies (African and Caribbean Council on HIV/AIDS in Ontario, 2013; Canadian Aboriginal AIDS Network, 2009; Toronto People with AIDS Foundation, 2018). In contrast, however, is a public policy trend towards the criminal prosecution of people with HIV (Canadian Coalition to Reform HIV Criminalization [CCRHC], 2019; Gagnon & Vezina, 2018). The *criminalization of HIV* is the enactment of "laws specifically directed at punishing behaviour that may transmit HIV" (Cameron, 2009, p. 63).

In Canada, people can be criminally charged for not disclosing their HIV-positive status prior to engaging in behaviour that poses a "realistic possibility of HIV transmission" (Canadian HIV/AIDS Legal Network, 2014, p. 1). Courts have come to differing conclusions, but disclosure is required prior to all sexual activity unless factual evidence can be provided that a "significant risk of bodily harm" did not exist, such as a low or

undetectable viral load (<40-50 copies of virus per ml of blood) *and* the use of a condom to protect against transmission (Department of Justice, 2017). Canada has the third highest number of recorded prosecutions for non-disclosure in the world (CCRHC, 2019). Since 1989, 155 people with HIV have been prosecuted, 78% of cases ended with a conviction, and the seriousness of charges have increased from negligence causing bodily harm to murder (Canadian HIV/AIDS Legal Network, 2014). People have been criminally charged regardless of whether or not HIV transmission occurs, and for conduct that is known to present a low risk of transmission, including penetrative sex with a condom and oral sex (Loutfy, Tyndall, Baril, Montaner, Kaul & Hankins, 2014). Despite a lack of scientific evidence that disclosure prevents transmission, the criminal law and disclosure counselling was integrated into public health policy and practice in 1998, when Ontario's Chief Medical Officer of Health (MOH) issued a directive to counsel all clients about "the need for individuals to disclose and not to lie about their HIV status to all sexual partners" (Ontario Advisory Committee on HIV/AIDS, 2003, p. 5). Ontario is not the only province where people with HIV can be criminally charged for non-disclosure, but currently Ontario reports the greatest number of prosecutions for non-disclosure of HIV in Canada (Hastings, Kazatchkine & Mykhalovskiy, 2017), as well as the highest number of new cases of HIV annually—almost double that of any other province (Bourgeois, Edmunds, Awan, Jonah, Varsanaeux & Siu, 2017).

Nurses are beginning to express concerns that the criminal law and disclosure counselling are not effective means of preventing transmission of HIV, and may instead be serving as a barrier to people for coming forward for HIV care (Gagnon & Vezina, 2018; O'Byrne, 2012; O'Byrne & Gagnon, 2012; O'Byrne et al., 2014; Phillips, Domingue, & Morrisseau-Beck, 2013). For example, many clients are choosing to test for HIV anonymously as a means to learn their HIV status without having their name requested, recorded, or reported to public health (Ontario Ministry for Health and Long-Term Care

[MOHLTC], 2019). Today, there are over 50 centres across Ontario that offer anonymous testing—more anonymous test sites than public health units (N = 36) in the province (MOHLTC, 2019). Evidence of avoidance of public health by clients, along with growing rates of HIV in communities with a history of marginalization, call into question the social and cultural relevancy of public health's current HIV policies and services.

1.1 Research Aims

A critical reflection on public health policies and practices appears to be an important first step in improving the progress of the public health response to HIV in Ontario. The Public Health Association of Canada (2018b) initiated research aimed at capturing and tracking the concerns of people from communities most affected by HIV. Missing, however, are studies involving direct care providers, namely case management nurses, involved in the HIV response (Wilson et al., 2013). The goal of this study is to identify strategies to better engage people at risk and living with the virus in testing, treatment and support services. The objectives are to describe the experiences of case management nurses involved in the follow-up of people who test positive for HIV in public health units across Ontario and identify how public health policies shape the boundaries of nursing care and client outcomes in the response to HIV/AIDS. It is important to understand and support case management nurses as they work at the interface of public health's policies and clients' responses to HIV care and are public health's link to the communities most affected by HIV/AIDS. The research provided public health nurses with the space to reflect on their practice. The findings establish the foundations for a new knowledge base about case management nurses' experiences engaging with people on the "frontlines" of public health care and the strategies that may be required to strengthen the HIV response, as well as nurses' capacity to participate in practice and policy debates, and form more effective partnerships with the people at risk and living with HIV in Ontario.

1.2 Research Questions

The research question guiding this study is: “How are public health nurses' experiences in case management in Ontario aligned with policies governing the response to people affected by HIV/AIDS?” Specifically, this study asks:

1. How do public health nurses describe their role in case management?
2. What are the policies, strategies and rationalities used by nurses to engage people at risk and living with HIV in HIV care?
3. What discourses dominate the social and spatial organization of case management practice, and how do they shape nurses’ experiences with clients?

1.3 Epistemic Stance

> [W]e must keep in mind that the struggle for rationality in the epidemic has always been to secure equivalent treatment for those with and at risk of HIV. If we do so, our task becomes clearer. (Cameron, 2009, p.74)

My ultimate concern in a study about case management is with the ability of nurses to better engage people with a history of marginalization in efforts to improve the outcomes of public health care. Therefore, my work is aligned with a poststructuralist approach from the paradigm of critical theory for its philosophical opposition to oppression and marginalization, and commitment to multivocality and pluralism (Holmes & Gagnon, 2018; Mill, Allen & Morrow, 2001). My motivation in engaging in a critical reflection on public health policies and practices stems from a commitment to social justice, and the belief similar to that expressed by Justice Cameron above, that public health’s obligations include securing equivalent treatment for people affected by HIV in efforts to protect the health of the public.

I am interested in research with case management nurses to understand nursing’s potential to assume a greater leadership role in public health’s efforts to respond to the unequal distribution of disease evident in the HIV epidemic in Canada. My motivation to

support public health nurses is related to a professional interest in helping nurses explore and actualize their potential, and “reclaim and reawaken their individual and professional sovereignty” (Georges, 2003, p. 50). Currently, there are few avenues for case management nurses to discuss ideas and concerns arising at the point-of-care, and little evidence that nursing experiences are accounted for in the policies, practice recommendations, and research being designed to improve the outcomes of the public health response to HIV. By involving nurses in research and using a critical theory perspective, this study is meant to help create an opportunity for nurses to reflect on their role and ability to influence public health practice, policy and research. Underpinning my interest in a critical theory perspective is a transformative worldview, and a shared belief that research about case management nurses’ experiences with a critical theory framework can help foster “transformational leadership” (Bronner, 2017; Guba & Lincoln, 1994).

Leadership in public health is needed, for example, to clarify the purpose of public health’s alignment with the criminal law and review public health’s role in monitoring, reporting, and participating in the enforcement of compliance in cases of non-disclosure. A potentially problematic area of disclosure counseling is the focus on ‘reckless conduct.’ This involves an implicit acceptance that there is a proper code of conduct for all people with HIV and holds people legally accountable despite a lack of agreement about what that acceptable conduct might be. The result is often confusion and anxiety for both clients and nurses (Mykhalovskiy, 2012; Kilty & Orsini, 2019; O’Byrne & Gagnon, 2012; Sanders, 2015; Sanders & Bisaillon, 2019). For example, HIV can be transmitted through breastfeeding—does that mean breastfeeding is a crime? What happens in cases of non-disclosure when the condom breaks? Or a person with HIV tests positive for other sexually transmitted infections linked to a lack of condom use like Chlamydia? Are these grounds for sexual assault or evidence of attempted murder?

Subsequently, the legal requirement to disclose is in many ways a potential source of further stigma and discrimination for people living with HIV and may explain fears people have about learning their HIV status and preferences for anonymous testing in Ontario (Gagnon & Vezina, 2018; UNAIDS, 2013). In my own experience as a case management nurse with Ottawa Public Health from 2010-2014, it was clear that a number of clients employ strategies to avoid public health, and their avoidance appears to reflect an attempt to regain privacy and control over the management of their HIV infection and sexual conduct. This study explores these observations, and the practice concerns and ideas of other case management nurses across the province.

Therefore, through this research I critically reflect not only on the rationalities underlying HIV case management in other health units, but on my own perceptions and practices in HIV care. As a former case management nurse, I realize I carry an insider perspective with me to this research, as well as an outsider view informed by my full-time move to academics. I have undertaken this research recognizing my own experiences are inseparable from the research process. My work does not presuppose an objective or value-free science. Rather, it incorporates a methodological push for honesty, attention to diversity, explication, description and rigour consistent with a critical theory philosophy. A critical theory approach offered the methodological tools for questioning accepted norms and practices and eliciting information about the variety of nursing insights and strategies considered in case management practice across the province.

The role of 'researcher as participant' is fundamental to a critical theory approach, as it is directly linked to epistemological conceptions about the production, use, and dissemination of knowledge (Mill, Allen & Morrow, 2001). Guba and Lincoln explain that, in a critical theory paradigm, "what can be known is inextricably intertwined with the interaction between a *particular* investigator and a *particular* object or group" (1994, p. 110). By engaging in dialogue and reflexivity, nurses involved in this study were given the

potential to arrive collectively at a heightened awareness of how their individual and common values determine perceptions of the world (Campbell & Wasco, 2000). The research is subjective, participatory, transactional, and value mediated *in order* to arrive at a "unity of reason in the diversity of its voices" (Habermas, 1992, p. 115). Dialectic transactions between the researcher and other participants helped excavate and uncover articulated and previously unarticulated experiences and perceptions. Intensive explication and reflection are the tools for deconstructing accepted and opposing views, and arriving at new interpretations of knowledge, a process of 'consciousness raising' about a situation under study (Mill et al., 2001). The promise of this approach for case management nurses was the ability to unpack and make sense of current divergences and tensions in practice. These steps were meant to foster a new collective understanding about 'what is going on' in case management, as well as sense of collective ownership over the knowledge that was produced. By arriving at a critical standpoint, case management nurses are potentially better positioned to describe and debate how public health policy affects the quality of nursing care provided at the point-of-care.

The uniqueness of critical theory in comparison with other paradigms is that it is attuned to the socio-political context as well as individual perceptions, and the rules that govern both (Mill et al., 2001). Foucault's description of the complex interrelationship between ontology and epistemology, and view on the relationship of knowledge and power, provides the foundation for this conceptualization (Melies, 2014). According to Foucault, "[t]ruth is linked in a circular relation with systems of power that produce and sustain it, and to effects of power that induce and extend it" (1980, p. 133). Ontology and epistemology are blurred in this reality. The 'realm of the possible' in an institution is shaped, enforced, and normalized over time by those in power to define it. In the absence of insight, those on the margins of power are subject to a reality that exists outside of them, yet "govern his or her own inner experiences and significant values" (Holmes, Murray,

Perron & Rail, 2006, p. 183). Intensive explication and consciousness raising are the emancipatory tools available to individuals to break free from the constraints of "the panoptic kind of 'expert seeing'" that determines in advance what will appear as reality and as options or choices in that system (Holmes et al., 2006, p. 183). In this way, critical theory is a context-specific approach based on a theory of beliefs about how institutions work (Creswell, 2014). In public health, critical theory can help understand the assumptions and processes linked to nurses' decisions and explain why certain approaches to practice may be more supported than other approaches.

In case management, nurses are simultaneously responsible in HIV care to the client, their contacts, and the community. They operate in the context of public health as an institution comprised of a variety of different disciplinary roles and perspectives, within the context of public perceptions of the management of epidemics as "wars," and public health policy that accepts the criminalization of people with HIV. Therefore, in a study with case management nurses, meaning would be lost without a context-specific approach and analysis of the relationship of social, political, legal, cultural, economic, and gender related factors. I have approached the complicated practice reality of case management nurses from a critical theory paradigm for its ability to embrace complexity and the tools it offers for arriving at an understanding of how nurses filter and are shaped by these factors. By pursuing emancipatory knowledge, through a critical dialectic, I also have tried to uncover the conditions for nurses to operate more freely, experience their unique voice, and participate in the restructuring necessary to enable public health units to offer quality care that is meaningful and satisfactory from the perspective of all members of the public—the people who are living with HIV as well as those public health units aim to protect from its spread.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

HIV care is relatively new to the field of case management (Chernesky & Grube, 1999). The origins of case management practice can be traced to the de-institutionalization of people with mental health, and the need for a cadre of professionals capable of offering health and social support from the community (Mueser, Bond, Drake & Resnick, 1998). A search of the CINAHL, Medline, and ERIC data bases using the key search terms "case management," "nurse," and/or "HIV/AIDS" revealed that the majority of research is related to the experiences of case managers in mental health or long-term care (e.g. Corazzini, 2000; Crook & Vinton, 2000; Mueser et al., 1998). Less is known about the experiences of case managers in HIV care (Wilson et al., 2013). The reference lists of articles about case management nurses involved in HIV care were scanned for additional literature related to HIV follow-up and nursing. Articles were included in this literature review if they were published in English in peer reviewed journals since the onset of the pandemic in 1981, involved nurses as authors or in the sample and discussion of results, and it could be determined from a full text reading that the participating nurses were involved in any aspect of case management equivalent to the role of public health nurses in Canada as described by PIDAC (2009) such as counseling, education, prevention and/or referral of people diagnosed with HIV/AIDS to treatment and support services. Articles were excluded if the focus was on acute or palliative care, did not involve nurses, or were not available in English. The search yielded 54 articles, of which only 16 were studies and 2 were theoretical papers. The majority of publications by nurses were editorials or clinical case studies (n=33), and over half (n=22) were published prior to the availability of effective treatment for HIV/AIDS in 1997. No policies were identified through the library databases; however, 4 policies were identified from an online search of provincial and federal websites that were also relevant to HIV case management nursing in Canada.

Few studies or policies focus specifically on nurses. Topics of studies vary from knowledge levels to stigma in nursing care (Gagnon, & Vezina, 2018; Mill et al., 2013; Scherer et al., 2014; Wagner, McShane, Hart, & Margolese, 2016). Much of the nursing literature in HIV care is from international settings such as the United States, Brazil and Kenya (Mill et al., 2013; Richter et al., 2013; Rossi, Amaral, & Makuch, 2011; Van der Elst et al., 2013), and very few studies or policies are concerned with or directly involve public health nurses (Cohen, 2006). However, an examination of recurring results, commonalities and differences among the issues reported in studies related to nursing care, and the recommendations in both studies and policies related to the follow-up of people with HIV, led to the identification of three themes that are relevant to helping better understand public health nurses' experiences: perceptions of case management practice; interpretations and implementation of policies; involvement in policy, practice and research decisions.

2.2 Perceptions of Case Management Practice in HIV Care

Only one study could be found that attempts to describe the role of case managers in HIV care, which was completed when HAART was not yet widely accessible, and "compassion" was the main treatment available for people with HIV. Chernesky and Grube (1999) conducted chart reviews, and interviewed 17 case managers, from 8 different HIV/AIDS programs across the state of New York, in order to understand the HIV/AIDS case management process early in the pandemic. The case management process was described partly as disease management, but primarily as a supportive role. Case managers saw their main tasks as the creation of supportive environments and helping clients navigate the healthcare system (Chernesky & Grube, 1999). Wilson and colleagues (2013) arrived at a similar definition for case management in a more recent scoping review of research about case management interventions in counselling, health promotion, and HIV care. Definitions of HIV case management varied across studies, but

case managers were found to have in common a focus "on helping service users to identify their unmet needs, and linking them with the required health and social services to achieve desired outcomes" (Wilson et al, 2013, p.1613). Research also shows that case managers have in common steps, such as assessing clients' coping and risks, educating clients about HIV and transmission, counselling about stressors, offering emotional support, advocacy, capacity development, and making referrals (Chernesky & Grube, 1999; Mueser et al., 1998; Robillard, Gallito-Zaparaniuk, Braithwaite, Arriola & Kennedy, 2013; Wilson et al., 2013).

Despite commonalities, there are ambiguities and differences both across and within programs of HIV care. Variations in HIV care among service providers exist in terms of comprehensiveness of case management services (Chernesky & Grube, 1999; Wilson et al. 2013), knowledge and topics included in counselling (Drainoni, Dekker, Lee-Hood, Boehmer, & Relf, 2006; Rossi et al., 2011; Scherer et al., 2014; Van der Elst et al., 2013), and end goals and the extent of counselling provided (Freedman, Binson, Ekstrand, & Galvez, 2006; Robillard et al., 2013; Van der Elst et al., 2013). HIV case managers and direct care providers in many community-based HIV/AIDS organizations, can be nurses, social workers, or peer counsellors, but research results have not been described in relation to the training or professional background of the health care providers involved (Chernesky & Grube, 1999; Drainoni et al., 2009; Freedman et al., 2006; Robillard et al., 2013; Scherer et al., 2014; Van der Elst et al., 2013). It is possible that differences in the definitions and content included in the care provided were related to the professional background of service providers (Wilson et al., 2013).

Few studies in HIV care specifically focus on nurses. A study comparing the roles of nurses and social workers in HIV care by Olivier and Dykeman (2003) found that nurses focus on transmission and treatment of HIV infection, while social workers are more concerned about clients' legal rights and social support. Research with nurses involved

with HIV care in Africa also demonstrates a nursing focus on transmission but suggest personal and nursing values play a role in counselling (Mill et al., 2013; Van der Elst et al., 2013). In Canada, Cohen (2006) interviewed public health nurses in northern Manitoba about the role of health promotion in practice, and also found that personal and nursing values are factors in decision-making. Along with organizational policies and time constraints, values influenced how some nurses prioritized health promotion activities. However, no research could be found about the role of values in public health nurses' decisions about HIV care.

Rossi et al. (2011) noted that time constraints, a lack of priority, lack of policies, and limited knowledge were all factors associated with the decisions of nurses and managers not to include information about reproductive options in counselling with HIV positive women in a study of women's healthcare centres across 26 state capitals in Brazil. Scherer et al. (2014) surveyed a mixed sample of healthcare providers involved in HIV care in the United States and the findings were similar. There were wide variations in knowledge levels within and among professionals about reproductive care, and over one-third of respondents expressed reluctance to counsel people who were HIV positive about their options, despite agreement expressed by 91% of those surveyed that individuals infected with HIV should have the same rights to reproductive assistance as non-infected individuals. Scherer et al.'s (2014) survey did not include questions about the participants' rationales for choosing to counsel or not counsel clients. Van der Elst et al. (2013) conducted post-training focus groups with HIV care providers in Kenya and learned that many participants' anticipated problems integrating new knowledge into practice because of conflicting values and discrimination in their work environment. Nurses and administrators believed that their training about the needs of men who have sex with men would be difficult to incorporate into routine counselling due to homophobia and stigma in their institutional settings. Further research is needed to better understand nurses'

perceptions of their role in HIV care, what values and knowledge are given priority in practice, the rationales used for decision-making in a Canadian context by nurses and managers, and nurses' experiences with clients in public health settings.

2.3 Interpretations and Implementation of Policies

There are few guidelines and policies published relevant to the role of a public health nurse in case management in Canada. The *Canadian Guidelines on Sexually Transmitted Infections (STIs)* is the main reference available and is used primarily for information about treatment standards and contact tracing periods for STIs (Public Health Agency of Canada, 2016). The *Infectious Diseases Protocol* outlines the case definitions and partner tracing obligations for physicians and public health nurses for all reportable infections in Ontario including HIV/AIDS (MOHLTC, 2013b). However, there appear to be no policies specifically outlining the expectations for HIV follow-up care. Two documents were produced by advisory groups to provide interim guidelines: the *STI Case Management and Contact Tracing Best Practice* document (Provincial Infectious Diseases Advisory Committee, 2009), and the *Persons Who Fail to Disclose their HIV/AIDS Status: Conclusions reached by an Expert Working Group* (Public Health Agency of Canada, 2005). Both documents recommend a focus in counselling on risks related to transmission and on behaviour modification. A "least intrusive, most effective" approach proportional to the risk of transmission posed by a particular behaviour is advised, with the end goal being to "modify the risky conduct" (Public Health Agency of Canada, 2005, p. 1). Notable is that both documents are outdated; the former is under revision, and the latter has been archived. It is not clear what guidelines or policies are being used in Ontario by case management nurses involved in public health care.

Freedman et al. (2006) conducted an extensive qualitative study involving STI clinics across the San Francisco Bay area with the purpose of illuminating both "articulated and unarticulated notions of what direct care providers thought would facilitate behaviour

change" in their clients (Freedman et al, 2006, p. 216). Ironically, the implicit theory mapping revealed divergences in counselling, often away from a focus on behaviour modification. The findings showed that many prevention workers believed that establishing a sense of connectedness with clients and building self-esteem were more important than probing about reasons for unsafe behaviour, especially among populations that were both disenfranchised and at high risk for HIV (Freedman et al., 2006). Freedman et al. (2006) reported that many prevention workers focused instead on creating safe spaces where clients could open up and discuss emotional issues important to them without fear of being judged. Based on semi-structured interviews, Drainoni et al. (2009) similarly reported that, among healthcare workers at a large STI clinic in the United States, "provider styles tended to move away from the biologic perspective and toward the social or relationship perspective as they got to know the patients" (p. 348). A harm reduction approach, based on an overall acceptance of the idea of slow, incremental behaviour change, including a philosophy of caring for clients even if they engage in risky behaviour, was evident in a number of studies (Chernesky & Grube, 1999; Drainoni et al., 2009; Freedman, 2006; O'Byrne & Gagnon, 2012; Robillard et al., 2013).

However, it is not clear from the research which approach to HIV care is preferred by nurses. In a report from a workshop on HIV disclosure counseling in Ontario by O'Byrne and Gagnon (2012), various perspectives on counselling were apparent among the providers present, and the sample included case management nurses. Some focused on behaviour change and compliance, while others emphasized supportive care and informed choice in counselling (O'Byrne & Gagnon, 2012). O'Byrne et al. (2014) later speculated that the emergence of two different approaches in case management might be related to public health nurses' dual, and sometimes conflicting, obligations to protect the public from transmission on one hand and promote client-centred care for individuals infected with HIV on the other hand. Further research is needed to determine how case

management nurses navigate these obligations.

A number of other policy issues are raised in the literature. For example, participants in Drainoni et al.'s (2009) study universally requested more training and guidelines for dealing with resistance to prevention messages, and an interest in learning new prevention approaches "beyond just educating clients about risks and not to use condoms" (p. 352). Drainoni et al. (2009) also reported that healthcare providers expressed a need for more support and resources for culturally sensitive care to help meet the needs of clients. In Freedman et al.'s (2006) study, prevention workers were concerned about achieving greater consistency in counselling. One of the objectives of O'Byrne and Gagnon's (2012) workshop about disclosure counselling, was to formulate guidelines and a more consistent approach among providers for addressing clients' confusion around disclosure laws. Participants also suggested policies were needed to address their own confusion over their role in disclosure counselling, documentation, and follow-up (O'Byrne & Gagnon, 2012).

O'Byrne et al. (2014) subsequently undertook a systematic review of outcome research to investigate how legal obligations for HIV status disclosure have impacted clients' engagement in high risk behaviour and concluded that nurses should critically reflect on their role in disclosure counselling. The findings support concerns that the rationalities requiring nurses to promote the mandatory disclosure of a positive HIV status may not be consistent with the goals of public health nurses (O'Byrne et al., 2014; O'Byrne & Gagnon, 2012; Phillips, Domingue, & Morrisseau-Beck, 2013). O'Byrne et al. (2014) further demonstrated the relevance of Foucault's framework of governmentality for investigating the link between nurses' practice decisions, institutional policies and expectations, and public policy. Further research using a framework of governmentality could help clarify which expectations, policies, and processes are influencing public health nursing priorities and practice decisions in HIV case management.

2.4 Involvement in Practice, Policy and Research Decisions

Richter et al. (2012) recently led a major research project in Canada and four countries in Africa, in order to describe nurses' influence on policy development in HIV care. A participatory action research design was employed to increase awareness of nurses' capacity to shape HIV care. Overall, nurses expressed a sense of disconnectedness from the decision-making processes in their institutions. Many were concerned about the one-way, top-down flow of information about practice standards, and a tendency of administrators to assume the role of gatekeeper to research and new ideas about HIV care. It was not clear how much diversity existed among the responses. Differences across continents, or practice settings, were not discussed.

However, results from an extensive survey of public health nurses and their work-life experiences in various health units across the province of Ontario lend support to Richter et al.'s (2012) findings. Underwood (2010) reported a common perception among public health nurses of a lack of flexibility, autonomy, and tension over practice and policy decisions. Nurses largely attributed the tension to differences in values and priorities between the nurses in direct care roles and nurses who assume a supervisory role. New research is needed to determine the extent to which these findings are representative of the experiences of public health nurses in STI case management in Ontario, and if so, to better understand the nature of the tensions, and the conditions that would increase the potential for greater collaboration in practice, policy, and research in the future.

2.5 Research Gaps

The research about nurses' experiences in the case management of people with HIV is sparse. However, based on a review of the literature, three themes emerge. By examining the links between: (1) public health nurses' description of their role in case management; (2) the rationalities and strategies used in practice; and (3) the discourses dominating the organization and experiences of nurses with clients in HIV care, this research explores

how the three themes and gaps in the literature might be related (see Figure 1). A critical theory approach is employed to understand how differences in nurses' knowledge, goals, and perceptions of the role of case management in Ontario is linked to divergent approaches in HIV care, and tensions over autonomy and priorities in public health nursing practice and policies. The links are explored using a theoretical framework based on the writings of Michel Foucault (1972-2008), Chris Weedon (2008), and David Sibley (2007).

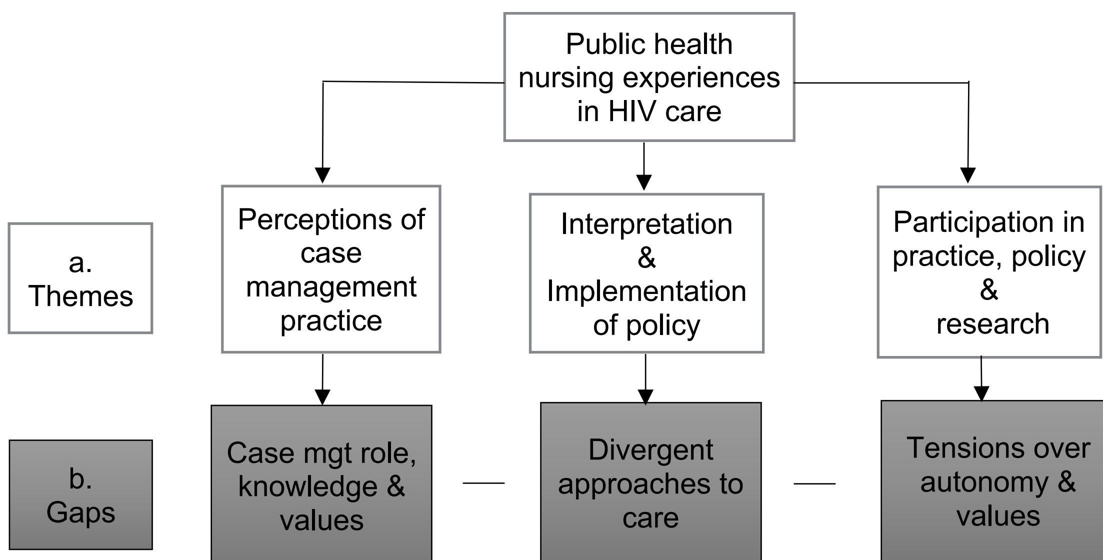

Figure 1:
Research Focus: Gaps in the Literature. © Linda Juergensen, Ottawa, Canada, 2020

CHAPTER 3: THEORETICAL FRAMEWORK

Three theoretical perspectives are used to explore nurses' experiences in the public health response to HIV/AIDS in Ontario: Michel Foucault's (1972-2008) writings related to governmentality; David Sibley's (2007) geographical analysis of exclusion; and Chris Weedon's (1999; 2008) work on gender, identity, and experience in patriarchal societies. Each perspective helps illuminate and conceptualize different aspects of the socio-political context in which public health nurses are situated, and their influence on the direction of case management practice and HIV care. At the same time, all three perspectives are rooted in the paradigm of critical theory and congruent with a poststructuralist approach regarding the social construction of knowledge, including a central concern with subjectivity, discourse, power, and resistance. Therefore, taken together, the three theoretical lenses offer unique but complimentary concepts and considerations for helping unravel, describe, and understand the complexities associated with nurses' decision-making in case management.

3.1 Michel Foucault: Governmentality

According to the French philosopher, Michel Foucault, we live in an era of governmentality (Dean, 2010; Elbe, 2009). The term governmentality can be traced to Foucault's writings about 'governmental rationality' (Gordon, 1991). "The art of governing is rational," posits Foucault (Gordon, 1991, p. 9), and governmental "'practices' don't exist without a certain regime of rationality" (Foucault, 1991a, p. 79). In this line of thinking, governmentality involves "examining how forms of rationality inscribe themselves in practices or systems of practices, and what role they play within them" (Foucault, 1991a, p. 79). Governmentality is useful as a framework for this study for its ability to help identify and describe forms of rationality inscribed in public health, how they influence the rationalities and strategies used by nurses in case management, and what role they play in shaping HIV care.

Through his discussions in *Power/Knowledge (1972-77), The History of Sexuality (Volume 1), Security, Territory, Population (1977-78), The Birth of Biopolitics (1978-79),* as well as later essays, lectures and interviews, Foucault assembles a genealogy of modern systems of government, governmental practices, and a particular rationalization of political rule that has been gradually emerging in the West since the eighteenth century. A hallmark of this work is his arrival at a novel way to conceptualize government and power that corresponds with the transition in the West away from societies organized around monarchies and feudalism to systems of government shaped by the values of democracy and liberalism, and the economic rationalizations of capitalism (Dean, 2010; McHoul & Grace, 2002). Under liberalism and capitalism, it is Foucault's view that government and governing extend beyond the state, and singular institutions or authority figures (Holmes & Gastaldo, 2002). Foucault suggests that the state should now be seen as a "network of institutions, deeply embedded within a constellation of ancillary institutions associated with society and the economic system" (Hall, 1986, p. 170). In this arrangement, power is more accurately understood as the manifestation of the *power relations and processes* that develop within and through networks of institutions and individuals in response to liberal and capitalist demands (McHoul & Grace, 2002).

Foucault argues that a defining feature of modern forms of government and power in the West is the merging of knowledge from the medical and social sciences with techniques of governmental management as the means to preserve social order and accomplish its social and economic goals (Foucault, 1978). It is in this context, that a framework of governmentality appears to have particular relevance for nurses involved in public health (Holmes & Gastaldo, 2002; O'Byrne et al., 2014; Petersen & Lupton, 2000). That is, in contemporary Western societies, the population has become the object of governments, and the primary objective, Foucault (1978) explains, is the *promotion of life* and production of 'healthy' bodies and behaviours capable of sustaining the governmental

system. Both biomedical knowledge of individuals and populations, and the assemblages of institutions, practitioners, and practices that support its dispersion and implementation, subsequently play an important, even privileged, role in modern government (Foucault, 2003a; 2008). Both are necessary for the accumulation of an efficient and effective workforce required for capitalism to function, and for social control in liberal traditions where values of individual freedom and prosperity need to be accommodated (Dean, 2010; Foucault, 1980).

In this arrangement, government as an activity or practice can be seen to exist not only in one particular political body or institution, but where any form of activity aims to shape, guide or affect the conduct of some person or persons. In short, Foucault views *government* as the "conduct of conducts" (Gordon, 1991, p. 2), and *governmentality* as involving methods of control over rationalities and practices of others and oneself, or more broadly, a concern for authority over "the bodies of knowledge, beliefs and opinions in which we are immersed" (Dean, 2010, p. 27). A study of governmentality, therefore, is not a study of states, leaders, legitimacy, or ideologies in the traditional sense, but a deconstruction of the rationalities and political processes governing social order, and their socio-political effect.

Specifically, understanding governmentality involves a process of *analytics of government*, an investigation of how the government of others and government of one's self are interconnected through the 'rationality of government' and institutional practices (Dean, 2010). In this thesis, the experiences of nurses in governmentality are examined through an "analytics of government" based on how Foucault conceptualizes power/knowledge, biopower, and the government of self and others. In the following sections, the relevance of each of these concepts for understanding the role of HIV case management nurses in governmentality are described in turn.

3.1.1 Power/knowledge

Foucault's interest in rationalities and governmental practices, and an "analytics of government," stem from an ontological and epistemological stance that questions claims about the 'truth or falsity' of knowledge and its power. Foucault (1991a) explains:

> If I have studied 'practices' like those of the sequestration of the insane, or clinical medicine, or the organization of the empirical sciences, or legal punishment, it was in order to study this interplay between a 'code' which rules ways of doing things (how people are to be graded and examined, things and signs classified, individuals trained, etc.) and a production of true discourses which serve to found, justify and provide reasons and principles for these ways of doing things. To put the matter clearly: my problem is to see how men govern (themselves and others) by the production of truth (… the establishment of domains in which the practice of true and false can be made at once ordered and pertinent). (p. 79)

According to Foucault, truth is socially constructed, and circulated as discourses. An important effect of discourses is the power to shape the limits and possibilities of individual and social life, a relationship Foucault describes as *power/knowledge*. The products of power/knowledge are *subjectivity* and the *normalization* of a set of preferred beliefs and behaviours, two processes that are central to what Foucault (2008) considers *biopower* and the government of oneself and others. These concepts and processes are described below, beginning with a description of Foucault's views on ontology and the social construction of truth.

The social construction of truth

Foucault's concerns with claims about the 'truth or falsity' of knowledge is consistent with a poststructuralist perspective and paradigm of critical theory. From a poststructuralist standpoint, truth, knowledge, and science, like the institutions that make up the state, are believed to be socially constructed (Guba & Lincoln, 1994). Truth is thought to be relative, and 'reality' an interpretation of social, political, cultural, economic, and gender values and experiences (Campbell & Wasco, 2000). What can be known is linked to the values and rules employed by those producing knowledge and intertwined

with their interaction with a subject or the object of inquiry (Guba & Lincoln, 1994).

Knowledge, therefore, cannot be considered 'pure fact' or 'common sense.' In this line of thinking, claims about truth and knowledge should always be situated, contingent, and viewed as transactional in nature. While reality exists independent of thoughts, the truth and knowledge available to individuals is linked to politics and the power to influence what knowledge is valued, developed, and dispersed in a social context (Foucault, 1980). In other words, critical theory assumes a critical realism at the level of ontology, and pluralism in epistemology and methodology (Mill et al., 2001). Governmentality, likewise, is based on Foucault's assumption that in reality a multiplicity of truths are possible, but *truth* becomes a function of the practices that govern what may, or may not, be thought, said, or written (McHoul & Grace, 2002).

Discourse and subjectivity

According to Foucault, truth, knowledge, and reason are ordered, absorbed, and perpetuated through discourses and institutional practices (Dean, 2010). *Discourses* can be defined as "statements" (Foucault, 1980, p. 59), spoken or written words that represent bodies of knowledge (McHoul & Grace, 2002). On the relationship between truth and discourses, and their significance, Foucault (1980) adds:

> Now I believe that the problem does not consist in drawing the line between that in a discourse which falls under the category of scientificity or truth, and that which comes under some other category, but in seeing historically how effects of truth are produced within discourses which in themselves are neither true nor false. (p. 118).

The significance of discourses is not whether they are intelligible, legitimate, or 'true or false,' but that they exist, and under what rules, criteria, and conditions they become possible, and to what effect.

An important function of discourses is their ability to establish the parameters of what is known, and therefore, their power to produce *subjectivities* (Foucault, 1980). Based on the premise that individuals perceive and construct a sense of self, or *identity*, through the

established forms of knowledge and rationalities available to them, discourses play a powerful role (Holmes & Gastaldo, 2002). Discourses, and the bodies of knowledge they represent, in themselves, establish the limits and possibilities of what is considered 'right,' normal, acceptable, different and intolerable in reality. Foucault (1989) explains: "The meaning of a statement would be defined not by the treasure of intentions that it might contain, revealing and concealing it at the same time, but by the difference that articulates it upon the other real or possible statements, which are contemporary to it or to which it is opposed" (p. xix). The power of discourses, therefore, lies in their role in establishing the theoretical conditions of possibility, or the *episteme*, and by extension, the groundwork for a heterogeneous system of relations (Foucault, 1980, p. 197). On the power of discourses to shape reality, Foucault elaborates:

> Our world does not follow a programme, but we live in a world of programmes, that is to say in a world traversed by the effects of discourses whose object (in both senses of the word) is the rendering rationalisable, transparent and programmable of the real. (Gordon, 1980, p. 245)

This is clear in the sciences, for example, where four paradigms of thought have been described by Guba and Lincoln (1996): positivism; postpositivism; constructivism; and critical theory. Each corresponds to and drives the development of a particular perception of reality, body of knowledge, set of accepted as well as unacceptable scientific rationalities and methodological procedures, and community of individuals and institutions that support or refute them (Kuhn, 2012).

According to Foucault (1980), the task of research, therefore, consists of "making all these discourses visible in their strategic connections" (p. 38). Subsequently, a first step in a study of governmentality is to identify the discourses circulating as truth in a social setting, and the second, to examine the effects of discourses on the perceptions, values, roles, and goals, or identity of the subject under study. Third, an examination of discourses involves illuminating how they are perpetuated, and how some discourses become

privileged over others in the field of what can be considered as real.

Constructing the subject

Understanding subjectivity in HIV case management nursing involves a conceptualization of how nurses can be seen to be both subjected to, and participate in, the production of knowledge and perpetuation of discourses in their practice settings—either intentionally or unintentionally (Holmes & Gastaldo, 2002). According to Foucault (1980), "[w]e are subjected to the production of truth through power and we cannot exercise power except through the production of truth" (p. 93). By this Foucault implies that individuals are both the vehicles and the drivers of the production and dissemination of knowledge. As such, individuals are simultaneously affected by and can affect the way truth is perceived. Consequently, in a web of social relations individuals "are always in the position of simultaneously undergoing and exercising power" (Foucault, 1980, p. 98).

In order to grasp nurses' position within a web of power relations, and describe how case management nurses' identity and practice in HIV care have been socially constructed, Foucault (1980) insists, "[o]ne has to dispense with the constituent subject, to get rid of the subject itself, that's to say, to arrive at an analysis which can account for the constitution of the subject within a historical framework" (p. 117). In line with a poststructuralist perspective, Foucault (1980) sees the subject as neither a passive object nor solely an agent in the creation of knowledge, and an analysis of subjectivity as requiring "something more than the simple revitalization of the phenomenological subject" (p. 117). Consideration must be given to the idea that:

> …the 'subject' here is thought of by Foucault as a fictive or constructed entity (as are certain objects) though this does not mean that it is *false* or *imaginary*. Power does not itself give birth to people, but neither does it dream its subject into existence.

This means that understanding subjectivity must involve unraveling how the subject, or in this case the nurse, is in a position of being both acted upon and engaged in the production

of knowledge circulating as 'truth.'

A study of governmentality, therefore, necessarily includes not only an exploration of case management nurses' perceptions of themselves, and the beliefs, values, reasoning and opinions underlying their decisions in practice, but an analysis of the context of nurses' perceptions and practice decisions. This involves tracing the lines of communication in nurses' networks, and an investigation of how case management nurses' values, beliefs and behaviour are allied with forms of knowledge postulated as truth by various authorities in the social systems in which they work. In his analysis of the influence of power/knowledge on the subject, it is important to note:

> The key here to Foucault's position is his methodological scepticism about both the ontological claims and the ethical values which humanist systems of thought invest in the notion of subjectivity. To repeat: the point is not to judge or to subvert these values, only to investigate how they become possible and not to content oneself with ascribing them to the teleology of progress. (Gordon, 1980, p. 239)

As Petersen and Lupton (2000) explain, "[l]ittle attention has be paid to analyzing the fundamental principles, discourses and practices of public health from an epistemological position, or to exploring public health as a sociocultural practice and a set of contingent knowledges" (p. x). It is likely because the fields of medicine, nursing and public health have been built on a scientific base grounded in assumptions about objectivity that many public health practices tend to remain relatively "unsullied by questions of power" and critiques of progress (Petersen & Lupton, 2000, p. xi). In this study, understanding nurses' role in absorbing and perpetuating specific discourses involves identifying implicit and explicit theories used by nurses in practice, tracing the link between their subjective perceptions and beliefs to institutional practices and policies, and questioning accepted rationalities and norms, not as a means to judge nursing practice, but to more clearly conceptualize the power of nurses to shape reality—in relation to their own practice as well as the experiences of their clients in public health.

3.1.2. Biopower

Discourses emanate from and through individuals, as well as the institutions that make up the state. Correspondingly, "power is everywhere" (Foucault, 1979, p. 93). Subsequently, it is no longer relevant to talk of a central governmental authority in describing modern forms of government, or of sovereignty as a single authoritative body in terms of the state. In place of a central authority responsible for the domain of government, one must now look to a *dispositif*, a state apparatus, to understand sovereign power (Foucault, 1980). Power/knowledge emanates from and through the dispositif, or apparatus, as a means of meeting the objectives of the state, while at the same time, ensuring the continual existence or prosperity of the individuals and institutions allied with the state. In effect, the individuals and institutions aligned with state objectives, and the discourses they help perpetuate, become privileged in this arrangement of government, through the allocation of resources for example (Petersen & Lupton, 2000). It is these apparatuses, and how they join individuals and institutions to the aims of the state, that Foucault links to his conception of *biopower*: anatamo-politics and biopolitics (Perron, Fluet & Holmes, 2005). Foucault's conceptualization of sovereignty, anatamo-politics, biopolitics, and power relations and their effect of *normalizing* beliefs and behaviour, will be explored with greater depth in the sections that follow.

Sovereignty

According to Foucault (1980), the concepts of sovereignty and sovereign power have been transformed in the transition of the West from societies organized around monarchies and feudal systems to systems of government organized around liberal values and a capitalist economy. In the modern forms of government that emerged, it has become increasingly difficult to point to a central authority, whether a parliament, judicial council or sovereign power in the figurative sense. Instead, as laid out in the *Birth of Biopolitics*, Foucault (2008), would have us imagine that the duties and interests of a state, and the

power to delineate and regulate them, are dispersed throughout society. The domain of government can be seen to be carried out through collections of individuals and institutions at all levels of the state. In Foucault's (1980) words, "The eighteenth century invented, so to speak, a synaptic regime of power, a regime of its exercise *within* the social body, rather than *from above* it" (p. 39).

Government and governing can now be traced to what Foucault (1980) terms, a "dispositif" or apparatus operating in the social body. Specifically, Foucault (1980) describes the *dispositif* as:

> …a thoroughly heterogeneous ensemble consisting of discourses, institutions, architectural forms, regulatory decisions, laws, administrative measures, scientific statements, philosophical, moral and philanthropic propositions—in short, the said as much as the unsaid. (p. 194)

An "analytics of government" and the *art of governing*, therefore, are not about the authority and techniques of a national figurehead, international body, or in this thesis, about an administrator, nurse, scientist, or expert, and their exercise of power over a less powerful subject(s) (Dean, 2010). Rather, an "analytics of government" is about "the nature of the connection that can exist between these heterogeneous elements" (Foucault, 1980, p. 194). Government and governing can be understood by mapping the dispositif, its structural arrangement and the discourses originating within and flowing through its constituent elements, as well as by identifying the power relations and techniques of power in operation and analyzing their effect.

Foucault proposes a novel way to view and analyze power. Given the transformation of sovereignty and reconfiguration of government, he asserts that "[p]ower in the substantive sense, *'le' pouvoir*, doesn't exist;" rather, in the context of the dispositif, "power means relations, a more-or-less organized, hierarchical, coordinated cluster of relations" (Foucault, 1980, p. 198). Subsequently, "one must free oneself of the juridical schematism of all previous characterizations of the nature of power" (Foucault, 1980, pp. 120-121).

Instead, Foucault contends:

> Power is everywhere; not because it embraces everything but because it comes from everywhere…Power comes from below; that is there is no binary and all-encompassing opposition between ruler and ruled at the root of power relations, and serving as a general matrix—no such duality extending from top down and reacting on more and more limited groups to the very depths of the social body. One must suppose rather that the manifold relations of force that take shape and come into play in the machinery of production, in families, limited groups and institutions, are the bases for wide-ranging effects of cleavage that run through the social body as a whole. (1979, pp. 93-94).

Power is not 'owned' and 'applied,' but at the macro-political as in the micro-political level, circulates with discourses, and can be harnessed through human sciences, claims about truth, the formation of discourses, institutional practices, the process of subjectivity, and establishment of norms and boundaries about what is acceptable as well as what should not be tolerated in a social setting. Subsequently, the authority of government is not uniquely measurable in a single sovereign body, but evident in the fractures and tensions in a society, for example, in its institutions and communities, where inequalities exist, where dominant discourses overpower counter discourses, where conduct is shaped by one discourse at the expense of others, and the conduct of individuals or subgroups of the populations are limited to a specific set of behaviours and unequal outcomes, compared with the multiplicity of possibilities available in life.

Therefore, a study of sovereignty and governmentality in case management nursing is not about who has power, but about identifying and understanding the conditions associated with unequal power relations and the unequal distribution of resources in the domain HIV case management. This includes describing the hierarchy of discourses circulating in social body and institutions in which case management nurses work, as well as the processes that shape and maintain which discourses become dominant, how they influence the science and practice of HIV case management, nurses' experiences, and for what ends.

Anatamo-politics and biopolitics

The apparatus "has as its major function at a given historical moment that of responding to an *urgent need…*a dominant strategic element" (Foucault, 1980, pp. 194-195). Foucault (1980) and others argue that in their current form, the needs, 'interests,' ends, or objectives of contemporary systems of government are linked to the social and economic goals of liberalism (e.g. Benatar, 1998; Dean, 2010; Nixon, 2006), and increasingly, neoliberalism (Farmer et al, 2013; Petersen & Lupton, 2000; Ruger, 2012). *Liberalism* encompasses a variety of forms of democracy, all rooted in ideals of individual freedom and capitalism (Dean, 2010). The focus on populations within liberalism is tied to the governmental task of having to balance individual participation in democratic decision-making about what constitutes a healthy lifestyle with the need for productive citizens to meet capitalist demands. From a *neoliberal* perspective, the role of government is to promote individual responsibility for health, risk management and surveillance to achieve socioeconomic prosperity with minimal intervention (Petersen & Lupton, 2000). Citizens are "governed and expected to conduct [themselves], right from the privacy of one's own home to the administration of public institutions" (Ayo, 2012, p. 101).

Therefore, in Foucault's (1980) view, "government has as its purpose not the act of government itself, or individuals in themselves, but the welfare of the population, the improvement of its condition, the increase of its wealth, longevity, health, etc.…The population now represents more the end of government than the power of the sovereign" (p. 100). The *object* of government is 'the population,' and the *objective* of governmental practices is to manage "the forces and capacities of living individuals, as members of the population, as resources to be fostered, to be used and to be optimized" (Dean, 2010, p. 28-9). Foucault refers to the state's interest in 'optimizing life,' and involvement in the management of both individual bodies and control over the domain of health and welfare of populations, as *biopower* (Perron, Fluet & Holmes, 2005).

Foucault (1978) argues that biopower was indispensable for the development of capitalism, in that "the latter would not have been possible without the controlled insertion of bodies into the machinery of production and the adjustment of the phenomena of population to economic processes" (p. 141). Biopower currently accomplishes this goal in contemporary society in two ways: one, through *anatomo-politics*, knowledge about the body and the encouragement of self-discipline in matters of health at the level of the individual; two, through *biopolitics*, and the allocation of resources to the development and perpetuation of bodies of knowledge about individual and population health as a means to regulate 'healthy lifestyles' at the level of the population (Perron, Fluet & Holmes, 2005). This "great bipolar technology" of government is described by Foucault in *The History of Sexuality (Volume 1),* where he explains how biopower emerged:

> One of these poles--the first to be formed, it seems--centered on the body as a machine: its disciplining, the optimization of its capabilities, the extortion of its forces, the parallel increase of its usefulness and its docility, its integration into systems of efficient and economic controls, all this was ensured by the procedures of power that characterized the *disciplines:* an *anatomo-politics of the human body*. The second, formed somewhat later, focused on the species body, the body imbued with the mechanics of life and serving as the basis of the biological processes: propagation, births and mortality, the level of health, life expectancy and longevity, with all the conditions that can cause these to vary. Their supervision was effected through an entire series of interventions and *regulatory controls: a biopolitics of the population*. The disciplines of the body and the regulations of the population constituted the two poles around which the organization of power over life was deployed.
> (1978, p. 139)

In this passage, Foucault (1978) describes how the biological life of individuals and populations became a matter of more explicit political concern in the transformation of political rule that accompanied the rise of an era of governmentality, and identifies new forms of knowledge and techniques of governmental management that emerged in the transition to biopower.

The techniques for maintaining social order that accompanied a shift to biopower involved ways to promote life, as opposed to historical forms of power associated with

sovereignty that relied on the right to destroy life as a means of social control (Foucault, 1978). In this form, with the aim of promoting life, anatomo-politics and biopolitics have continued to operate today as the main means for accomplishing “the management of population in its depth and its detail” (Foucault, 2003a, p. 102). For example, biopolitics can be seen where the human sciences are combined with regimes of practices in order to identify risks, project population trends, and prescribe formulas, technologies, medical treatments, health and safety guidelines, institutional best practices and other prescriptions and policies for the purpose of shaping individual beliefs and behaviour into a manner that supports the health and stability of the population (Dean, 2010). According to Foucault (2003a; 2008), the sciences of medicine, epidemiology, sociology, business and economics, that specialize in articulating the medical, social, economic and administrative concerns related to ‘the state of life,’ are involved in biopolitics. These disciplines produce discourses and stimulate the use of techniques of power directly intertwined with population control including:

> …forecasts, statistical methods, and overall measures. And their purpose is not to modify any given phenomenon as such, or to modify a given individual insofar as he is an individual, but, essentially, to intervene at the level at which these general phenomena are determined” (Foucault, 2003a, p. 246).

According to Holmes and Gastaldo (2002), nurses’ work has also become integrated into biopolitics: “Nurses are health care professionals who are in direct contact with individuals, groups, communities, and populations. They are a powerful group of experts upon whom the state and institutions rely” (p.558).

The challenge of biopower is understanding the interplay between the two poles of anatamo-politics and biopolitics. More specifically, a central question is: ‘What mechanisms of power are used to shape and regulate individuals into an efficient workforce “without at the same time making them more difficult to govern?”’ (Foucault, 1978, p. 139). Governmentality necessitates an understanding of the mechanisms of

power that account for how “thought becomes linked to and is embedded in technical means for the shaping and reshaping of conduct” (Dean, 2010, p. 27). Foucault (1980) considered the issue during an interview in *Power/Knowledge*:

> But in thinking of the mechanisms of power, I am thinking of its capillary form of existence, the point where power reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives. (p. 39)

Foucault subsequently identifies three main forms of power associated with governmentality that emerged in relation to biopower, and the need to control individuals through biopolitics: *sovereign power* actualized by state security forces; *disciplinary power* linked to surveillance and regulation; and *pastoral power* related to the authority wielded by experts that promotes conformity to dominant rationalities and discourses (McHoul & Grace, 2002).

According to Holmes and Gastaldo (2002), disciplinary and pastoral power are most relevant to nursing: “Nurses operate within a web of power relations defined by a society ruled by disciplinary and pastoral power strategies which are the main tools to govern conduct in our contemporary era” (p. 564). Therefore, nurses’ experiences with disciplinary and pastoral power were explored in this study in order to understand how case management may be aligned with policies governing the ‘conduct of conduct’ of self and others.

Disciplinary power and pastoral power

If the ‘conduct of conduct’ is associated with the control of individuals through the control of populations, power in modern social institutions necessarily involves techniques to manage heterogeneity, and promote not only life, but conformity to the goals and needs of the state (Dean, 2010). Foucault conceptualized how disciplinary power and pastoral power, and the techniques of ‘panopticism’ and “the confession’ in particular, have become important strategies for affecting the government of others by influencing the

governing of oneself. The aims of these technologies of power are to promote conformity, to produce responsible behaviour, complicit subjects, even “docility” (McHoul & Grace, 2002, p. 67). When combined with rationalities, disciplinary and pastoral power constitute the *art of government,* the ability of individuals and institutions to moderate the power/knowledge circulating in social settings to achieve specific goals and ends (Dean, 2010).

Panopticism is a form of disciplinary power that involves methods of regulation to encourage individuals to practice self-discipline, while the *confession* is associated with pastoral power and a way of promoting discourses through caring for others by helping construct desirable subjectivities (McHoul & Grace, 2002; Holmes & O’Byrne, 2006). They are effective techniques for producing and perpetuating what is considered as truth, through power that is considered productive, as opposed to negative, violent, or destructive (McHoul & Grace, 2002). Both disciplinary and pastoral power are evident in the operations of a number of institutions, including penitentiaries, psychiatric institutions, hospitals, and schools. They involve practitioners such as police, psychiatrists, social workers, teachers and nurses, and rely on scientific knowledge related to human conduct (Dean, 2010; Holmes & Murray, 2011). Indeed, both involve *hierarchal observation*, or one-way interaction with an ‘expert,’ or authority, in a position to create an *examination*, an assessment of knowledge and training, as well as a *normalizing judgment*, which determines an individual’s level of deviancy from the norm and the means of reward, correction, or punishment to address it (McHoul & Grace, 2002, p. 71). Consistent with his view of ‘the subject,’ the outcome of these modern forms of power, Foucault elaborates, “is not that the beautiful totality of the individual is amputated, repressed, altered by our social order, it is rather that the individual is carefully fabricated within it, according to a whole technique of forces and bodies” (Foucault, 1977, p. 217). Disciplinary power and pastoral power help create productive and “obedient” individuals, and therefore, are “a

fundamental means of preventing civil disorder" (McHoul & Grace, 2002, p. 70).

Disciplinary power encompasses strategies for surveillance and regulation that establish the conditions for individuals to govern themselves in accordance with the needs of the state. Panopticism is metaphor that helps conceptualize how disciplinary power is actualized (McHoul & Grace, 2002). The concept of panopticism is linked to the physical structure, known as a *Panopticon*, first visualized and described by British philosopher and social reformer, Jeremy Bentham, for the purposes of prison reform in the period of early modernity (McHoul & Grace, 2002). Foucault (1977) likened the architecture of the Panopticon to the design and purpose of modern forms of government. The Panopticon featured a central observation tower with full view of a ring-like building where prisoners could be partitioned in cells according to their security risk. The design encouraged conformity to institutional regulations by creating a sense of continuous observation among the individuals it imprisoned, while requiring a relatively minimal investment in resources for surveillance and security. "Hence the major effect of the Panopticon," Foucault (1977) explains, "to induce in the inmate a state of conscious and permanent visibility that assures the automatic functioning of power" (p. 201). The Panopticon exemplifies how modern government, in its current decentralized form, is able to promote individual self-government, 'the conduct of conduct' through a web of power relations, and 'govern from a distance' (Dean, 2010).

In Bentham's Panopticon, similar to a society ruled through knowledge and power, "[t]he human body was entering a machinery of power that explores it, breaks it down and rearranges it" (Foucault, 1977, p. 138). Similarly, the individual entering the state apparatus is subject to a series of discourses from the health and human sciences about what is desirable for optimizing life, and *regimes of practices* that encourage compliance through rewards or restrictions and punishments. Regimes of practices include education, guidelines, policies, licensing, annual reviews, and any other institutional practices aimed

at identifying, dividing, categorizing, examining, training, and evaluating an individual's compliance with the rationalities and routines preferred for a population (Foucault, 1980). Individuals are encouraged to engage in self-discipline or be disciplined, not necessarily through coercion, but through a more subtle application of tactics such as the implementation and surveillance of social policies that individualize, categorize, and segregate individuals based on how they meet the norms established in the policy (O'Byrne et al, 2014; Petersen & Lupton, 2000).

More specifically, according to Foucault, 'discipline' proceeds in four major ways: (1) through *spatial* distribution that partition individuals into subgroups or rankings in order for 'one to knows one's place;' (2) methods that establish and control what *activities* contribute to maximal productivity; (3) the stratification or *staging of training* using hierarchies that enable differentiation and ways to mark progress; and (4) *coordination* of these elements to help ensure individual achievement of required knowledge, attitudes, and skills (McHoul & Grace, 2002, pp. 69-70). The importance of these criteria for discipline, according to Foucault (2003a), is how they together help "to rule a multiplicity of men to the extent that their multiplicity can and must be dissolved into individual bodies that can be kept under surveillance, trained, used, and if need be, punished" (p. 296). Disciplinary power is applied to guide, train, enhance, and if necessary correct individual behaviour, so that individuals learn to 'how' to become productive members of society.

Pastoral power also involves subtle tactics, mainly 'the confession,' which typically includes forms of interrogation, interviews, conversations, or consultations (Foucault, 1980). The confession is a practice that extends historically from early notions of pastoral care, and techniques of government in Christianity, linked to the concern of pastors for the welfare of the individuals and communities that comprised the pastorate (Dean, 2010). Transformed under secular authority, pastoral power and the confession are often considered forms of governing 'by caring,' due to their continued reliance on a

"compassionate ear" that inspires the trust and confidence of individuals (O'Byrne et al., 2014).

The confession involves a pastoral agent who is a trained listener, who is not only empathetic, but also knowledgeable, and able to elicit intimate information without inducing negative feelings in the speaker subject (O'Byrne et al., 2014). In exchange for a confession, the pastoral agent is expected to scrutinize information shared by the speaking subject, and then produce in-depth understandings on the topic of interest, give expert advice about how the subject's concerns compare to accepted norms, and provide guidance (Foucault, 1980). The confession therefore is a most intimate form of hierarchal observation, examination, and normalizing judgment. O'Byrne et al. (2014) conclude: "The result is a highly individualized form of regulation which ensures that persons only engage in practices deemed socially appropriate and that uses detailed understandings of the person who are to be managed as its basis" (p. 3).

In their work, "Nursing as a means of Governmentality," Holmes and Gastaldo (2002) suggest that nurses' therapeutic practice is a form of pastoral power and social control in that its aim is also to establish a trusting relationship in order to encourage clients to share their concerns, and in exchange, provide expert judgment and scientific advice meant to stimulate self-care that conforms with ideas about 'best practice' in healthcare. In addition, the confession, according to Foucault, has long played a major role in constructing the 'truth about sex' and generating discourses that range from eroticizing to medicalizing sex and human sexuality (McHoul & Grace, 2002). Holmes and O'Byrne (2006) explain:

> ...it is no longer the priest to whom one must confess sexual practices (sins) but rather to a healthcare professional. In addition, the confessional mechanism became not only the method by which individuals became capable of realigning their sexual desires with the norm and by which they were liberated from the burden of sinful thoughts and practices; it also functioned as a primary source for expanding the body of knowledge related to human sexuality, thereby exhibiting the two aspects of confession: entrapment and

> liberation. The impetus for pastoral power is located outside the one who is cared for because the expert (the guide) initiates the reflective process. However, once this opening phase has been initiated, technologies of the self, which permit individuals to engage in self-transformation, are employed. (p. 433).

Subsequently, techniques of discipline and pastoral power appear to have particular significance for research exploring policies and practices in nursing related to counselling about healthy sexuality and safer sex in HIV care.

Holmes and Gastaldo (2002) raise another relevant issue: "The limits of disciplinary and pastoral power…are often blurry, and nurses frequently use the two types of power at the same time" (p. 561). Therefore, this study explores how pastoral power and disciplinary power may be linked in nursing practice. For example, in managing infectious diseases, case management nurses engage clients in intensive counseling and contact tracing, while simultaneously implementing guidelines that categorize clients according to their risk for the purpose of decision-making about the need for restrictions and penalties (isolation and quarantines in the case of Ebola, and criminalization in the case of HIV). An understanding of disciplinary and pastoral power raises important questions about how case management nursing practice may be allied with regulatory practices that "actively seek to cultivate a certain type of body on the basis of knowledge considered 'true'" (McHoul & Grace, 2002, p. 69).

Normalization

In summary, disciplinary power and pastoral power link discourses from the health and human sciences to individual behaviour through institutional practices. Institutional practices embed knowledge about populations in standards or norms (Dean, 2010). Here, discourses and their lines of reasoning serve to normalize ways of thinking and behaving, by acting as 'codes of conduct' to which individuals in that institution, or populations served by it, are compared, categorized, and through institutional practices, encouraged to conform (McHoul & Grace, 2002). The important effect of disciplinary and pastoral power,

and regimes of practices like social policy, regulations, surveillance, discipline, counselling, caring, and curing, is therefore *normalization,* the ability to affect and shape in some way who and what individuals are and should be (Dean, 2010). Subsequently, Foucault (1978) concludes: “A normalizing society is the historical outcome of a technology of power centered on life” (p. 144).

To be clear, normalization is not as much about “the monotonous regularity of identities,” as it is concerned with the ability to determine what behaviour is considered ‘normal’ and what constitutes ‘deviance’ in a social setting (McHoul & Grace, 2002, p. 72). Normalization is a process that divides and classifies individuals into categories or ‘risk’ groups based on how they ‘measure up’ to what is considered normal or desirable in the population, and this is generally determined by how one “deviates from the average statistical distribution of a phenomenon within a population” (Elbe, 2010, p. 139). Subsequently, while the intention of disciplinary power and pastoral power may be to produce regularity, “the *effect* was quite the opposite: a multiplicity of disparate and variegated identities” and a spotlight on *individuality* and *difference* (McHoul & Grace, 2002, p. 72).

From a governmentality perspective, and governing concerned with the conduct of conduct, identifying the “dividing line between the ‘normal’ and ‘abnormal’ is crucial…to the administration of life” (McHoul & grace, 2002, p. 68). Individuals identified as ‘at risk,’ including risk groups, can then be targeted with social policies and other regulatory practices to further train, correct, reform and assist them until they can engage in society at the level of the norm on their own (Foucault, 2008). As such, the techniques of power related to discipline and the confession become the means of establishing not only the parameters for what constitutes ‘good health,’ but also ‘good citizenship’ (Petersen & Lupton, 2000).

In this regard, it is necessary for an “analytics of government” to include a critique of the role of normalization and its benefits for the population. For example, social policies may be justified as ‘optimizing life’ or ‘empowering’ individuals, and the cadre of experts who are in a position to shape policy may be operating under the rationality that they are acting in the best interest of the population; however, one problem with normalization is that it can be individualizing or totalizing (Holmes & Gastaldo, 2002; Holmes et al., 2007). *Individualizing* and *totalizing* involve the denial of difference including the total subjection of an individual or population to the political imperatives of an institution or system of government (McHoul & Grace, 2002). The “Seek and Treat” HIV testing strategy in British Columbia can be seen as an example of a policy that is totalizing. The policy recommends routine screening for HIV infection in the population and began with all hospital admissions and emergency room visits in the city of Vancouver. The entire population was targeted as a means to find, diagnose, and increase the number of people infected with HIV on antiretroviral treatment based on a rationality of “treatment as prevention” of the spread of the disease in the public (Gusafson, Montaner, & Sibbald, 2011). The risk of a totalizing policy such as “Seek and Treat,” is not only that it subjects people with low to no risk for HIV infection to unnecessary testing, but that it imposes on all people the duty to test, as well as assumes all people with HIV are willing and able to bear the consequences of learning their positive status, including the stigma and discrimination that is often associated with a diagnosis (Elbe, 2009).

This raises another problem with normalization. Conversely, it can result in internal divisions within the population, and the experience of stigma or disenfranchisement of those members of the public whose beliefs and behaviour do not match the norms (Petersen & Lupton, 2000). In his research on governmentality and the securitization of HIV/AIDS, Elbe (2009) explains:

> Normalizing populations through the use of risk-based methods of differentiation can give rise to further dangers…To be "at risk" is effectively to be at odds with, or even a danger to, the welfare of the population—creating a close connection between the notions of risk and danger. (p. 140)

In this context, biopower and the effects of normalization offer a way to conceptualize power relations and explore the tensions between public health and the groups categorized as disproportionately high risk for HIV by the Public Health Association of Canada (2012): gbMSM; newcomers from Africa and the Caribbean; Indigenous people; people who use injection drugs; at-risk women (including trans women and partners of people who inject drugs). For example, in Foucauldian terms, identifying risk groups and shifting the focus of prevention and treatment strategies on each as 'priority populations,' effectively constructs a 'truth' around all members linked to these categories. It creates assumptions about their potential to engage in 'dangerous' behaviour, regardless of their individual beliefs, behaviours, and risk (Elbe, 2009). It is the penchant for arriving at 'wholesale' truths and group-specific surveillance and interventions, that may be creating stigma and a sense of being discriminated against among members of these risk groups (Petersen & Lupton, 2000). Given the 'counter-discourse' noted in the guidelines put forth by coalitions of members of 'priority populations' calling for greater cultural sensitivity, it was important in this study to investigate nurses' understanding of normalization, and how the concerns of individuals from these groups are navigated in case management practice.

An analysis of normalization also raises questions about dominant frameworks used for managing infectious diseases. This study examines how the aims of infection control might be viewed in relation to biopolitics as "efficiently managing diseases in the population, and keeping them within socially and economically acceptable limits," and its applicability to current policies and practice guidelines (Elbe, 2009, p. 66). Finally, if the art of government involves navigating a continuity between the objectives of the state and

the subjectivity of members of the population, nurses' perception of this link, and their role in shaping clients' views about what is 'normal' and 'abnormal' must also be explored.

3.1.3 Government of the self and others

Nurses can be seen to be involved in governmentality (Holmes & Gastaldo, 2002; O'Byrne et al., 2014). There is evidence, for example, that they are both governed and govern others. According to Perron (2013): "Nurses are also at the centre of a complex web of administrative forms, policies, technologies, strategies, and discourses that rigidly control nurses' words, actions, decisions, movements, priorities, and schedules (and) … have never been so heavily regulated" (p. 155). At the same time, Holmes and Gastaldo (2002) explain how nurses are in control of the conduct of others: "Working at the junction of the individual and collective body within power relations that promote and recuperate life, nurses are able, through their interventions, to mould, conduct or affect people as well as to construct, with the help of other health care professionals, people's subjectivities" (p. 563).

Using an "analytics of government" to understand case management nursing practice, therefore, can help nurses gain awareness of how their own reality is shaped by discourses circulating as truth in the domain of public health, and as well, help nurses reflect on their own role in shaping the subjectivity of others. In this final section on the concepts and themes relevant to governmentality, issues related to government of the self and professional sovereignty are examined. This includes Foucault's conceptualization of inequality, as well as his views on the importance of critical reflection, counter-discourse, and challenging the status quo, and their implications for case management nurses.

Inequality and the 'battle for truth'

Governing, in liberal societies, leaves room for self-government. However, in preserving (a liberal) order, normalization explains how the rights of the majority outweigh individual rights as a rule, meaning increased limits on individual freedom may be imposed

when the welfare of the population as a whole is perceived to be at risk, often in proportion to the risk perceived (Elbe, 2009; Petersen & Lupton, 2000). This has been evident, for example, in the experiences of individuals in the past management of pandemics (Dean, 2010; Farmer et al., 2013; Garrett, 2000), and helps explain the response of Western states in the most recent international outbreak of Ebola, where quarantines and border closures were implemented despite a lack of medical evidence for their use, and regardless of complaints that these measures infringed on individual rights (Botehlo, 2014; "Ebola crisis," 2014; Farmer & Panjabi, 2014; McKirdy, 2014; Minder, 2014; Panetta, 2014). It may also explain some of the tensions in nurses' workplaces, including how differences in viewpoints about HIV care between administrators and nurses have been addressed, as well as tensions between nurses and clients in case management practice.

For example, nurses in STI case management are tasked with balancing the concerns of individuals infected with HIV with public health concerns about the spread of the virus to the general (uninfected) public (Holmes & Warner, 2005). The question is how much freedom should clients have to make their own choices in the management of their infection including when and to whom to disclose their HIV status, when to use a condom, and what type of sexual contact is considered acceptable, when it comes to maintaining the right of the general public to be protected from contracting HIV? Subsequently, at the core of modern forms of government, mirrored in case management practice, are ethical issues tied to governmental concerns with the 'conduct of conduct' regarding how much individual difference should be tolerated (Foucault, 2008).

At the same time, inherent in governmental practices that encourage normalization is an acceptance of inequalities as a rule. According to Foucault (2008b), the goal of contemporary government is not equality or equity, but equilibrium, or maintaining a socially and economically efficient status quo. Foucault (2003b) explains: "Regulatory mechanisms must be established to establish an equilibrium, maintain an average,

establish a sort of homeostasis, and compensate for variations within the general population and its aleatory field" (Foucault, p. 246). Subsequently, individual variance, and social and economic inequality are accepted, even expected, in the population (Foucault, 2008). The central political concern of modern governmental practices, ultimately, is one of containing difference (Elbe, 2009; McHoul & Grace, 2002). In conjunction with the authority to 'optimize life,' as a result, are decisions and concerns at the core of governmental practices about when and how to discipline, punish, and even 'let die' individuals whose behaviour does not meet established norms (Foucault, 1978). The tolerance of certain level of unemployment or homelessness in society represent political acceptance of economic and social failure to thrive, as does the tolerance of unsafe injecting with Bill-C2, the *Respect for Communities Act* in Canada, that impedes efforts to establish supervised injecting sites known to help prevent the spread of chronic infections like HIV, Hepatitis C, and deaths by overdose (AIDS Law, 2015). Both are examples of governmental policies and practices that indirectly accept disease and 'death' as a consequence of economic and rational decision-making about the allocation of public resources.

Relatively little can be found in Foucault's body of work regarding his position on social justice or human rights. However, regarding his viewpoint on the dangers of a system content with 'homeostasis,' Foucault (2000) writes:

> Because they claim to be concerned with the welfare of societies, governments arrogate to themselves the right to pass off as profit or loss the human unhappiness that their decisions provoke or their negligence permits…The suffering of men [sic] must never be a silent residue of policy. It grounds an absolute right to stand up and speak to those who hold power. (pp. 474-475)

Foucault (2000) goes on to insist that "the will of the individual must make a place for itself in a reality of which governments have attempted to reserve a monopoly for themselves, that monopoly which we need to wrest from them little by little and day by day" (p. 475).

Furthermore, in his view, the junctures where government secure a hegemony over the discourses that control individual and social life within the *governmentalization of the state, "*constitute the only real space for political struggle and contestation" in contemporary societies (Foucault, 2009, p. 103). In line with these passages and the concepts described above, it appears that for Foucault, the challenge related to health inequities is not human rights in the juridical legal sense, but the right of subjects to wrestle control from the state over the discourses and practices that shape reality.

From a critical theory perspective, issues of oppression and inequity in society are in reality, a "battle for truth" (Foucault, 1980, p. 132). As such, the regimes of practices that encourage and regulate 'truth,' are necessarily the objects of resistance rather than a sovereign authority. This Foucault (2003b) makes clear where he writes:

> When we want to make some objection against disciplines and all the knowledge-effects and power-effects that are bound up with them, what do we do in concrete terms? What do we do in real life? …We obviously invoke right, the famous old formal, bourgeois right. And it is in reality the right of sovereignty. And I think that at this point we are in a sort of bottleneck, that we cannot go on working like this forever; having recourse to sovereignty against discipline will not enable us to limit the effects of disciplinary power… If we are to struggle against disciplines, or rather against disciplinary power, in our search for a non-disciplinary power, we should not be turning to the old right of sovereignty; we should be looking for a new right that is both anti-disciplinary and emancipated from the principle of sovereignty. (pp. 39-40)

The implications of Foucault's message for HIV infection control and case management nursing is that inequalities are socially constructed. To address health inequities related to HIV in the population, and competing concerns about the direction of HIV care, one ultimately has to investigate competing truths, and the social and economic conditions related to their existence, starting with the role of institutions and their regulatory practices in perpetuating and dedicating resources to one truth above all others, and how it impacts different individuals.

Therefore, examining case management nursing practice from a framework of governmentality supports the position that health inequities are not inherent to the rule of

a single authority or law, merely the result of the natural distribution of disease, nor accidental, but linked to truths established through discourses related to political, social, historical, economical, and ethical rationalities that enable them to emerge (Benatar, 1998; Gahagan, 2013; Garrett, 2000; Gilson, Doherty, Loewenson, & Francis, 2007; Kim, Farmer, & Porter, 2013; Mill, Ogilvie, Astle & Opare, 2005; Nixon, 2006; Petersen & Lupton, 2000; Picketty & Goldhammer, 2014; Ruger, 2012). A framework of governmentality can be used to illuminate the rationalities and governmental techniques responsible for creating and perpetuating the unequal positioning of individuals in society, by raising questions about underlying truths, their objectives and ends. An "analytics of government" involves reflection on how various truths are weighted and balanced at the level of populations, starting with an analysis of the considerations given to the benefits and dangers of discourses and practices circulating as truth in institutions, and the fate of competing truths at the level of the individual. In this way, governmentality highlights not only institutional and individual norms, but just as importantly, sheds light on 'difference' – the experience of people with ideas, viewpoints, and concerns that vary from the norm, and who challenge the status quo.

Critical reflection and practices of the self

A framework of governmentality incorporates an analysis of the role of self-government including the concept of resistance and the ability of individuals to regain some control over the discourses that shape reality. According to Foucault, "[g]overnment concerns not only practices of government but also practices of the self …(and) practices of the self can be not only instruments in the pursuit of political, social and economic goals but also a means of resistance to other forms of government" (Dean, 2010, p. 20-21). In this study, case management nurses were engaged in two forms of *practices of the self*, self-reflection and critique, through dialogical engagement about their practice. For Foucault, these processes are a form of micro-politics important to the governing of the

self, self-formation, and the potential for exercising a degree of mastery over subjectivity (Perron, 2013). Self-reflection and critique are therefore important steps for nurses for developing professional sovereignty.

Self-reflection and critique combined, or *critical reflection*, “allows for careful analysis of current events, policy, decisions, trends, movements, advances, and discoveries, and the interrogation of the meaning and value of these events” (Perron, 2013, p. 159). Honestly examining one’s values, motivations, practices, accomplishments, and failures, from a governmentality perspective, can help public health practitioners better understand the ethical, scientific, social, and economic issues inherent in HIV care, as well as raise awareness of a wider range of possibilities available to address the challenges of HIV/AIDS (Farmer et al., 2013). In case management nursing, critical reflection on oneself is a way “to find alternatives to the objectifying mode of subjectivity which characterizes our present (Macmillan, 2011, p. 4).

Engaging case management nurses in discussions around a framework of governmentality, is necessary for revealing how the field of knowledge and ethical choices made available to an individual is limited by the forms of knowledge and ethical standpoints circulating as truth in an institution, and how circulating truths reflect the boundaries of the science and discourses dominating public health. In revealing and describing these limitations, a framework of governmentality simultaneously ‘opens up’ the possibilities available for nursing practice. That is, by unpacking what knowledge and moral imperatives are privileged in an institution, critical reflection uncovers the scientific, professional, economic, social, cultural, and historical perspectives that may have been repressed under current regimes of practices and makes them available for individual and collective consideration (Dean, 2010). In this way, an understanding of governmentality as a reflexive exercise can help meet the emancipatory goals of this study.

Foucault (2009) is clear, however, that an understanding of governmentality and

self-government is not a means to ‘overthrow’ or replace one rationality with another or insert a new set of values in place of an old ethical position. Rather, it is a means to recognize the power of rationalities, the power each individual has to participate in how discourses are shaped, and how knowledge might be relayed to others in a way that accounts for, or helps mediate, the effects of domination and control over subjectivities. An analytics of government is not meant to provide solutions, but lead individuals to reflect on how they are situated in a sociopolitical matrix, what is required of the individual, whether such requirements are in accordance with the individual’s own ethos, and help them envision how things could be different (Foucault, 1988, 2001).

Another aim of understanding the link between governmentality and governing the self, is for individuals to recognize that there is a process behind the formulation of dominant discourses, including how rationalities and moral standpoints become established and normalized. According to Holmes, Gastaldo and Perron (2007), “[d]ominant discourses in the nursing domain, as in other scientific disciplines, are, in reality, simply highly regulated consensus” (p. 88). O’Byrne et al. (2014), for example, believe that the decision to accept disclosure counselling as a preventative measure may be based on political consensus, as no medical evidence has been presented to support its uptake. O’Byrne (2014) and colleagues subsequently recommend critical refection as a means for nurses to identify the discourse being perpetuated when supporting mandatory disclosure of HIV status in practice: “Nurses who engage in, or promote, disclosure counseling must review the literature and engage in critical reflection to determine if this practice is an appropriate and efficacious intervention, or if it is simply the propagation of the criminal law system” (p. 10). Nurses must unpack what values are reflected in this stance, and whether or not they are consistent with nurses’ own values and professional mandate (Gagnon, 2012; O’Byrne, 2012; O’Byrne & Gagnon, 2012; Phillips, Domingue, & Morrisseau-Beck, 2013).

It is possible in the process of normalization, for example, that discourses can become 'taken-for-granted,' and that nurses can intentionally or unintentionally be complicit in practices that are inconsistent with the concerns of nursing and clients (Dean, 2010). Through the joint processes of normalization and subjectivity, rationalities and strategies can evolve without awareness of their contingency on a particular set of values, privileged perspective, or hegemony over the production of truth. Holmes, Murray, Perron and Rail (2006), for example, posit how many rationalities used in healthcare may be taken-up unquestioned: "The health sciences take their lead from institutional medicine, whose authority is rarely challenged or tested probably because it alone controls the terms by which any challenge or test would proceed" (p. 181). This may help explain the long-term reliance on a rationality of epidemics as 'wars,' the unquestioned use of the term 'frontline' nurses, and regimes of practices perpetuating biopolitics in HIV and Ebola care based on a biosecurity framework, that positions the virus as 'the enemy,' and by extension, infected individuals and their bodies, as public health 'threats' (Elbe, 2010). Critical reflection, and the self-work involved, are the means to disrupt, or interrupt a cycle of normalization, analyze intended and unintended consequences of rationalities, consider counter-discourses, and re-think 'taken-for-granted' practices (Perron, 2013).

Counter discourse and challenging the status quo

Foucault believes that counter-discourse, and counter-conduct are inherent in a system of government based on 'the conduct of conducts,' and that they originate in the domain of micro-politics, or government of the self (Dean, 2010). Given that truth is situated, contingent, and transactional, subjectivity is a process that essentially involves *agonism*, a "moral judo," and continuous positioning between subject-subject or subject-object relations (Gordon, 1991, p. 48). Counter discourses are apparent in an analysis of not only the 'said' but the 'unsaid,' as well as in the space between polarities of normal and different (Foucault, 2003a). Critical reflection on discourse consequently helps

highlight counter-discourse. For example, normalization establishes the boundaries of truth in the form of binaries about what is considered socially responsible or reckless, normal or deviant, risky or not risky in a social situation (Petersen & Lupton, 2000). Critical reflection enables individuals to consider lines of thinking linked to either position, and as such, is a means "to visualize the creative space that exists between polar opposites," and exercise autonomy relatively free from established expectations and discourses in decision-making (Thorne, Henderson, McPherson & Pesut, 2004, p. 210).

The importance of this process is as Holmes, Roy, and Perron (2008) point out: "[I]t is institutionalized dissent rather than consensus formation that is a cornerstone of a robust democratic order in all societies" (p. 49). An awareness of the processes inherent in governmentality, can enable nurses to *challenge the status quo*. It gives nurses the tools and information to problematize differences, tensions, and disagreements in a productive way, based on an analysis of discourse and counter-discourse in relation to science, knowledge, and values, and in this way, promote greater attention to pluralism, or a greater equality in the truths considered for professional practice. Foucault (1983) once argued:

> My point is not that everything is bad, but that everything is dangerous, which is not exactly the same as bad. If everything is dangerous, then we always have something to do. So, my position leads not to apathy but to hyper—and pessimistic—activism. (p. 231)

Identifying, unpacking, and addressing tensions and inequalities are the means for individuals to react to the social conditions of the day, and participate in a democratic society by helping shape, from the multiplicity of possibilities, how unequal positions might be more effectively managed so that dangers are considered and minimized along the way (Foucault, 1991b).

Therefore, a framework of governmentality, and the many concepts it incorporates, is useful for its attention to the variety of conditions underlying a social problem, helping

describe a wide range of options, and identifying the parameters requiring consideration if problems are to be more sensitively addressed in all their complexity. In this study, an understanding of nurses' involvement in the government of self and others provides the intellectual space for self-reflection about case management experiences, and the promise of opening up discourses that may have been repressed in public health practice, including ideas from a nursing perspective, about how to address issues in HIV care with sensitivity to the complex relations and concerns involved in the management of HIV/AIDS in Ontario.

Analyzing case management nursing with a framework of governmentality provides a means to help nurses illuminate and account for the discourses and ethics involved in HIV case management practice that are linked to how nurses govern themselves and govern others. Governmentality highlights nurses' individual beliefs, values and practices, but within the context of the domain of public health, by also focusing on the rationalities and moralities circulating in and through nursing practice. That is, Foucault's framework of governmentality can help make intelligible the ways nurses' understanding of themselves, is linked to how they govern themselves and others, under the rationalities and moral imperatives postulated as truth by various authorities. As such, a framework of governmentality is useful for exploring the links between the three themes identified in the literature relevant to HIV case management practice, particularly the gaps in the literature about how case management nurses' knowledge and values may be related to divergent approaches in practice emerging in HIV care, and tensions with administrators over autonomy, priorities, and the direction of public health policies (see Figure 2).

Furthermore, an “analytics of government” in case management nursing creates a space for dialogue and reflexivity on both dominant discourses and those that have been repressed in the context of the current social and economic order. In this way, a framework of governmentality can help nurses consider alternative ways to assess and address the

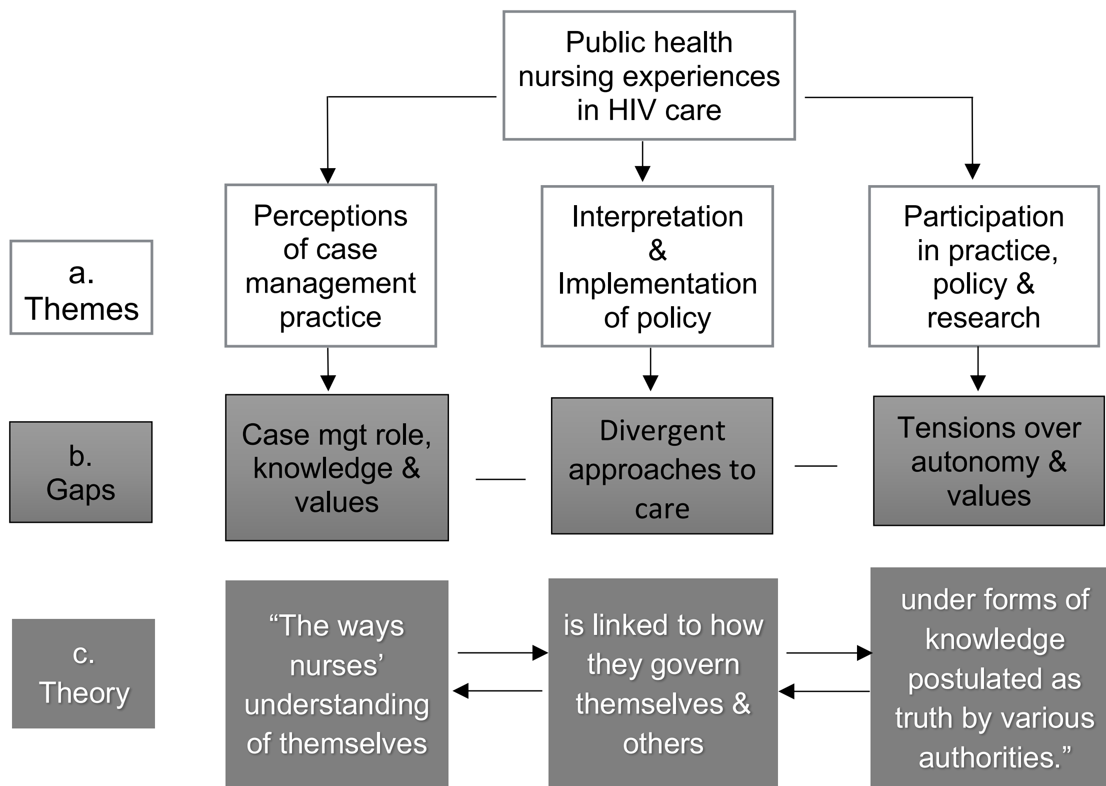

Figure 2:
Research Focus: Exploring the Links. © Linda Juergensen, Ottawa, Canada, 2020

complexities of HIV case management, realize their own power to promote greater inclusiveness and equality in infectious disease management, and be part of solutions that are more effective in minimizing the danger of marginalizing others that appears to be inherent to the current political system and public health response to HIV.

3.2 Chris Weedon: Gender, Identity and Experience in Patriarchal Societies

Chris Weedon's (1999; 2008) work on the relationship of gender, identity and experience in patriarchal societies provides an additional way to conceptualize case management nurses' role in the public health response to HIV/AIDS. Weedon (1999; 2008) proposes a link between discourse, subjectivity, and the experiences of women that is in line with a poststructuralist approach and Foucauldian perspective. In *Feminist Practice and*

Poststructuralist Theory (2008) and *Feminism, Theory, and the Politics of Difference* (1999), Weedon examines the impact of dominant discourses in the West on women's experiences, and outlines critical concerns about their effects on gender, the sexual division of labour and diversity. Weedon's analysis also includes a critique of the fate of pluralism under various forms of feminist thought and praxis. Weedon (1999; 2008) then suggests that a poststructuralist perspective provides important concepts for helping feminists more fully comprehend and respond to the limitations imposed on women by gender roles and power relations in the West.

In particular, Weedon (1999; 2008) advocates for a greater consideration of *feminist poststructuralism,* defined as the integration of critical social theory and a poststructuralist perspective with feminist thought and action. Feminist poststructuralism provides a means for conceptualizing and addressing the continued subjectivity of women to discourses that perpetuate patriarchy in the current liberal and capitalist social order that is particularly sensitive to 'difference,' time, and space. Specifically, Weedon makes an argument for the applicability of Foucault's work. In Weedon's words (2008):

> Power is a central concern of feminists, and many postmodern feminists have taken up Foucault's work to produce analyses which start from detailed examinations of the many localized forms which gender power relations take in a particular area of discursive practice. (p. 174)

In Weedon's (1999; 2008) view, Foucault's conceptualization of discourse, power/knowledge and subjectivity are relevant for unravelling and describing the politics of identity, gender relations, and the varied, even competing, interests of women and should be given greater consideration by feminists in future research and praxis.

In this study, Weedon's writings on feminist poststructuralism are included in the theoretical framework to help conceptualize the role of gender relations in case management nursing practice, and how they impact nurses' ability to incorporate a gender-based analysis and broad understanding of diversity in sexual health into HIV

policy and prevention interventions. Specifically, the power of nurses to shape HIV care within the context of how gender has been socially constructed, and in relation to an analysis of the sexual division of labour in contemporary western societies is explored. The implications of feminist poststructuralism for more fully understanding and describing the organization and practice of public health in Ontario is described below.

3.2.1 The case for feminist poststructuralism

According to Weedon (2008), a central issue for women and feminism is “challenging, on one hand, what constitutes useful knowledge and, on the other, access to knowledge as it is already constituted. These are key political issues, since knowledge brings with it the possibility of power and control” (p. 13). In the West, Weedon adds, gender relations “have structured women’s absence from the active production of most theory within a whole range of discourses over the last 300 years” (2008, p. 13). The knowledge of healing from ‘witches, midwives and nurses’ are well-known examples offered by Weedon (2008) of knowledge produced by women that has been historically excluded from the dominant discourses of medicine in healthcare. Weedon (2008) also footnotes the dominance of men in academia in defining what is generally accepted as knowledge about the ‘human’ experience and lists the omission of women’s experiences from early theories of development and ‘normal’ behaviour in the work of Piaget or Erikson as a case in point. Weedon (1999; 2008) concedes that many important gains for women have since been made in the fields of medicine, social science, academia and other areas. However, the underrepresentation of women and their experiences in health and social science theory and practice continues today. The feminist response includes on-going engagement in efforts to deconstruct science, policies and practices for their relevance to women’s lives. Weedon’s (1999; 2008) concern is that despite these efforts, and the best intentions of feminist thinking and action from liberal, radical and a variety of other perspectives,

women's experiences continue to be treated as 'equal but separate' relative to men's, and ultimately subject to a marginal status.

There is evidence, for instance, that women's knowledge is currently marginalized in the field of HIV care, particularly in relation to women of color. Notably in Canada, it is estimated that 95% of the workforce in public health nursing are women (Underwood et al, 2009). Also, women account for approximately one quarter of new HIV infections annually (CATIE, 2015). In 2013, Aboriginal women and women who identify as black each accounted for over one third of new cases of HIV infection among women (Public Health Agency of Canada, 2013). Yet, little is known about the link between gender, culture, and women's experiences as nurses or clients in HIV care (Gahagan, Ricci, Jackson, Prentice, Mill & Adam, 2013; Underwood et al, 2009).

It is not clear, for example, how gender might be related to nurses' concerns around autonomy in case management practice, or limitations in their ability to contribute to policy development about HIV prevention and treatment services in the domain of public health. More has been written about women at risk or living with HIV; however, overall, their experiences are largely underrepresented in research, policy and practice about HIV/AIDS as well (Arthur, Beausolieil, Guay & Gahagan, 2013; Gagnon & Holmes, 2011). Knowledge is lacking about the explicit and implicit factors that contribute to HIV infection among women, and how gender-related expectations serve to shape and impact HIV prevention and treatment efforts (Gagnon & Holmes, 2011; Gahagan, 2013). As a result, research shows that existing prevention and treatment strategies appear to lack the specificity needed to address the unique constellation of social determinants of health among the diverse populations and communities of women in Canada (see for e.g. Arthur et al, 2013; Patten, 2013). Arthur et al (2013) recently conducted a meta-ethnographic synthesis of qualitative HIV research in Canada, and regarding the needs of women in HIV care concluded:

> HIV prevention services must provide support and safe spaces for women by ensuring health care providers understand the impact of the social determinants of health, such as culture, gender, and poverty, on women's HIV-related prevention needs. Women's experiential knowledge must be integrated into programming and policy to improve the fit, quality, and longevity of interventions. Existing HIV prevention programs and policies that apply biomedical approaches to HIV without exploring and addressing the root structural causes and social determinants of HIV need to be challenged and revised. The federal government should consistently require gender-based and sex-based analysis as mandatory in research and programming grants and provide adequate funding and support for gender-focused strategies. (p. 76)

Greater attention in HIV/AIDS research, policy, and practice needs to be given to understanding and documenting women's day-to-day lived realities, both clients' and providers' perspectives, and their relationship to the social and structural contexts that shape definitions of HIV risk and direction of HIV care.

Feminist poststructuralism is particularly useful for conducting a gender-based analysis of the experiences of women in HIV care. According to Weedon (1999; 2008), feminist poststructuralism links the concerns of feminists about women's lived experiences and a poststructuralist perspective about the social construction of reality through discourses and institutional practices. As a theoretical framework, therefore, feminist poststructuralism offers the potential of exposing power relations in a way that simultaneously accounts for both the individual and contextual mechanisms that maintain power over women's lives. Weedon (2008) explains the importance of this theoretical approach for studies with women when she states:

> The analysis of the patriarchal structures of society and the positions that we occupy within them requires a theory which can address forms of social organization and the social meanings and values which guarantee or contest them. Yet it must also be able to theorize individual consciousness. We need a theory of the relation between language, subjectivity, social organization and power. We need to understand why women tolerate social relations which subordinate their interests to those of men and the mechanisms whereby women and men adopt particular discursive positions as representative of their interests. This is the agenda which a feminist poststructuralism might consider. (p. 12)

Weedon (2008) then suggests that feminist poststructuralism is capable of linking the individual with the social, and the personal with the political, through an analysis of discourse and how discursive positions are shaped by institutional structures and practices that perpetuate patriarchy and women's roles in it. In addition, feminist poststructuralism is an approach that is sensitive to complexity yet preserves diversity. Therefore, feminist poststructuralist theory offers the potential in this study to help understand how nurses' perceptions and roles in case management are related to discourses about women and gender circulating in and through public health, and the influence of current definitions of gender and gender norms on nurses' ability to conceptualize and account equally for the diverse needs of women and men in HIV case management. The link between poststructuralism, the social construction of gender, and the sexual division of labour is described in the following section.

3.2.2 Poststructuralism, gender, and the sexual division of labour

"Feminism is politics," claims Weedon (2008, p. vi). *Feminism* can be defined as a political movement involved in the active force for change in women's lives (Weedon, 2008). In Foucauldian terms, Weedon (2008) explains, feminists are concerned with the power relations and structures that determine the "very question of what it is to be a woman, how our femininity and our sexuality are defined for us and how we might begin to redefine them for ourselves" (p. 1). The starting point for feminism is *patriarchy*, "the power relations in which women's interests are subordinated to the interests of men" (Weedon, 2008, pp. 1-2).

Feminist poststructuralism takes as its subject discourse, in comparison to liberal feminism, for example, which focusses on rights, or radical feminism which considers biology as the defining feature in gender relations. The central concern for feminist poststructuralism, therefore, is *patriarchal discourse*, where "the nature and social role of

women are defined in relation to a norm which is male" (p. 2). In line with the ontological and epistemological standpoint of poststructuralism, the main issue for feminists with discourses, any discourse—patriarchal or feminist—from a Foucauldian perspective, are claims about their truth or falsity, and how contemporary discourse 'fixes' women in unitary subject positions compared to the multiple subject positions available in reality. Weedon elaborates:

> These subject positions—ways of being an individual—and the values inherent in them may not all be compatible, and we will learn that we can choose between them. As women we have a range of possibilities. In theory almost every walk of life is open to us, but all the possibilities which we share with men involve accepting, negotiating or rejecting what is constantly being offered to us as our primary role—that of wife and mother. (p. 3).

In the current social order, Weedon (2008) argues, the effect of patriarchal discourse on women is subjectivity to a heterosexist norm where women are mainly valued for their attractiveness to men, role in procreation and childrearing.

Subsequently, women are generally evaluated in relation to their desirability to men and ability to manage a household; these roles are central to women's identity, whether they are embraced or not, and reflected in the liberal and capitalist infrastructure in the West. As Weedon points out, the dominant discourse is that "[o]ur sexuality should be given to one man and our emotional energy directed at him and the children of the marriage," and this message is reinforced by a wide range of social institutions and practices including religion, popular media like magazines, television advertisement, adult romance and children's books, taxes, welfare and other economic security arrangements, to name a few (2008, p. 3). It is through these mechanisms that patriarchal discourses of heterosexuality are inscribed on women's bodies and the social body and become normalized in society. "All those discourses—medical, psychological, religious, demographic, familial and cultural . . . from a Foucauldian perspective can be seen as constituting the domain of sexuality, [and] privilege heterosexuality as the natural way to

be" (Weedon, 1999, p. 45). By circulating in and through individuals and society, patriarchal discourses have the effect of socially constructing a truth about women and men, gender and gender roles.

Biological differences between women and men have predominantly been used to define gender, and by extension, differences in women's and men's value and roles in society. Patriarchal views of heterosexuality as the natural order of things can be traced to binaries about women/men and nature/culture produced over time through discourses grounded at different points in history in the authority of God, science, and 'common sense' that "take women's bodies as their referent and guarantee" of a structural arrangement of power relations based on comparisons of males to females (Weedon, 1999, p. 13). According to Weedon (1999):

> In Western thought gender tends to be conceptualized as a set of polarized binary oppositions in which one term is privileged over the other…Such hierarchal structured discourses of gender value aspects defined as male over those as female, for example, reason over emotion, or activity over passivity. Moreover, theories of gender difference have most often written from perspectives that assume the white male to be the norm against which all others should be measured, and which see all women as deviating from this norm in ways that fit them for domesticity and motherhood. Their supposed natural attributes both contrast with and complement those of men. (p. 6).

The effect of binaries about men and women are a gender and identity politics. Women's and men's identities become shaped "by approval or punishment" of behaviour that reinforces gender differences between them from birth through adulthood, which in turn, perpetuate gendered social roles, or rather the structuring of social life around divisions of labour deemed normal or suitable on the basis of gender (Weedon, 1999, p. 95). As Weedon (2008) explains, "the day-to-day practice of education and socialization constitutes differences in strength and skills between girls and boys, endowing individuals with specific perceptions of their identity and potential, which appear natural to the subjected individual, rather than as a product of diffuse forms of power" (p. 118).

The separation of men and women by gender appears as a natural consequence despite the social construction of identity and social roles by gender. According to Weedon (1999), “[p]atriarchal masculinity is not, however, natural. It is acquired through processes of socialization which teach boys and men that their collective strength depends upon a colossal commitment to covering up their own individual weakness” (p. 33). Women, on the other hand, tend to be socialized as either objects of sexual desire or patient, nurturing, naturally passive, even virginal; “we are encouraged to accommodate ourselves … at the expense of our own feelings” to the interest and satisfaction of male desire, the patriarchal family, as well as the patriarchal political and economic order (Weedon, 2008, p. 38). The subject positions predominantly available to women are largely a reflection of patriarchal discourse, ranging from “career woman to romantic heroine, from successful wife and mother to irresistible sex object” (Weedon, 1999, p. 25). In turn, dominant discourses about masculinity and femininity bear centrally on men’s and women’s decisions about which role(s) to choose and how they are actualized, “the effects of which are to conserve patriarchal interests” (Weedon, 2008, p. 122).

Gender norms define the boundaries, or acceptable limits and possibilities, for individuals as men and women in society, and leave people at risk for oppression on the basis of gender and sexual preference. Adherence to gendered qualities and roles mark men and women as either normal or deviant; difference in contemporary societies in the West is considered a ‘lacking’ or sign of inferiority (Weedon, 1999). The result is a sexual politics not only involving women, but in relation to any experience of difference or person deviating from the heterosexual norm. People who identify as lesbian, gay, bisexual, queer, or transitioning women or men are seen as threats to the naturalness of heterosexuality and the patriarchal family (Weedon, 2008). The challenge for case management nurses is to understand how their own values and roles are shaped by gender norms. Also, nurses must reflect on definitions used for healthy sexuality, explore

the limitations imposed on women and men with behaviour change models of HIV care, whether or not they too impose conformity with patriarchal discourses around heterosexual norms, and if so, determine ways the effects of gender norms might be mediated especially among people who identify as different from socially-accepted norms. In this section, it was outlined how feminist poststructuralist theory helps understand the relationship of gender, subjectivity, and marginalization, as well as the link between the social construction of gender and the sexual division of labour. In the next section, how feminist poststructuralism addresses difference and equality is discussed, along with further considerations for nurses in HIV case management.

3.2.3 Feminism, difference and the meaning of equality

"For a longtime heterosexuality remained an unspoken and barely examined norm for many women," and feminists have only recently begun to problematize the binary relationship of women/men, and biology as the natural boundary of difference in the experience of gender (Weedon, 1999, p. 36). Many important questions have been raised within feminism about how to better accommodate competing definitions of gender, often in attempts to establish what experience it is that actually unifies women. The question of 'unity' stems from concerns voiced by women about the ability of current feminist theories and praxis to account for diversity in the experience of oppression, starting with the range of different subject positions noted by women of color and women from developing countries (Weedon, 1999). Another issue it relates to is the different meanings of 'lesbianism,' and subsequent demands on feminists to help "sharpen our awareness of the contemporary modes through which gender and sexual power are exercised" (Weedon, 2008, p. 155). Many heterosexual women also experience ambiguity or even alienation with feminism related to their identification with heterosexuality and/or the 'traditional' qualities (caring, nurturing, mothering) generally depicted as at odds with the fundamental struggle of feminism against patriarchal definitions of gender. This latter

concern may, in part, explain nursing's uneasy relationship with feminism, and slowness in embracing feminist theory in its own professional struggle for power within patriarchal institutions (see for e.g. Allen, Allman & Powers, 1991; Smith, 2000; Reverby, 2013). Therefore, in order to better account for diversity and avoid the risk of marginalizing women within the movement, feminism needs to "look at what heterosexuality means for heterosexual women who are also feminist (Weedon, 1999).

According to Weedon (2008), in order to account for both biology and diversity:

> Feminist theory must be able to analyze the range of meanings which biological difference has in our society, and the political structures which particular meaning justifies. This analysis is not merely an intellectual process. It is a process founded in the day-to-day practices in which we constantly assume feminine subject positions, and find ourselves subject to definitions of our femininity, often at variance with the ways in which we define our interests as women. The degree to which the meaning of biology is to the fore will vary according to the specific discursive context. (p. 123)

Weedon (2008) argues, subsequently, for a shift in feminist theory towards the analysis of not only dominant discourses but its context within the discursive field relevant to women's experiences, how discourses intersect and to what effect. "The poststructuralist answer to the problems of the plurality of meaning and change is to question the location of social meaning in fixed signs" (Weedon, 2008, p. 24). By locating identity and gender politics in the variety of discourses that shape the meaning of gender for and by women, as opposed to focusing either on biology, race, class, or rights, poststructuralist theory opens up the infinite ways gender can be defined, and both in theory and in women's lived experiences, acknowledges the possibility of pluralism and the intersection of multiple interests in women's lives. Simultaneously, feminist poststructuralism questions the meaning of women's 'freedom to choose' or 'informed choice' and in doing so, identifies new avenues for resisting the restrictions imposed on women and possible sites for influencing change.

The task of feminist poststructuralism becomes one of examining the multiple discourses circulating as truth and questioning the binaries and boundaries each impose

on people's perceptions of gender and how it is actualized, as well as the interests served, and voices left out at any given time and place. In Weedon's (2008) words: "Rather than patriarchy as a fixed structure, and femaleness and the female voice as a response to this structure, we need to look at the web of modes of patriarchal power and the range of feminine voices and subject positions which support and resist them" (p. 150). By illuminating the range of discourses related to gender in circulation along with the subject positions available to women, feminist poststructuralist theory can be used to help demonstrate what it is possible for women to think, say and do according to discourses and practices lived in any variety of patriarchal societies or social settings. At the same time, feminist poststructuralism offers a way to describe how these discourses are reflected in specific structures and patriarchal practices, and subsequently raises awareness of the many sites of conflict where resistance and change may be negotiated (Weedon, 2008).

That is, by shifting the focus on discourses, feminist poststructuralism shifts an analysis and response to patriarchy from a natural and 'fixed' position, to a socio-cultural position that subsequently opens up the possibility of pluralism and transformation. From a Foucauldian perspective, "[p]atriarchy implies a fundamental organization of power on the basis of biological sex, an organization which, from a poststructuralist perspective, is not natural and inevitable, but socially produced" (Weedon, 2008, p. 123). Power/knowledge and its relation to subjectivity and resistance becomes the conceptual tools for deconstructing binaries as well as the means for understanding where and how new discourses, grounded in women's experiences and voice, might be produced (Weedon, 2008). According to Weedon (2008) and a feminist poststructuralist perspective, "[s]ocial meanings are produced within social institutions and practices in which individuals, who are shaped by these institutions, are agents of change, rather than its authors, change which may either serve hegemonic interests or challenge existing

power relations" (p. 25). The ability of women to have their voice counted, to define for themselves the meaning of 'woman,' and help shape social institutions in a manner that is more representative of the diversity in women's lives, primarily involves a struggle over control of the *meaning* of gender, or in Foucauldian terms, a battle for truth over how gender is defined and women are socialized.

Therefore, the task for feminists in advocating for equality is to help articulate women's various subject positions and unequal voice within the discursive fields relevant to their lived experiences, and raise awareness of how discourses shape those positions, by what means, and for whose purpose. In summary, Weedon (2008) explains:

> The options available to women in the battle to define our femininity, social role and the meaning of our experience are many. However, they exist in a hierarchal network of antagonistic relations in which certain versions of femininity and the sexual division of labour have more social and institutional power than others. In order to develop strategies to contest hegemonic assumptions and the social practices which they guarantee, we need to understand the intricate network of discourses, the sites where they are articulated and the institutionally legitimized forms of knowledge to which they look for their justification. (pp. 121-122)

In this study, a feminist poststructuralist perspective is used to illuminate the voices of nurses in case management and examine the relation of subjectivity and power to the various meanings used to define gender and gender roles in public health practice. Case management nurses are asked to reflect on how their sense of powerlessness and power may be grounded in discourses about gender and gender roles circulating in and through public health. For example, "How have the roles for case managers and goals for HIV care been 'fixed' by discourses about gender? What is the effect on clients?" A feminist poststructuralist perspective also provides the impetus and conceptual tools for exploring nurses' views on diversity, cultural differences, and the meaning of feminist theory for HIV care and how infectious diseases are managed.

Weedon's (1999; 2008) work, therefore, provides a way to examine the

relationship of the social construction of gender to the division of labour in public health, and the experiences of nurses in their current position alongside others on the margins of decision-making about HIV policy and practice in Ontario. A feminist poststructuralist perspective also provides the conceptual tools to help case management nurses look beyond both epidemiological and patriarchal categories of risk and gender, more fully account for diversity in practice, and arrive at ways in HIV care to be more inclusive of clients' concerns and definitions of healthy sexuality. In order to map the relation between these dominant discourses, the discursive field, and the ability of case management nurses in Ontario to implement practices and policies that account for diversity among clients in HIV care, this study turns to geography, and David Sibley's writings about the relationship of spatial and social exclusion.

3.3. David Sibley: Geographies of Exclusion

Governmentality and feminist poststructuralism are comprehensive frameworks for investigating inequalities in HIV care, including the unequal positioning of clients' voices and concerns in the 'war on HIV/AIDS,' and tensions that may be undermining nurses' ability to help bridge the gap in services with more culturally safe care. Foucault's conceptualization of power/knowledge, biopower, and government of the self and others are important starting points for unraveling the variety of discourses circulating in and through case management nursing practice and their effect on HIV care. Foucault's writings on governmentality also help understand how the rationalities and strategies currently used for HIV case management practice shape and are shaped by the truths and power relations operating in public health in Ontario. Weedon's (1999; 2008) writings provide a means for analyzing the experiences of gender and their impact on nurses' and clients' ability to shape policy and practice, and the attention given to diversity in HIV case management. A geographical analysis, however, is necessary to arrive at a more detailed conceptualization of nurses' positionality in public health. Geographic theory was

consulted to help document the extent to which case management nurses' decisions are a reflection of the regional and local organization of public health across the province of Ontario. In this study, concepts from critical geography are used to help map the physical as well as socio-political matrix in which case management nurses work, and to describe the relationship between the 'space' allocated for case management nursing and the limits and possibilities experienced by nurses in their practice.

David Sibley's (2007) work offers a geographical perspective that is particularly relevant for a study of the social organization of case management nursing in this regard. In his landmark book, *Geographies of Exclusion: Society and Difference in the West*, Sibley (2007) employs a definition of space that is congruent with the ontological and epistemological concerns with a 'battle for truth,' power/knowledge, subjectivity, and the fate of pluralism described by Foucault in relation to governmentality. Sibley (2007) bridges Foucault's conceptualization of power/knowledge with concerns from human geography about the nature of space and provides important concepts for understanding the link between spatial organization and the social production of identities. In particular, Sibley (2007) demonstrates a link between spatial and social exclusion. His work on geographies of exclusion is recognized for laying the foundations for understanding how strategies of spatial organization are embedded in power/knowledge relations, and reflect psychological processes that associate difference with *abjection*, fear and exclusion (Mahtani, 2004). Tying together concepts from Foucault's work on power/knowledge, Julia Kristeva's work on abjection, and geographical perspectives about the social construction of space and social boundaries, Sibley (2007) delineates the integral role played by space in perpetuating the social construction of binaries about norms and difference created through dominant discourses in contemporary capitalist societies, and how it reinforces stereotypes and stigma associated with deviance.

In this section, the implications of geography and relevance of Sibley's (2007) work for understanding nurses' experiences with competing discourses in HIV case management are discussed. First, Sibley's (2007) views about the social construction of space, and second, the relationship of subjectivity and spatiality are described. Third, methodological considerations for mapping contested boundaries, the spaces where competing discourses intersect, and their relevance for nursing practice, are reviewed in light of Sibley's (2007) ideas about borders, transgression, and inclusive geographies. These concepts are applied in this study to help map the spatial boundaries associated with case management nursing, identify the practices that define the spatial and therefore social possibilities and limits of HIV case management, and examine the fate of nursing knowledge that pushes the limits of established boundaries about what is normal and deviant.

3.3.1 The social construction of space

'Space' is the domain of geography, and how it is interpreted, defined and mapped depends on the philosophical underpinnings and theoretical perspective being applied (Johnston, 1991). A poststructuralist approach and Foucauldian perspective has been applied by many postmodern human geographers, including David Sibley (2007), in order to help realize the aims of those in the discipline with "a shared commitment to: expose the socio-spatial processes that (re)produce inequalities between people and places; challenge and change those inequalities; and bridge the divide between theorization and praxis" (Fuller & Kitchin, 2004, p. 5). Geographers' interest in Foucault acknowledges Foucault's own engagement with geographical concerns. Indeed, many of Foucault's writings are infused with references to space and spatiality:

> From architectural plans for asylums, hospitals and prisons; to the exclusion of the leper and the confinement of victims in the partitioned and quarantined plague town; from spatial distributions of knowledge to the position of geography as a discipline; to his suggestive comments on heterotopias, the space of libraries, of art and literature; analyses of town planning and urban

> health; and a whole host of other geographical issues, Foucault's work was always filled with implications and insights concerning spatiality. (Elden & Crampton, 2007, p. 1)

According to Foucault, power/knowledge, subjectivity, governmentality and space are interrelated (Crampton & Elden, 2007). *Space* is understood as being socially constructed, and *spatiality* characterizes "the conjoint social production of space and the spatial construction of society" (Johnston, 1991, p. 237).

Specifically, Foucault's research is concerned with *spatial techniques*, "how particular specifications of spaces, buildings, environments, suburbs, cities and regions enter into unstable, heterogeneous, assemblages of technologies of rule" (Huxley, 2007, p. 200). The metaphor of Bentham's Panopticon is a direct expression of Foucault's conceptualization of the implicit ties between space and power, or spatiality and 'the problems of the population,' biopolitics, and the conduct of conduct, with its explicit use of architecture and techniques of social organization for encouraging discipline and achieving political-economic ends (Elden, 2007). In Foucault's view, discipline is "above all an analysis of space" (in Elden & Crampton, 2007, p. 5). In this regard, relative to the field of nursing, Foucault (1978) provides the example of the hospital. The history of the medicalization of the hospital in the eighteenth century illustrates the significance of spatial organization for a study of the techniques used for discipline and social control. In the eighteenth century, hospitals were transformed from institutions to assist the poor into treatment centres for the management of illness and epidemics. The management of space, the management of infectious diseases, and the management of individuals are all intertwined in the mechanisms that were used to control the spread of disease in the eighteenth century hospital, such as the assignment of individual rooms, attention to the arrangement of wards, quarantines, the ability to observe symptoms, the training and positioning of nurses, and the implementation of registries as a means to identify and keep track of the infected. In relation to both the internal structuring of the hospital and the

building itself, distancing, hierarchies, control over staff and patient activity, and surveillance all became important features for optimizing the function of the hospital, which involved "in this case, purifying it of its harmful effects, of the disorder it created" (Foucault, 1978, p. 144).

Foucault (1978) points out that through the mapping of space and the use of space, "[t]here, thus arises a new way of viewing the hospital" (p. 145). Long considered a mechanism of treating illness, it becomes apparent in an analysis of the internal factors of the hospital structures, the distribution of patients, and the configuration and location of the building, rather, that this model of hospitalization "does not conceive of the hospital as an instrument of cure" (Foucault, 1978, p. 145). It is not shaped and organized for the purpose of treating individuals for their own sake, but in the interest of containing the spread of epidemics within the hospital and the population. While the hospital provided a means of assisting the sick, it was, in effect, "an institution of separation and exclusion" (Foucault, 1978, p. 143). Its spatial organization largely reflected a focus on preventing medical, social and economic disorder. As a result, Foucault (1978) concludes: "The hospital then is no longer a simple architectural figure and comes to form part of a medical-hospital complex that must be studied the same way one studies climate, illness, etc." (p. 142). An analysis and description of space helped more fully grasp the function of the hospital, the position and roles of doctors, nurses and patients within it, and the corresponding socio-political effect.

Above all, Foucault's (1978) study of how the hospital became medicalized and how hospital medicine was achieved illustrates how space and spatial techniques are embedded in power/knowledge and power relations. It demonstrates how individuals constitute space, and space constitutes individuals. Therefore, an analysis of the social construction of space is included in this study to understand in line with a Foucauldian view of subjectivity and governmentality, and from a feminist poststructuralist perspective,

how the social organization of public health in Ontario reflects the rationalities governing the public health response to HIV/AIDS. Specifically, this research questions: How is the positioning of nurses in public health shaped by the spaces allocated for HIV case management? What effect does spatiality have on nurses' roles, ability to shape policy and practice, and their experiences with clients?

In *Geographies of Exclusion: Society and Difference in the West*, David Sibley (2007) provides the tools for unraveling the relationship between space, power/knowledge, and social relations, including what Foucault (1978) calls "the art of spatial distribution of individuals" (p. 146). Sibley (2007) is particularly concerned with socio-spatial exclusion and studies the examples of the social experience of English "gypsies," children and family dynamics, and racial minorities and women in academics. Specifically, Sibley explores the psycho-social processes that underlie the relationship between space, identity, and marginalization, and introduces a distinctive theory of the interconnectedness of spatiality, power/knowledge, subjectivity, difference, and social exclusion that helps illuminate in conjunction with Foucault's work how "strategies of spatial organization are always embedded with the social production of identities" (Mahtani, 2004, p. 262). Sibley (2007) also discusses theoretical and practical considerations for mapping spatiality and understanding the potential for resistance in territorialized spaces. Sibley's (2007) conceptualization of the link between subjectivity and spatiality, and ideas for mapping space and understanding resistance are described in the following two sections.

3.3.2 Subjectivity and spatiality

In critical geography, "spatial structure is now seen not merely as an arena in which social life unfolds, but rather as a medium through which social relations are produced and reproduced" (Gregory & Urr, 1985, p. 3). Therefore, in order to understand the social

relations involved in marginalization, Sibley (2007) explains, "it is necessary to examine the assumptions about inclusion and exclusion which are implicit in the design of spaces and places" (p. x). Subsequently, Sibley (2007) combines a geographical understanding of spatiality with elements from psychoanalytic theories about 'object relations' as a means by which to conceptualize how social and spatial processes are involved in the establishment of boundaries that separate some individuals and groups from the mainstream. The result is a novel approach, a *spatialization of object relations theory*, the importance of which is that "[t]his engagement with psychoanalytic 'object relations' theory offered new ways for thinking about processes of marginalization, implying that the way people seek to exclude Other groups can only be understood with reference to the manner in which people identify with or against particular stereotypes on a psychic level" (Mahtani, 2004, p. 259).

Sibley's (2007) argument is that spatial exclusion is both a product of and reinforces social boundaries and stereotypes about the meaning of difference in societies. In particular, he claims, "[w]ho is felt to belong and not to belong contributes in an important way to the shaping of social space" (Sibley, 2007, p. 3). Regarding the link between the psyche, identity, and spatiality, Sibley (2007) explains:

> Repulsion and desire, fear and attraction, attach both to people and to places in complex ways. Central to this question is the construction of the self, the way in which individual identity relates to social, cultural and spatial contexts. (Sibley, 2007, p. 4)

In Sibley's (2007) view, psychoanalytical theories help explain the way the social construction of identity is related to the social construction of society. Social spaces can be seen as constructions of socio-cultural perceptions ingrained in the psyche of individuals from birth, that perpetuate ideas circulating in socio-cultural discourses about the boundaries between normal/difference, and the desired order of people and things. Introjection, projection, and abjection, concepts from psychoanalytic theories about the

lifelong process of identity formation, account for how the borders separating normal from different prevalent in dominant discourses in Western society become deeply ingrained in the psyche and behaviour of individuals. Sibley's (2007) view of a *spatialized object relations theory* explains how psychological views subsequently become operationalized in the organization of social space. According to this process, the ideas absorbed in the subconscious about what is normal/deviant and good/bad shape individual desires and perceptions of belonging/not belonging, which in turn, provide the impetus for individuals to accept and perpetuate the social divisions and stereotypes on which they are based.

Introjection and projection

The concepts of introjection and projection are the starting point for understanding "how particular social and spatial outcomes are tied to particular cultures, to particular histories and to individual life experiences" (Sibley, 2007, p. 78). *Introjection* involves the absorption of perceptions about objects and people into the psyche, and subsequently the integration of lived experiences into one's personality (Sibley, 2007). *Projection* is the process of relating these perceptions to others, or the capacity to attribute feelings to other people and things, "predominantly love and hate" (Sibley, 2007, p. 6). Introjection and projection start from the moment of birth and occur simultaneously throughout life as a means of connecting the developing self to the social and material world, a process called *object relations*. According to psychoanalytic theories, object relations is the way in which individuals develop a sense of self-hood while developing a sense of the social (Sibley, 2007).

The importance of object relations theory for understanding marginalization, Sibley (2007) maintains, is how it helps conceptualize the nature of boundaries by providing a way to describe their emergence in the self and society. For instance, it helps explain how subjectivity occurs in relation to power/knowledge and ideas about difference. Boundaries

established in discourses between normal/different and good/bad can shape individual identities through the process of introjection. Simultaneously, these boundaries influence individual perceptions and behaviour involving other people and objects though the process of projection. Sibley (2001) summarizes the connection of introjection and projection with the experience of subjectivity, and their effect on identity and society when he writes:

> Experience of the world in childhood also involves the confirmation of the boundaries of the self and situating the self in the social world though the sorting of people and things into 'good' and 'bad' categories. 'Good' and 'bad' enter the unconscious and, in the process of socialization, they are projected onto others who become the objects of fears and desires (p. 244)

In his view, boundaries are socially constructed, and the processes by which individuals absorb and perpetuate distinctions between normal/different, good/bad, and establish borders around what or who belongs or does not belong in a social setting—in a home, social institution or between nations--is through introjection and projection. The concept of abjection, Sibley (2007) then suggests, helps explain how feelings such as desire or fear become tied to notions of normal/different and insider/outsider, and motivates individual decision-making about conformity with norms and the rejection of difference. Abjection is also related to an ongoing drive to maintain individual and social boundaries. Introjection and projection help explain the circulation of discourses, while these aspects of abjection provide the key to understanding the relationship of space to the process of social exclusion in society. When Sibley examines spatiality in relation to object relations theory, he "relates the search for spatial order to the personal search for certainty and security" through the concept of abjection (Mahtani, 2004, p. 259).

The abject and abjection

The concepts of the abject and abjection are borrowed from the work of late postmodern psychoanalyst, Julia Kristeva (1982) and her writings about the pure and

defiled. “What Kristeva describes as the *abject* is ‘opposed to I,’ it is ‘radically excluded,’ but it is always a presence,” and *abjection*, “[w]e may call it a border; abjection is above all ambiguous” (see Sibley, 2007, p. 8). Kristeva gives the example of excrement and its equivalents, such as dead skin, sweat, decay, infection, disease, corpses and the “never-ending battle against residues” from which the body must defend itself (Sibley, 2007, p. 8). Sibley (2007) explains that the abject is an impossible object, one that defies both complete absorption or expulsion by a subject; it is distinctly separate but at the same time can never be fully separated from an individual. Sibley also points out that its significance extends beyond a concern with bodily residue. The experience with abjection is relevant for understanding the experience of subjectivity and concerns with social order. The issue is that “one cannot exist without the other” and the abject, therefore, “goes beyond the perception of one’s body. It even goes beyond fluid subjectivity” (Rudge & Holmes, 2010, p. 4). The abject represents a challenge to the established order, a breakdown in the symbolic order of truth, meaning, and the rules that govern psychological and social boundaries about good/bad, what belongs/what does not belong (Rudge & Holmes, 2010). Abjection therefore helps explain the significance in the West of social control (Sibley, 2007).

Abjection is important for understanding the existence of a perpetual concern in society with maintaining insider/outsider boundaries, in both personal and social contexts. In Sibley’s (2007) words:

> This hovering presence of the abject gives it significance in defining relationships to others. It registers in nervousness about other cultures or about things out of place. (p. 8)

The presence of abject objects and people give rise to uncertainty and ambiguity. At both the level of the individual and the social, abjection represents a threat to integrity and order, a potential dissolution of boundaries between the self and the Other (Sibley, 2007).

Abjection therefore creates feelings of anxiety, disgust, or fear about people and objects not belonging to the norm. This is how, in Sibley's (2007) view, abjection accounts for "the ways in which an abject fear of the self being defiled or polluted is mapped onto those individuals and groups depicted by hegemonic society as deviant or dangerous" (Mahtani, 2004, p. 259). Difference becomes associated with the potential for pollution and disorder, and the feelings of anxiety related to its constant presence creates an on-going concern with both establishing certainty, though scientific measurement, classification and surveillance of individuals for example, and securing psychological and social boundaries through various forms of purification. This leads to Sibley's (2007) thesis that "'spatial purification' is a key feature in the organization of space" (p. 77).

Difference, distancing, and the purification of space

In Sibley's (2007) view, how space is organized, including the location of physical structures and borders, the distribution of people and things, and the *distantiation* of people and things from each other, can also be seen to represent a concern for certainty and securing boundaries between what is felt to be 'normal' and what is considered different or deviant. Spatial organization can "reflect the desire of those who feel threated to distance themselves from defiled people and defiled places" (Sibley, 2007, p. 49). Space and spatiality, therefore, are involved in practices used for purifying places.

In the discourses that dominate the West, Sibley explains, there is a "tendency of powerful groups to 'purify' space and to see minority groups as dirty and polluting" (Mahtani, 2004, p. 258). According to Sibley (2007), families, communities and social institutions are "all implicated in the construction of deviance and the exclusion of deviant individuals and groups," through attempts to regulate behaviour through the organization of space (p. 81). As Sibley (2007) explains:

> There is a history of imaginary geographies which cast minorities, 'imperfect' people, and a list of others who are seen to pose a threat to the dominant

> group in society as polluting bodies or folk devils who are then located 'elsewhere.' This 'elsewhere' might be nowhere, as when genocide or the moral transformation of a minority like prostitutes are advocated, or it might be some spatial periphery, like the edge of the world or the edge of the city. (p. 49)

Hospitals, prisons and asylums, as described by Foucault, are obvious examples cited by Sibley (2007) of the structuring of social space to mirror imagery, feelings and beliefs held about people who are different from the norm. Respectively, sickness, crime, and mental illness represent three categories of difference seen to require containment, and all three buildings demonstrate the erection of boundaries around people viewed as unable, deprived, even depraved and dangerous, as a means to separate them from the 'normal' public, who in a patriarchal, liberal capitalist order is generally 'the white, able-bodied male' and his family (Sibley, 2007). Sibley (2007) also describes the response to race, and sites the segregation of people of colour in south Africa under apartheid, as well as the reallocation of indigenous peoples in Australia and Canada onto reserves and to residential schools, as further examples of attempts to purify space in order to preserve the dominant social order.

Sibley's (2007) own research is concerned with illuminating more subtle, taken-for-granted divisions of space. Sibley (2007) uncovered assumptions of "Gypsies as a criminal minority" coupled with "language of pest control—reference to infestations—and a Manichean opposition of good and evil" behind the drive to restrict the use of rural space in England and deny Gypsies a place in the English countryside" (p. 106). Sibley (2007) also studied the bounding of domestic space and the effect of spatiality on youth. The division of household rooms and rules about the timing and purpose of their usage were an indication of youth-parental relationships. Tensions over space were found to "represent a clash between adults' desires to establish order, regularity and strong boundaries, and children's preferences for disorder and weak boundaries" (Mahtani, 2004,

p. 260). Alternatively, the allocation of a bedroom for their own use demonstrated an impulse for securing boundaries and the importance placed on allowing each individual a pure space with minimal subjection to (parental) control. Sibley (2007) extended his theorization of the relationship between purification and exclusion to academia. Sibley (2007) investigated the connection between the lack of integration of research by people of colour and women into mainstream geography and demonstrated that their marginalization was linked to paternalism. Here, Sibley (2007) demonstrates that knowledge too can be viewed as abject. In his words:

> Exclusion in the home, in the locality and at the national level are not discrete issues. . . there are common strands . . . though the problems considered are very different, ranging from conflicts within families and homes to international relations…we can use the same arguments to explain the exclusion of knowledge as to explain the exclusion of discrepant others. I suggest that the production of knowledge involves both the exclusion of knowledge which is deemed dangerous and the exclusion of some categories of intellectual. (Sibley, 2007, p. xvi)

The exclusion of voices from what is seen as constituting legitimate science and knowledge can be considered another form of boundary maintenance and purification.

In all these examples, spatiality and subjectivity are reciprocally related. Divisions in the spaces of the English countryside, the home, and academia could be described as reflections of boundaries assumed between normal/different, good/bad, belonging/not belonging ingrained in the psyche and reinforced in the social order. Distancing was a common strategy used to uphold psychological boundaries, either through the creation of physical distance between the self and Other, or psychological distancing through the act of disregarding the Other. In either scenario, social exclusion can be seen as being linked to concerns about mixing and maintaining boundaries around a specific worldview that aim to preserve conformity in a space through exclusion of those who are viewed as threats. Restrictions helped erect or maintain boundaries meant to avoid the pollution of a certain way of thinking and living with the views and ways of others who are different

and perceived as discrepant, inferior and potentially problematic. These strategies for organizing space therefore represent attempts to purify spaces and make places more reflective of what is perceived as the ‘normal’ order of people and things. Sibley (2007) summarizes his work as follows:

> The determination of a border between the inside and the outside according to ‘the simple logic of excluding filth,’ as Kristeva puts it, or the imperative of ‘distancing from disgust’ translates into several different corporeal or social images which signal imperfection or a low ranking in a hierarchy of being. Exclusionary discourse draws particularly on colour, disease, animals, sexuality and nature, but they all come back to the idea of dirt as a signifier of the imperfection and inferiority, the reference point being the white, often male, physically and mentally able person…[P]sychoanalytic theory has been used in the deconstruction of stereotypes [around] those ‘others’ from which the subject is distanced. (p. 14)

Object relations and the concept of abjection created the means for analyzing the interconnectedness of people and objects with space and spatial organization by helping to illuminate social divisions and their assumptions. A critical geographic perspective offered a way to identify and map exclusionary structures and practices. In the following section, Sibley’s (2007) views about the use of stereotypes for navigating ambiguity at the borders of contested spaces, as well as methodological considerations for mapping space and its relationship to spatiality are discussed, along with their relevance for this study.

3.3.3 Mapping the boundaries of contested space

Space can be both representative and supportive of any variety of subject positions. The concern for Sibley (2007), similar to Foucault and Weedon, is the fate of pluralism in the current Western social order. In particular, Sibley (2007) takes issue with how dominant discourses in liberal and capitalist societies in the West create “images of difference and the ways stereotypes collude to create landscapes of exclusion” (Mahtani, 2004, p. 262). In his spatialization of object relations theory, Sibley (2007) demonstrates how “[t]here are implicit and explicit rules of inclusion and exclusion in a built form that contribute to the structuring of society and space in a way which some will find oppressive and others

appealing" (pp. xi-xii). That is, social structures and the organization of space are simultaneously shaped by and contribute to the constitution of boundaries between what is considered normal and deviant, to the detriment of diversity, equal acceptance of heterogeneity, and the integration of difference into the structure of society. It is the social construction of society according to the philosophical frame-of-reference of a dominant group over all others that threatens pluralism and leads to ambiguities, alienation, and in many cases conflicts over space—both psychological and social space. In Sibley's (2007) words:

> We can envision the built environment as an integral element in the production of social life, conditioning activities and creating opportunities according to the distribution of power in the socio-political system. For some, the built environment is to be maintained and reproduced in its existing form if it embodies social values which individuals or groups have both the power and the capacity to retain. For others, the built environment constitutes a landscape of domination. It is alienating, and action on the part of the relatively powerless will register in the dominant vocabulary of deviance, threat or subversion (p. 76).

Built environments and spatiality both are a reflection of the hierarchy of knowledge, values and subsequently the power structures dominant in a given social order. Simultaneously, they are involved in subjectivity and the imposition of a specific way of ordering a sense of 'what belongs' and what 'does not belong' on the imprint of psychological and social landscapes.

Built environments

What Sibley (2007) ultimately illuminates with the spatialization of object relations theory is that "the self is a cultural production" as are accepted boundaries between what is considered normal/different. Subsequently, the decisions of individuals to reject or embrace difference, and the inequalities that result from rejection and exclusion, are not based on "an innate sense but a consequence of relating to others and becoming part of a culture" (Sibley, 2007 p. 7). The importance of this, according to Sibley (2007), is its

meaning for resistance, the possibility of change, the potential for pluralism, and the option of embracing difference. Sibley (2007) explains that by “[r]ecognizing that people have a capacity to change their environment and, more generally, that individuals retain some autonomy as thinking and acting agents, leads to the question of the distribution of power within the social system and of spatial structures as embodiments of power relations” (pp. 75-76). Awareness of the relationship between spatiality and subjectivity helps illuminate the possibility of transformation through attention to the power relations and assumptions underlying the way people and things are classified and organized in a social setting. Applied to the analysis of space, object relations theory subsequently opens up debates about the viewpoints and reactions of people and institutions to otherness. It highlights questions about the role of physical structures and spatial strategies in the repression of knowledge, the sublimation of desires, and the creation of constraints on individual and social activity in built environments (Sibley, 2007). Sibley (2007) subsequently equates the engagement in *geographies of exclusion* with “the literal mappings of power relations and rejection” (Sibley, 2007, p. 11).

Therefore, in this study, mapping the spaces allocated for case management nursing practice in health units across Ontario can help bring to the foreground the assumptions underlying the interactions of people in their built environments, and how they are tied to power relations in public health. The conceptualization of built environments and its ability to influence the beliefs and behaviours of individuals has already been established in the domain of public health. A focus on built environments was introduced in the latest public health sector strategic plan released by Public Health Ontario (MOHLTC, 2013c). “Promoting healthy environments—both natural and built” is the fourth of five strategic goals laid out by the Chief Medical Officer of Health in Ontario to guide the mission of public health and its affiliates between the years 2014-2019. The strategy is based on a recognition of the interconnectedness of built environments with

individual and community health. A *built environment* is defined as “encompassing all buildings, spaces and products that are created or modified by people” and the mission is for local public health to “work with municipalities to support healthy public policy and create or enhance supportive environments in the recreation setting and built environment” (MOHLTC, 2013c, p. 20). Public Health Ontario’s engagement with built environments reflects an effort to analyze and influence the structure of local environments in order to “reinforce the strong links between community planning and health outcomes” (MOHLTC, 2013c, p. 20). The purpose of this study, alternatively, is to understand the role of built environments in the work-life experience of public health nurses in Ontario’s local health units. Specifically, this study will ask: How does the current structure of public health reflect its explicit and implicit vision and mission for HIV case management in Ontario? How does the organization of health units across the province promote or repress nursing and client knowledge, and the ability of nurses and clients to participate in defining health, developing policies and the creation of community initiatives related to HIV case management?

A study by Holmes, O’Byrne and Gastaldo (2007) titled, “Setting the Space for Sex: Architecture, Desire and Health Issues in Gay Bathhouses,” is one of the few examples of research by nurses that attempts to conceptualize space and analyze built environments in order to understand their implications for nursing practice. The research set out to deconstruct the contested space and meaning of bathhouses for gay men. Specifically, the aim of the study “was to describe and compare the physical design, as well as the atmosphere of urban gay bathhouses, and reflect on how desire operates within these premises when it intersects with the bathhouse environment and health imperatives” (Holmes et al., 2007, p 273). Holmes et al. (2007) combine critical theory with an ethnographic design as a means to map the architectural features of bathhouses and demonstrate the link of space to the experience of gay sex in three different locations in

Ontario. The relationship between space, identity, sex and power was complicated. However, the mapping of the physical design and interior organization helped to identify competing meanings over the place of bathhouses in sexual health and illustrated the role of assumptions and stereotypes in creating misunderstandings and potential conflicts between public health and clients. The study had several implications for public health nursing strategies, that led the authors to conclude that "[t]he design of STI prevention campaigns aimed at the general public do not take in account the psychosocial and cultural complexities of specific sexual practices [and] this constitutes the main gap (shortcoming) in current prevention policies" (Holmes et al., 2007, p. 283). Attention to space and its use provided a new way for public health nurses to understand the connection of bathhouses to the identity and needs of gay men.

Deconstructing contested space

Sibley (2007) admits that understanding and mapping the interactions of people with built environments is complex. Both geographic designs and people's responses to them vary and "[v]ariations in the control and manipulation of different spatial configurations reflect different forms of power relations" (Sibley, 2007, p. 76). According to Sibley (2007), there are "several possible maps of social organization which we can deconstruct" (pp. 77-78). In his view, however, they are related. In line with a Foucauldian perspective about the diffusion of sovereignty and power in contemporary society, Sibley (2007) suggests that spatiality and power relations in specific localities reflect regional power relations and social boundaries. Sibley states, for example:

> [P]rivate spaces have a relationship with the public spaces of geography—they are reciprocally conditioned, and it is the process of reciprocal conditioning which requires illumination if we are to understand problems like the rejection of difference in localities. (2007, p. 77)

In Sibley's (2007) view, there is a significance to focusing on the mapping of localities and understanding life at the margins. That is, "[i]n the routine of daily life, most people are

not conscious of domination and the socio-spatial system is reproduced with little challenge" (Sibley, 2007, p. 76).

As the study of gay bathhouses by Holmes et al. (2007) illustrated, research at the margins provides a way to bridge divides by illuminating the different meanings space and its use can have for the mainstream in comparison to marginalized groups. Given the relationship of distancing to marginalization, understanding the meaning of space from the point of view of the excluded is a form of closing the distance. Sibley (2007) therefore advocates strongly for research to be based on engagement with individuals at the margins, and local knowledge to be integrated into research and praxis. This is clear where he writes:

> Postmodern discourse does not bring the academic writer closer to the 'other' if there is no real engagement. Engagement with texts does not remove the need for engagement with people. In other words, I see the question of making human geography radical and emancipatory partly as a question of getting close to other people, listening to them, making way for them…Without wishing to be too prescriptive, I would suggest that if geography is to represent difference authentically and to challenge exclusionary tendencies, practitioners need to transgress disciplinary and personal boundaries and to come much closer to the people whose problems provide the primary justification for the existence of the subject…What I would advocate is that geographers go out into the world…in order to experience the life-worlds of other people. (Sibley, 2007, pp. 184-185).

Local experience at the boundaries of contested space can provide important insights about the reproduction of space and power relations throughout society. For example, based on Sibley's view, nurses' workspaces can be seen as more than merely fixed or benign settings, and a map of their workspace and experiences in it, more than an isolated example of issues in healthcare. Rather nurses' workspaces and work-life experiences serve as an example of the context of the process of health and social policy development and the power relations that influence both public health's and case management nurses' stance in public health as a whole. Sibley (2007) explains that "[i]t should not be seen just as an arena where the particular power game was played, however, but as one instance

of the interaction of space and people which forms part of the routines for the reproduction of power relations in an advanced capitalist society" (p. xiv).

Subsequently, an important issue with built environments is that they represent constructed spaces on otherwise fluid experiences of space and time. Localities in themselves represent borders and transgressions. As Sibley (2007) explains, built environments including buildings are symbolic of "the act of drawing the line in the construction of discrete categories [that] interrupts what is naturally continuous. It is by definition an arbitrary act and thus may be seen as unjust by those who suffer the consequences of the division" (p. 35). Built environments are a form of *territorialization,* and in occupied spaces "[p]roblems arise when the separation of things into unlike categories is unattainable" (Sibley, 2007, p. 32). Given the concept of abjection, purified space is theoretically unattainable, therefore mixing of people, things, and subsequently worldviews, is inevitable. Subsequently, these intersections or zones of abjection in space create *liminal zones* "or spaces of ambiguity and discontinuity" (Sibley, 2007, p. 33). The experience of individuals at liminal zones, specifically the degree of anxiety created by boundaries and to which a space becomes contested, depends on the degree to which individuals or groups sharing the space are socialized into believing that the divisions are natural, necessary or desirable (Sibley, 2007). Tensions occur when *transgressions*, or "breaches in boundaries" or use of space are perceived as a threat of 'contamination' and challenge to hegemonic values (Sibley, 2007, p 39). Built environments in a sense depict the moral order imposed on a physical space. Therefore, mapping space must involve not only a depiction of the physical boundaries of a locality, but simultaneously requires an effort to chart the contours of what is considered normal as well as the exclusionary structures and practices in a setting, and their relation to competing discourses and tensions.

Sibley (2007) suggests that stereotypes are commonly used to cope with anxiety and ambiguity in liminal zones. *Stereotypes* are 'images of things feared and glorified,' and they play a central role in the structuring or bounding of the self and subsequently, in the structuring and bounding of space (Sibley, 2007). Therefore, identifying and deconstructing stereotypes is an important starting point for understanding and mapping the beliefs and behaviour of individuals and groups in relation to how space is configured. Sibley's (2007) research shows that "good and bad both emanate from stereotypical representations of others" (p. 15). Stereotypes can represent interest, reverence, or even a romantic fantasy about a social group, or represent abhorrence, revulsion, or fear. However, Sibley (2007) points out that in either case, stereotypes represent a form of distancing, a method of maintaining boundaries between the self and others:

> ...the stereotype is a simplification because it is an arrested, fixated form of representation which denies the play of difference. "Others' disturb the observer's world-view, but the stereotype removes them from the scene in the sense that they are distinct from the world of everyday experience. Because there is little or no interaction with 'others,' the stereotyped image, whether 'good' or 'bad,' is not challenged. (p. 18)

Therefore, identifying stereotypes is an important way of identifying the feelings and assumptions associated with boundaries in a social space. In particular, they offer a means to uncover the "place-related self," *(whose side you are on)* as well as perceptions about whether or not the stereotyped individual or group they refer to is 'in place' or 'out of place' (Sibley, 207, p. 19). Sibley (2007) suggests that an important source of tensions relates to the perception of individuals being out of place or out of line with a stereotype. Subsequently, a significant question for mapping social space in this study is: What stereotypes of nurses and clients are circulating in public health, and how do they relate to boundaries imposed on the spaces for case management nursing and tensions in nurses' work-life experiences?

In order to understand nurse' work-life experiences in relation to space, a final consideration must be given to forms of social organization in modern institutions that fix spatial and social relations. According to Sibley (2007), identifying the way space is classified and framed is one way of arriving at an anatomy of places and its influence on power/knowledge. Sibley (2007) uses the terms *classification and framing* to "describe the characteristics of mixing or purification of a space" (p. 80). In a *strongly classified* space, there is internal homogeneity, areas are strongly bounded, and people are kept separate with clear distinctions between their roles. In a *strongly framed* space, there is a hierarchal order and "[d]ecisions about what is permissible come from above and inter-subject communication is minimized" (Sibley, 2007, p. 80). In strongly classified and framed institutions, some knowledge may be seen as threatening and difference as subversive since ambiguous boundaries are not well tolerated. Conversely, in a *weakly classified* space, there is evidence of heterogeneity, weakly defined boundaries, and "less concern with singular and distinct identities" between people (Sibley, 2007, p. 80). *Weak framing* allows for sharing and transmission of a wide range of ideas and new ideas are absorbed. The classifications and framing of structures may occasionally be a combination of strong and weak, and Sibley (2007) provides the example of the hospital as an institution with a social structure that is strongly classified, but in terms of internal organization shows "instances of weak framing" (Sibley, 2007, p. 81). Classification and framing serve as a basis for connecting spatial structures to social structures and are therefore useful tools for mapping how individual public health units are structured, as well as for conceptualizing case management nursing's positionality within the broader framework of how public health is organized regionally.

In summary, Sibley (2007) claims that "[i]n the interaction of people and the built environment, it is a truism that space is contested but relatively trivial conflicts can provide clues about power relations and the role of space in social control" (Sibley, 2007, p. xiii).

By applying concepts from object relations theory to the concept of spatiality, Sibley (2007) provides a way to examine conflicts or tensions associated with power relations through an analysis of the interconnectedness of people and things as they constitute and are constituted by space. In particular, he links spatial concerns over contested boundaries to psychologically ingrained concerns with establishing distance between insiders and outsiders. His work demonstrates how boundaries are socially constructed; they reflect the psychosocial processes of introjection, projection and abjection that link dominant discourses in the West about the nature of difference as deviant to the "importance of maintaining self-identity (literally, maintaining the boundaries of the Self)" (Mahtani, 2004, p. 259). Subsequently social exclusion is tied to spatial practices that are motivated by a fear of deviance, the abject, and perceptions circulating in and through social institutions and individuals about the relationship of spatial purity to social order. Sibley (2007) summarizes these concerns and the connections between social and spatial exclusion in the following passage:

> [B]oth space and society are implicated in the construction of boundaries of the self but the self is also projected onto society and onto space. Self and other, and the spaces they create and are alienated from, are defined through projection and introjection. Thus, the built environment assumes symbolic importance, reinforcing a desire for order and conformity if the environment itself is ordered and purified; in this way, space is implicated in the construction of deviancy…The problem is not solely one of control from above where agents of an oppressive state set up socio-spatial control systems in order to remove those perceived to be deviant and to induce conformity…[Rather], exclusionary practices of the institutions of the capitalist state are supported by individual preferences for purity and order…A rejection of difference is embedded in the social system. (pp. 66-67)

Given the relationship between power/knowledge, object relations, exclusionary practices and space established by Sibley (2007), mapping the physical and social organization of public health units in this study is not an extra undertaking, but an integral part of understanding the relationship of dominant discourses in the management of epidemics

to the experience of marginalization of some clients in the public health response to HIV/AIDS in Ontario, and the positioning of case management nurses in relation to both.

3.4 The Battle for Truth: An Integrated Theoretical Framework

The theoretical framework guiding this study integrates different concepts from the writings of Michel Foucault (1978-2008), Chris Weedon (1999; 2008), and David Sibley (2007) to help identify and describe the variety of rationalities, strategies, and uses of space in case management nursing care, the power relations between the plurality of discourses competing for truth over how case management should be defined and practiced, and the effects on nurses and clients in Ontario. Collectively, the concepts related to governmentality, gender, and geographies of exclusion form a comprehensive framework (see Figure 3) for examining and articulating the extent to which the "War on HIV/AIDS" represents what Foucault (1980) refers to as a "battle for truth" in the social construction of case management nurses' practice (p. 132).

Foucault's (1978-2008) writings on governmentality are used to help unravel how individual and institutional practices are both "subject" to and involved in the reproduction of dominant discourses in liberal, capitalist societies, and the processes through which nurses absorb and resist narratives about the knowledge and conduct considered normal and deviant in the practice of case management. Therefore, Foucault's work forms the centre of this theoretical framework. Weedon's (1999; 2008) feminist approach to understanding potential links between beliefs about gender and gender roles in patriarchal societies, and Sibley's (2007) descriptions of the role of introjection and projection in the social construction of knowledge and use of space, offer additional ways to describe the experiences of case management nurses in public health units. All three perspectives are relevant for exploring how nurses govern themselves and others in case management.

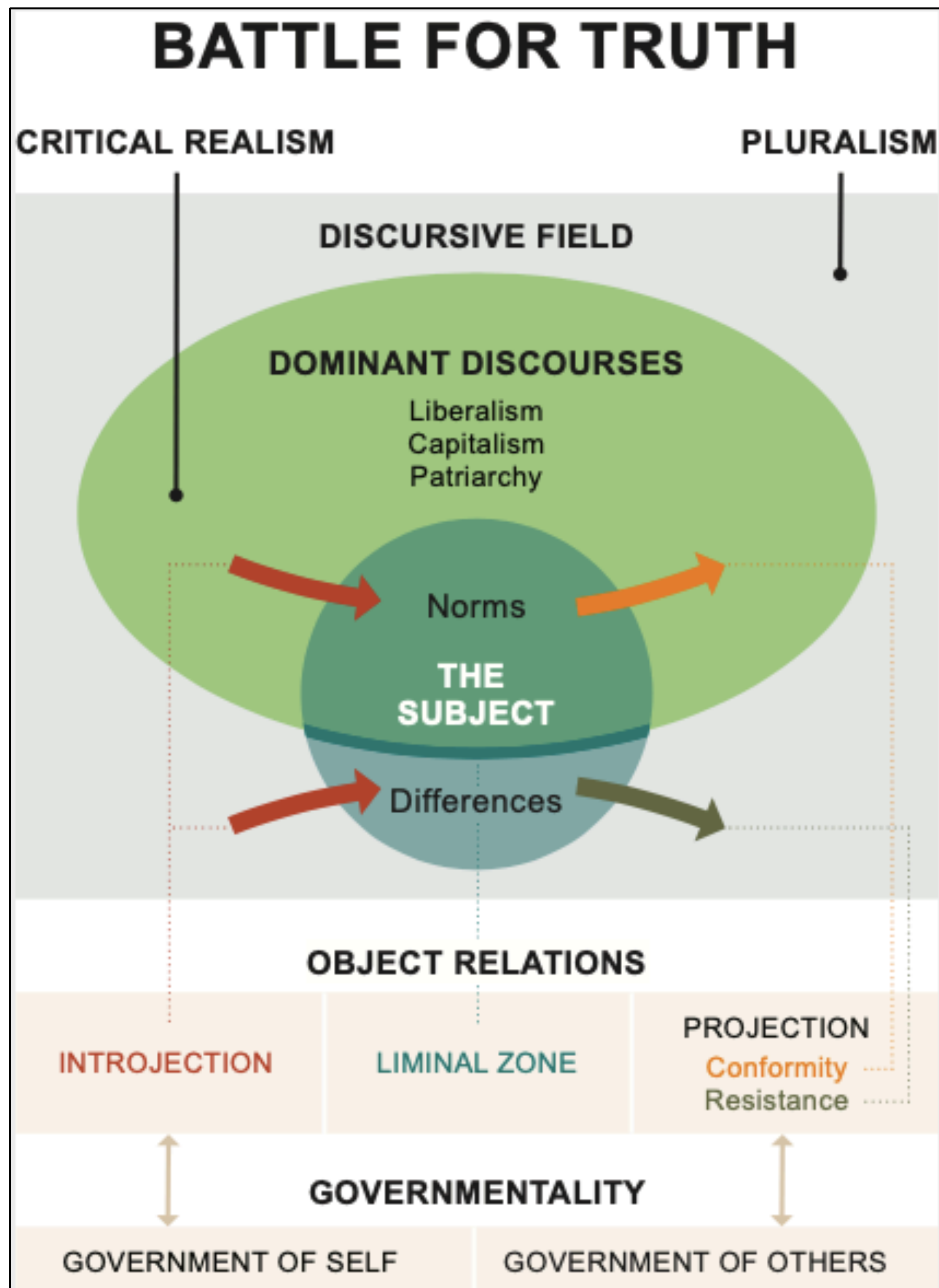

Figure 3:
Integrated Theoretical Framework:
Power/knowledge and the Social Construction of the Subject
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The theoretical perspectives of Weedon (1999; 2008) and Sibley (2007) build explicitly on Foucault's (1978-2008) conceptualization of power/knowledge and concern with the fate of pluralism under modern forms of government. Central to all three theoretical perspectives, and therefore at the core of the theoretical framework for this study, is the conceptualization that case management nurses are both shaped by and involved in shaping their sociopolitical and spatial environment. This assumption is rooted in a Foucauldian perspective of power/knowledge that can be traced to an ontological and epistemological understanding of the nature of truth and reality at the basis of the paradigm of critical theory (Guba & Lincoln, 1994). Therefore, while each theoretical perspective illuminates different aspects of the complex socio-spatial context in which case management nurses may be situated, all three are congruent at the level of *ontology*, defined as the nature of reality, and *epistemology*, what can be known (Guba & Lincoln, 1994).

3.4.1 The social construction of truth in case management practice

Foucault's interest in rationalities and governmental practices stem from an ontological and epistemological stance that questions claims about the 'truth or falsity' of knowledge and its power. From a poststructuralist standpoint, Foucault (1991a) argues that truth is produced and ordered through discourses, and the institutions that make up the state are also produced by the knowledge accepted as true in society. Therefore, theoretically, both case management nurses' practice and public health institutions are socially constructed (Guba & Lincoln, 1994). In a discursive field, truth is relative, and 'reality' an interpretation of the social, political, economic, and gender values circulating as truth (Campbell & Wasco, 2000). From a critical theory perspective, reality exists independent of thoughts, but the truth and knowledge available to individual nurses and subsequently their clients are linked to discourses and their power to shape the information that is valued, developed, and dispersed in a social context (Foucault, 1980). In other words, a

poststructuralist perspective in critical theory assumes pluralism exists at the level of epistemology, but critical realism at the level of ontology (Mill, Allen & Morrow, 2001).

Governmentality, likewise, is based on Foucault's assumption that in reality a multiplicity of truths are possible, but truth becomes a function of the knowledge produced by dominant discourses and institutional practices that govern what may, or may not, be thought, said, or written (McHoul & Grace, 2002). The main issue with discourses and institutional practices for Weedon (1999; 2008) and Sibley (2007) is the same. Weedon is concerned with claims about the 'naturalness' of patriarchal discourses, and how dominant discourses about gender 'fix' women and men in unitary subject positions compared to the multiple subject positions available in reality. From a feminist poststructuralist perspective, patriarchy and the organization of power it produces on the basis of biological sex, "is not natural and inevitable, but socially produced" (Weedon, 2008, p. 123). According to Sibley (2007), built environments in themselves represent social constructions on otherwise fluid experiences of space and time, and signify attempts to impose order on otherwise complex intersections of multiple truths.

Therefore, all three theoretical perspectives demonstrate in different ways how discourses have the power to produce subjectivities and shape identities. Discourses, and the bodies of knowledge they represent, establish the limits and possibilities of what is considered 'right,' normal, acceptable, different and intolerable in reality. As a result, discourses have the relative power to 'fix' and limit the theoretical conditions of possibility for nurses involved in case management, and to establish the groundwork for a heterogeneous system of relations that help perpetuate them (Foucault, 1980). Describing the effects of competing discourses on case management policies and individual nurses' perceptions of the "true," "right" or "best" way to practice case management will form the basis of the theoretical framework for this study.

3.4.2 Power/knowledge and the contours of normality in nurses' care

The relations between claims of truth and power, and discourses and subjectivity, and their meaning for individual nurses involved in HIV case management will be conceptualized and mapped using Foucault's (1980) definition of power/knowledge. According to Foucault's (1980) conceptualization of power/knowledge, "[w]e are subjected to the production of truth through power and we cannot exercise power except through the production of truth" (p. 93). As such, individual nurses are simultaneously influenced by and can influence the knowledge and truth circulating in society. Consequently, in a web of social relations case management nurses "are [theoretically] always in the position of simultaneously undergoing and exercising power" (Foucault, 1980, p. 98). This conceptualization of power/knowledge is embedded in each of the three theoretical perspectives.

Central to Foucault's (1978-2008) writings on governmentality is the concept that individuals are both governed as well as involved in the government of one's self and others. Individuals are situated in a web of power relations in which they are actively shaped by and help perpetuate liberal, capitalist, patriarchal and a variety of other social discourses that struggle agonistically for strategic space in the current sociopolitical order. Weedon's (2008) view is similar: "[s]ocial meanings are produced within social institutions and practices in which individuals, who are shaped by these institutions, are agents of change, rather than its authors, change which may either serve hegemonic interests or challenge existing power relations" (p. 25). From a feminist poststructuralist perspective, gender norms shape the beliefs about and roles for women and men in society, but individuals also have the ability to define for themselves what it means to be a 'woman' and a 'man,' and power to help shape social institutions in a manner that is more representative of the diversity in their lives. Similarly, Sibley (2007) envisions space as constituting individuals and individuals constituting space.

In this light, case management nurses' practice is the central subject of the theoretical framework for this study, and the objective is to understand how the sociopolitical and spatial context of nurses' work influences how policies and practices are socially constructed for and by nurses. This necessarily includes an examination of the processes of introjection and projection of discourses circulating as truth in case management policies and practices, and nurses' concerns with compliance and non-compliance with established norms. Each individual nurse's decisions to reject or embrace difference, and the inequities that result from rejection and exclusion, are not considered "innate" to nurses or public health nursing practice, but are examined critically for how they "may be a consequence of relating to others and becoming part of a culture" normalized through the dominant discourses in policies that establish the contours of normality in case management nurses' practice in the public health response to HIV (Sibley, 2007 p. 7).

Subsequently, in all three theoretical perspectives, individual "bodies, as well as our minds and emotions" are seen as the sites of an *identity politics*, a political struggle over the control of the meaning of gender in Weedon's case, value of diversity in Sibley's view, or in Foucauldian terms, a battle for truth over the process of governmentality and socialization of individuals in the response to HIV (Weedon, 1999, p. 104). Using Foucault's (1977) words, it "is not that the beautiful totality of the individual is amputated, repressed, altered by our social order, it is rather that the individual is carefully fabricated within it, according to a whole technique of forces and bodies" (p. 217). Together, the three theoretical perspectives form a framework that can be used to help trace the contours of normality and fate of difference for case management nurses, and identify the discourses and approaches with the potential to promote new strategies needed to improve the outcomes of nurses' engagement in public health care with people affected by HIV.

3.5. Summary

Three theoretical perspectives are used to explore nurses' experiences in the public health response to HIV/AIDS in Ontario: Michel Foucault's (1978-2008) writings on governmentality; Chris Weedon's (1999; 2008) work on gender, identity, and experience in patriarchal societies; and David Sibley's (2007) geographical analysis of exclusion. Together, the three theoretical lenses offer unique but ontologically and epistemologically commensurate concepts for helping unravel and understand the complexities associated with HIV case management. They are integrated around a conceptualization of reality as a "battle for truth" articulated by Foucault (1991a) and a poststructuralist perspective that truth is socially constructed through power/knowledge, to guide efforts in this study to understand and describe how the rationalities, strategies and spaces used by case management nurses are related to competing discourses about what is considered normal and deviant in the public health response to people with HIV/AIDS.

CHAPTER 4: METHODOLOGICAL CONSIDERATIONS

4.1 Design

A qualitative approach is employed in this study given the paucity of research on the topic of HIV case management. Also, a qualitative design is useful for describing the strategies involved in case management, as well as the meaning of nurses' practice experiences, including the rationalities underlying HIV care. That is, according to Denzin and Lincoln (2011), "qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomenon in terms of the meanings people bring to them" (p. 3).

4.1.1 Critical ethnography

Critical ethnography is a qualitative research design embedded in conventional ethnography, that is particularly well suited to this study, as it offers the ability to describe the "meanings, functions, and consequences of human actions and institutional practices in their local, and sometimes broader context" (Hammersley & Atkinson, 2007, p. 3). Critical ethnography is also consistent with a critical theory perspective and framework used to explore governmentality, in that it is concerned with individual perspectives as well as patterns of behaviour in a social setting, and identifying the assumptions that govern both (Mill, Allen, & Morrow, 2001; Simon & Dippo, 1986).

In addition, critical ethnography is both hermeneutic and emancipatory (Soyini Madison, 2012; Thomas, 1993). Its emancipatory potential is linked to *critique*, a focus on "the process of separation from constraining modes of thinking or acting that limit perception of and actions toward realizing alternative possibilities" (Thomas, 1993, p. 4). According to Thomas (1993): "Conventional ethnography describes what is; critical ethnography asks what could be" (p. 4). A critical ethnographic design was important for this study as it offers the methodological tools for questioning accepted truths and norms, eliciting information about the dominant rationalities and strategies used by nurses for case management, exploring their fit within the broader socio-political context of HIV care,

and uncovering alternative modes of thinking and action for future consideration.

The methodological tools for critical ethnography include a focus on cultural practices, researcher as participant, dialogical engagement, reflexivity, critique, field work, multiple sources of data, thick description, and a juxtaposition of data and theory in order to form an in-depth picture, and arrive at a new understanding about 'what is going on' in a social situation where competing discourses exist (Hammersley & Atkinson, 2007; Soyini Madison, 2012; Thomas, 1993). Each will be described in the following discussion about the research methods employed in this study.

4.2 Setting and Sample

Ethnography, by definition, is the study of cultures and cultural practices (Hammersley & Atkinson, 2007). In this research, case management nurses can be defined as a *cultural group* as they share issues of identity, community, and social control (Soyini Madison, 2012), as well as a common mandate (HPPA, 1990), and mission (Public Health Ontario, 2013). There are 36 public health units across Ontario, divided among six regions (see Appendix A). While there is variance between urban and rural settings, each health unit employs an average of 1-2 public health nurses in HIV case management. A multisite study was proposed for this research in order to construct a provincial profile of case management nursing and arrive at a "unity of reason in the diversity of its voices" (Habermas, 1992, p. 115).

4.2.1 Sampling

According to Hammersley and Atkinson (2007), "the more settings studied the less time can be spent in each. The researcher must make a trade-off between breadth and depth of investigation" (p. 31). To be clear, the goal of sampling in this study was not generalizability or to achieve a statistically representative sample as in quantitative research (Sandelowski, 1995). Nor was the aim to construct an exhaustive account of case management practice. The goal of sampling in a qualitative study is to "identify the

types of informants who are most likely to possess an 'insider's knowledge' of the research domain," in order to illuminate ideas about the research problem that are transferable to similar domains (Thomas, 1993, p. 37). Typically, a feasible sample for an ethnography involving the collection of multiple sources of data is 10-15 participants (Morse, 1994). However, sampling often continues until the workings of the cultural group become clear (Creswell, 2013).

Therefore, this study used purposive sampling to arrive at a sample of public health nurses with experience in HIV case management, along with epidemiological data about the number and rate of HIV diagnoses per health unit to assess the breadth achieved (see Appendix B). The sample consisted of 22 public health nurses who were active in case management from a total of 14 public health units across the province. Case management nurses were eligible for inclusion in the study if they were a Registered Nurse, employed in a public health unit in Ontario, active in case management for minimum one year with a caseload that includes HIV follow-up, had at least one case in the 12 months prior to the start of recruitment, and were able to speak and read English. Case management nurses who did not meet the inclusion criteria, or were on probation, were to be excluded.

All case management nurses who expressed interest in the study met the inclusion criteria. The 14 participating public health units accounted for 85% of the HIV caseload managed in Ontario since the beginning of the epidemic. At least one public health unit from each region was included, and the sample was comprised of health units from a range of urban and rural settings, including large metro (*n* = 5), partially non-metro (*n* = 5) and non-metro (*n* = 4) centres (according to the census definitions described by the Royal Ontario Institute, 2013).

4.2.2 Gaining entry and recruitment

According to Hammersley and Atkinson (2007), access to sites and participants largely depends on the approval of a sponsor and confidant who "com[es] to know the researcher

as a person who can be trusted to be discreet in handling information within the setting, and who will honour his or her promises of anonymity" (p. 57). A history of credibility as an insider, as well as continued affiliation with Ottawa Public Health has been a benefit in this regard. However, as a former case manager, I am simultaneously an outsider, and early attention to identifying a sponsor was required in order to gain approval from the Ministry of Health and Long-term Care to recruit participants from public health units in Ontario and establish a recruitment plan. In December 2015, the Manager of the Clinical Programs Branch at Ottawa Public Health expressed both interest and support for the research, and offered to write an email introduction to the Public Health Advisor of the Epidemiologist/Infectious Diseases Section of the Public Health Policy and Programs Branch, Population Health Division of the Ministry of Health and Long-Term Care (MOHLTC) in Ontario. The Public Health Advisor of the MOHLTC agreed to assist with recruitment planning, requesting permission, and gaining access to public health units for site visits. The offer of support included assistance with identifying and approaching gatekeepers across the province. *Gatekeepers* are "actors with the control over key sources and avenues of opportunity" (Hammersley & Atkinson, 2007, p. 27).

A first step in recruitment involved determining who "needs to as well as *ought* to be" consulted in order to gain access (Hammersley & Atkinson, 2007, p. 42). Based on the advice of the Public Health Advisor of the MOHLTC, recruitment began with obtaining a list of case management supervisors interested in learning more about the study. No formal structure existed for contacting case management nurses or their immediate supervisors to discuss their interest in participating in a scientific study. After internal consultation in the first quarter of 2016, a six-step process was formalized by the Public Health Advisor of the MOHLTC that enabled supervisors or other team members responsible for case management to either "opt out" or indicate their interest in being contacted about the study to the Public Health Advisor, who then assembled a list with the

names and contact details for the researcher based on the responses. In March 2016, a one-page letter describing the study was forwarded to Public Health Advisor as requested, who then shared it with the "STI Manager's group" with the disclaimer that "the researcher(s) are working independently of public health units and the Ministry." Managers were advised they had one week (5 business days) to respond to the MOHLTC. In April 2016, a list of the management team members from 35 public health units and their contact details along with approval to contact them directly was received by email. One public health unit had opted out and no reason was provided.

A brief follow-up email requesting an appointment to discuss the study with potential participants by telephone with an attachment of a recruitment advertisement (approved by the Research Ethics Board of the University of Ottawa) was forwarded to each management team. A total of 17 public health units obliged, and 14 granted permission for case management nurses to participate after discussing the study and receiving internal approval for site visits. The three health units that opted not to participate cited "internal restructuring" as the reason. Interested case managers were screened according to the inclusion/exclusion criteria, and appointments for site visits were scheduled at the convenience of participating nurses. Fieldwork proceeded from April to October 2016.

4.3 Data Collection

Four sources of data were collected at each site: oral interviews; observations; mute evidence; and field notes with reflexive journaling. Multiple sources of data are important for both constructing how participants' experiences are part of the world they describe, as well as deconstructing how they are shaped by and shape the contexts in which they occur (Hammersley & Atkinson, 2007, p. 97; Thomas, 1993).

4.3.1 Oral interviews

Interviews were *dialogical*, involving the researcher as participant (Soyini Madison, 2012). In critical ethnography, dialogical engagement provides an important opportunity to

explore the relationship between participants' perceptions and their context through mutual reflection and examining assumptions (Soyini Madison, 2012). Interviews were semi-structured around an interview guide, but open-ended, flexible and probing in response to observations and impressions to enhance dialogue and aid memory (see Appendix C for the Interview Guide). The questions for the Interview Guide were created using prompts similar to those described in Hammersley and Atkinson's (2007) guide, *Ethnography: Principles and Practice*, to arrive at open ended questions such as, "I think the best place to start would be if you could give your impression as to..." as well as clarifying or probing questions such as, "Could you give me an example of..." or "I wonder if you could give me a little more detail about..." (p. 118). The questions corresponded with both the flow of the site visit (e.g. "Can you show me the spaces used to carry out case management?) and were specifically targeted towards eliciting information that corresponded with the research questions identified at the outset of the study (e.g. "Tell me about your experiences as a case manager").

The interview process was subsequently *thematized* (Brinkman & Kvale, 2015), meaning dialogical engagement aimed to: (a) clarify the purpose of the study, explain the anticipated steps and timelines of the research, and answer any questions as they occurred in the interview process; (b) obtain information about the subject matter by encouraging description of the typical steps used for case management, divergences in practice, and the rationales for nurses' decisions; and (c) encourage reflection and sharing of insights on themes that emerged in the dialogue, for example, to elaborate on what was meant by a "lack of time" or "difficulties" with a case, as well as "what constitutes success in case management?"

Interviewing typically began informally, with questions about the number of nurses involved in case management, the organization of the team within the health unit, and range of health unit roles and duties the participant engaged in as a case management

nurse. Interviewees than suggested a private space for more formal discussion about the case management nursing process and experience, which mainly involved dialogue about the steps used when following-up with a person newly diagnosed with HIV and themes related to case management nurses' work. The formal part of the interview process was tape-recorded with the prior consent of participants and transcribed by the researcher onto a password protected laptop computer for later analysis. The formal interview process ended with a final open-ended question to the participant, "Is there anything we have not talked about that you believe is important to share about case management nursing?" The site visit was completed following a brief discussion at the end of the day to answer any mutual questions about the information exchanged.

4.3.2 Observation

Observations were also guided, as well as persistent throughout the site visits (see Appendix C for the Observation Guide). An Observation Guide was developed to ensure steps were taken during the site visit to obtain information specific to the research questions regarding the social organization and use of physical space in public health units; namely, how the institutional arrangements support or constrain the ability of nurses to implement different policies and practices in case management. Questions were created for the guide based on the description of "non-participant observation" by Hammersley and Atkinson (2007) as the process of "watching, listening, asking questions, formulating hypotheses" in order to "acquire a good sense of the social structure of the setting and begin to understand the culture(s) of participants" (p. 79). The questions developed included, for example, "How does space shape a case manager's role? Which behaviours are supported by the space and configurations available? What are the limitations?"

Mainly observation involved sketching the position of the case management team within the physical layout of each health unit in the field notebook and mapping the lines

of communication involved in HIV case management in conjunction with the sketches. Official organigrams were consulted if available and supplemented with nurses' descriptions of their patterns of communication with colleagues, clients and community partners, as well as information gathered about the different spaces used in the process of their work. Therefore, nurses' patterns of communication and other actions were also observed. According to Hammersley and Atkinson (2007) observations of actions are important in ethnographic research in order to "identify the contexts in terms of which people in the setting act, recognizing that these are social constructions not physical locations . . . One way of doing this is through shadowing particular participants; observing them as they move, over time, between different contexts that form part of their lives or their work" (Hammersley & Atkinson, 2007, p. 39). Note that client interactions with nurses were not observed as part of this study, given the research interest in nurses' experiences in HIV case management. However, nurses were observed in their interactions during the tour of the health unit and, for example, in efforts to clarify information, in order to arrive at questions capable of eliciting a deeper understanding of the "order of things" in the health unit. This information was used to more fully develop the organigrams and an understanding of how the organization of space fit with case management nurses' practice.

4.3.3 Mute evidence

In this study, mute evidence refers to organigrams, policies, forms, educational materials, and artifacts such as computers, cellphones and other devices used in the process of case management. Nurses are a literate culture, and particular attention was given to documentary evidence, such as policies and procedures, as these "depend for their intelligibility on shared cultural assumptions" and helped establish where practice "conforms to 'normal' categories or deviates from them in identifiable ways" (Hammersley & Atkinson, 2007, p. 133). These items were selected and collected in hard copy or

electronic form based on nurses' expressed use of, public access to, and prior consent to receive copies at each site visit.

A Document Guide (see Appendix C) was created using suggestions by Hammersley and Atkinson (2007) for questions that would help elicit information about the development, intention and use of various documents in each site visited, as well as to identify the types of documents that have not (yet) been developed. Suggested questions included: "How are documents written? Who writes them? Who reads them? For what purposes? On what occasions? With what outcomes? What is recorded and how? What is omitted? What does the writer seem to take for granted about the reader(s)? What do readers need to know in order to make sense of them?" (Hammersley & Atkinson, 2007, pp. 132-133). These questions were tailored to the study and helped to identify mute evidence related to the structure and practice of case management, as well as discussion with participants about the strengths, limitations, concerns and innovations in case management practice reflected in the policies, forms and educational materials.

4.3.4 Field notes and reflexive journaling

Field notes and reflexive journaling were used to record and store data such as mute evidence that could not be tape-recorded, but also involved constructing "compressed summary accounts" of impressions formed during site visits that helped guide dialogical engagement, probing, analysis of my own positionality, and member checking about the meaning of nurses' experiences in case management practice during data collection as well as later in the process of data analysis (Hammersley & Atkinson, 2007, p. 145). For example, preliminary notes about the similarities and differences in the steps used for case management and different definitions of success emerging in interviews were noted as the field work proceeded that were helpful in the construction of memos later used to synthesize the data. Lists of community partners and patterns of communication between case management nurses and the various stakeholders they encountered were also

completed during the site visit for comparison across health units. Organizational drawings were also made in the field notebook. Field notes and reflexive journaling were kept in a locked briefcase carried during fieldwork and secured in a locked cabinet in a locked room accessible only to the researcher and co-supervisors at the end of each visit.

4.3.5 Fieldwork

Fieldwork is a hallmark of ethnographic research (Thomas, 1993). In this study, fieldwork resembled a typical 'job shadowing' experience in public health. Participants were asked to accommodate the researcher during a typical 8-hour shift, or two 4-hour shifts. Each field visit began with introductions, obtaining informed consent and collecting demographic data about the participant and the setting. Next, a tour of the physical layout of the unit was requested, which included a discussion about the main spaces and equipment used for HIV case management. Each participant was then asked to review the documentation relevant for practice, and describe a typical day including the steps used in HIV case management. The first half of the 'shadowing' experience culminated with an in-depth interview session in a confidential location chosen by the participant. Interviews lasted from 1-1.5 hours. The second half, or second 4-hour shift, was used for reading documents, writing field notes and reflexive journaling. Each field visit ended with a member-checking session, where participants were either asked further questions to help clarify information previously discussed, or given time to provide feedback, or offer additional insights. Closure involved addressing any concerns, sharing details about the study timeline, and requesting permission to follow-up by telephone for further member-checking if necessary. Field work ended when all interested public health units were visited once and little new information was emerging from the site visits.

4.4 Data Analysis

Data collection and analysis occur concurrently in a critical ethnography (Thomas, 1993). Analysis started in the field, with reflexivity on both what was said and observed, as well

as assumed. While it is a distinctive feature of social research that the ‘objects’ studied are in fact ‘subjects,’ in the sense that they have consciousness and are able to produce accounts of themselves and their world (Hammersley & Atkinson, 2007), in a critical theory perspective, critique is also used in analysis to deconstruct verbal accounts, actions, and documentary evidence in order to understand how they were produced and the presuppositions on which they were based (Soyini Madison, 2012). Therefore, the aim of analysis in a critical ethnography was two-fold: to identify in the accounts of participants the story they are telling about themselves and the worlds they live in, as well as treating those accounts as social products whose analysis can tell us something about the socio-cultural processes that generated them (Thomas, 1993). The different types of data collected in this study were first analyzed separately, and then compared, in order to better capture the complexities of nurses’ experiences.

4.4.1 Analysis of oral interview data

The transcripts of interviews were analyzed using content analysis. Content analysis started with a line-by-line reading of “what the text says” or the *manifest content*, then “what the text talks about” or the *latent content,* moving from codes to abstractions and themes (Graneheim & Lundman, 2004, p. 106). This process was managed with NVivo software. First, memos were added to the text to highlight key words and ideas, followed by coding, to label and link elements in the text that appear in patterns, or show regularity in terms of similarities or forms of variances (Saldana, 2013). Codes were then further analyzed for their fit into categories and themes. A theme is “an abstract entity that brings meaning and identity to an experience and its variant manifestations” (DeSantis & Ugarriza, 2000, p. 362). Themes were compared to the theoretical framework during the memoing and writing process in order to raise additional questions, discover more layers under meanings, and contribute to veracity (Soyini Madison, 2012).

The first reading of the transcripts produced an understanding of the steps of case

management that appeared to be similar across all participants. The first codes developed were a reflection of the verbatim terms and the order of the steps that emerged as a pattern in the descriptions of the case management process provided in all of the transcripts, a form of “process coding” of the actions typical of case management practice (Miles, Huberman & Saldana, 2014, p. 75). This early reading of the data provided a glimpse into the perspective of the context of case management in which all of the nurses seemed to be immersed--“the temporal order” of the knowledge and skills case management nurses have acquired and are required “to perform as competent members” of the case management team (Hammersley & Atkinson, 2007, p. 179). A gradual shift to the use of “emotion and value coding” evolved in the second reading in an attempt to determine the links between references to “tensions,” “difficulties” and their links to definitions of success common to nurses that “clients feel supported” (Miles et al., 2014, p. 75). A third reading helped crystalize the data into three main themes with their respective subthemes, which represents the new knowledge this study contributes to the understanding of how case management is socially constructed. The process used for reflecting on the data, memoing, and coding in this study proceeded in a manner consistent with the process of content analysis recommended by Hammersley and Atkinson (2007):

> In the early stages the aim is to use the data to think with. One looks to see whether any interesting patterns can be identified; whether anything stands out as surprising or puzzling; how the data relate to what one might have expected on the basis of common-sense knowledge, official accounts, or previous theory; and whether there are any apparent inconsistencies or contradictions among the views of different groups or individuals, within the expressed beliefs or attitudes, or between these and what they do. Some such features and patterns may already have been noted in previous fieldnotes and analytic memos, perhaps even along with some ideas about how they might be explained. (p. 163)

Multiple readings and engagement in reflexivity with the transcripts helped ensure the themes emerging from the interviews reflected a systematic process of confirming interpretations of the data. The process also ensures the themes are representative of not

only how participants view their world, but the complexities in the practice of case management practice as well as the norms.

4.4.2 Analysis of documentary evidence

The content of the documents used in case management practice were analyzed in a process of content analysis consistent with the process recommended by Hammersley and Atkinson (2007) for analyzing the transcripts of interviews above. Similar to the interview transcripts, the texts used in the process of case management were engaged with reflexivity to identify how they were shaped by and involved in shaping case management nurses' practice. Four main questions were asked of the textual data guided by categories for consideration described by Fairclough (2003) for critical discourse analysis of texts:

1. What statements and assumptions are being made to describe case management?
2. What approaches are being recommended and what discourses, values and evidence underpin the recommendations?
3. What stakeholders are named/involved?
4. What issues are given/not given attention and urgency?

The data from the policies, procedures, forms and educational materials were first extracted onto a single Microsoft Word document under codes that initially reflected their common order across all health units (e.g. the purpose of case management, the definition of a case), followed by codes representing a list of variances (e.g. a description of the roles and responsibilities of nurses, managers and the A/MOH in case management in one policy that was not included in others). Commonalities and variances in the content under codes were then grouped in order of reoccurrence across documents. Differences in the types of statements, recommended approaches, and their frequency were then traced to supporting evidence in the documents, and finally, compared to the discourses evident in the analysis of the interviews to determine how they fit with different

assumptions about case management practice described by nurses. The textual data is presented alongside the themes that emerged from the interviews to provide a description of how the discourses and approaches used by nurses for case management are and are not represented in the documents created to guide nurses' practice. According to Miles et al. (2014), the advantage of making comparisons across cases and sites is the potential to arrive at "a deeper level" of analysis and "develop more sophisticated descriptions and more powerful explanations" in an ethnography (p. 101).

4.4.3 Analysis of organizational drawings

The organizational drawings of the spaces used for case management within a public health unit were analyzed with a form of content analysis used for photography. The sketches were deconstructed to identify themes related to how the physical space of public health units are structured and then analyzed with the intention of identifying "how participants consume space…or how they move in given environments" (Hammersley & Atkinson, 2007, p. 149). The sketches of the organization of public health units constructed during the site visits were viewed collectively and coded with circles drawn around commonalities and differences in: (a) the overall architectural arrangements of a public health unit; (b) the structuring of teams and their articulation to each other within a health unit; and (c) the flow of information between each stakeholder and nurses involved in case management within and through public health units. A singular conceptualization of the organization of physical space in public health based on the description from this analysis was then merged with organigrams to decipher the links between the use of social space and the governance structure in public health typical across the province with notations about variances. The outcome was a descriptive account of the similarities and differences in the organization of space across public health units that could then be compared to how it is related to the priorities of nurses, steps of case management practice, flow of information to and from clients and community partners, and the forms of

governance in the public health response to HIV/AIDS deciphered from the other forms of data. A comparative analysis of all the different types of data collected in this study helped understand how the institutional arrangements reflect the discourses privileged in case management practice, as well as how they may be contributing to the oppression of others.

4.5 Rigour

Rigour is measured in a critical ethnography by the quality of the picture achieved through the research about “what is going on” in the cultural setting under study (Creswell, 2013, p. 233). An in-depth picture of the role of case management nurses in the public health response to HIV/AIDS in Ontario was developed by presenting multiple forms of data, an outline of the different steps used for practice, thick description of nurses’ perceptions and the processes related to their decision-making, and a theoretical framework that is congruent with the research focus. The thick description includes verbatim quotes presented alongside thematic analysis and a theoretical discussion of the findings, in order for readers to judge for themselves the representativeness of the study results (Sandelowski, 1993; Thomas, 1993). Member-checking was used to help ensure the trustworthiness of the findings, as well as reflexivity made transparent by the declaration of my positionality at the outset of the research process in the epistemic stance in the introduction of this text (Rolfe, 2004). Credibility was fostered through extensive fieldwork, and efforts to recruit a purposive sample of nurses experienced in case management from health units representing each region in Ontario and 85% of the HIV caseload managed in the province (Lincoln & Guba, 1985).

Quality in critical ethnography is also dependent on arriving at ‘something new’ (Creswell, 2013). According to Thomas (1993): “When done correctly, we get new insights that we would not otherwise notice” (p. 36). In this study, several strategies have been integrated into the research design in order to help excavate meaning beyond surface descriptions about a case management nurse’s role. These include attention to both

commonalities and diversity in nursing policies and practices, participation in dialogical engagement, collecting and juxtaposing multiple forms of data, and the incorporation of a theoretical framework aimed at arriving at a *Foucault effect*--a description of the art and activities involved in case management practice including the different ways it has been made thinkable and practicable across the province (Burchell, Gordon & Miller, 1991). The dominant discourses circulating in and through case management nurses' practice are presented and discussed, as well as the social conditions that would need to be accounted for if the oppression of alternative discourses is to be addressed and greater diversity promoted in nurses' work at the point-of-care.

4.6 Ethical Considerations

Ethical approval for the study was acquired from the University of Ottawa's Research Ethics Board prior to engaging in recruitment with the help of the MOHLTC, as well as the ethics committees associated with the public health units involved in the research (see Appendix D for Ethics Approval Certificates). Consistent with the University of Ottawa's policies and the Tri-council Policy Statement on ethical conduct for research involving humans the following measures were taken to ensure the protection of the participants involved in the study. At the time of recruitment, each potential participant was emailed a consent form, which was reviewed at the start of the site visit. Nurses were assured that their participation was voluntary, and that they could withdraw at any time without consequence. At the outset, they were informed that one benefit of participating in the study is the potential to contribute to a new knowledge base about case management practice. The risks of participation were also discussed, including the potential that workplace concerns and contrary practices may be raised. It was made clear to nurses that the aim of this study is to understand similarities and differences in practice, however, contact information for the Employee Assistance Program was available to any nurse who experienced distress in this situation. No untoward effects were noted in the process of

this study. Measures to protect the confidentiality of participants include: no names of participants or health units appear on records, transcripts or in publications; a number code was used on raw transcripts to protect nurses' identity; all data is stored in a locked cabinet in a locked room accessible only to my supervisors and myself, and data will be destroyed after 5 years. I acknowledged that nurses may be concerned about how they might be represented in the findings, and the role of member-checking, multiple data sources, and thick description was reviewed in this regard. In addition, it was recognized that participants' time was valuable, and a $10 gift card was offered at the beginning of the fieldwork to participants as compensation for any interviews occurring over coffee or lunch breaks.

CHAPTER 5: RESULTS

Similarities and differences exist in the organization, policies and practices of case management nursing in public health across the province of Ontario. Based on a thematic analysis of the different sources of data collected for this study, it is evident that diversity in case management is partially linked to the challenges of managing the epidemic unique to each rural and urban centre. These include differences in clients' access to specialized care with an Infectious Disease Specialist and the support of a locally based AIDS Service Organization (ASO). However, a key finding is that variations across the province in how case management is practiced appear to be largely related to the hierarchical structures governing nurses' abilities to respond to clients' concerns, the lack of evidence-based policies to support case management nursing practice, a reliance on decision-making by consensus, and nurses' adaptations of different conceptualizations of "engagement" operating within the public health response to HIV/AIDS.

In particular, the data illuminate how nurses both accommodate and resist different discourses circulating in and through case management about what constitutes 'best' practice for engaging people in HIV care. As outlined in Table 1, three key themes with corresponding subthemes emerge from the data that characterize the complexity of nurses' work engaging people newly diagnosed with HIV and their contacts in testing, treatment and support services. From a public health nursing perspective, case management involves:

1. "Avoiding trouble:" Encouraging conformity to biosecurity measures;
2. "Living with a client for a while:" Collaborating with clients to meet their needs;
3. "That whole dance we do:" Balancing dual obligations.

In this chapter, the data related to each theme and subtheme are presented following a description of the characteristics of public health nurses who participated in the study.

Table 1

Outline of Themes and Subthemes characterizing the meaning of "Engagement" in Case Management Nursing in Ontario

	Themes	Subthemes
1.	**"Avoiding trouble:"** Encouraging conformity to biosecurity measures	a. Mandatory engagement b. Following a predetermined pathway c. Explaining what is expected d. Making it easy and making sure e. Judging each individual's ability to conform f. Intervening with graduated intensity and forced measures
2.	**"Living with a client for a while:"** Collaborating with clients to meet their needs	a. Learning a client's story b. Starting where the client is at c. Sharing mutual concerns d. Matching information to needs e. Facilitating connections
3.	**"That whole dance we do:"** Balancing dual obligations	a. Combining relational goals with directional care b. Ambiguities and tensions in HIV care c. Resistance and innovations in practice

5.1. Characteristics of Public Health Nurses in Case Management

In most public health units involved in the study, either one or two nurses were responsible for case management with people who test positive for HIV/AIDS. There was also little diversity among the characteristics of nurses involved in case management across the

province. For example, nurse participants identified primarily as Caucasian, heterosexual, and cis women (see Table 2). A lack of diversity among the nurses in a public health unit (PHU) was frequently mentioned as an issue. As one participant explained:

> And you know, it is an issue that we're all white women that work here. There are no men, there's no ethnic diversity. There's no MSM people that work here. And I think, ideally, that's what some of our clients would like to see. It just seems to be that's what we get for applicants. (P1)

The demographic characteristics of the people most at risk for HIV in each jurisdiction varied, but in most places, the profile of nurses did not reflect the diversity of the populations served by the health unit. The nurses responsible for following-up with people at risk or living with HIV tended to be one of the most experienced nurses on a team. In this sample, more than two-thirds of nurses had at least 15 years of experience as Registered Nurses, were 40 years of age or older, and had been involved in case management practice between 5-15 years.

Nurses explained that experience was necessary for navigating the challenges in case management related to living with HIV/AIDS in Ontario. One case manager with over 15 years of experience explained that "a lot of nurses get scared off by HIV" and experience in case management helped "not to be nervous yourself" (P18). A nurse at a different health unit further elaborated:

> I think that the angst is related to confidence, and I think sometimes the cases are such that, sometimes the situations are somewhat unpleasant and challenging. I think sometimes that people who don't have as much confidence are not as keen to take on those cases. (P13)

Confidence equated with "accepting being cross-trained or interested in becoming confident in that infection" (P14). Not every case management nurse on a health unit team was willing or interested in engaging with people at risk or living with HIV due to the difficult situations encountered in the follow-up of people who test positive for the virus.

Table 2

Demographic Characteristics of Nurse Participants

Category		**N = 22**
Age	<20 years old	-
(1996-1987)	20 - 29	3
(1986-1977)	30 - 39	4
(1976-1967)	40 - 49	5
(1966-1957)	50 - 59	8
(1958+)	60+	2
Gender	Cis woman	21
	Cis man	1
Sexual Orientation	Heterosexual	21
	LGBTQ2+	1
Ethnic Identity	Caucasian	20
	Asian	2
	Aboriginal	-
	African, Caribbean	-
	Latin	-
	Jewish	-
	Greek, Algerian, Arabic, Persian, Middle Eastern	-
Nursing degree(s)	Bachelor's Degree	20
	Master's Degree	2
	Doctoral Degree	-
Years of practice in	1	-
HIV Case Management	2 - 4	7
	5 - 9	4
	10 - 14	2
	15+	9
Years of practice as a	1	-
Registered Nurse	2 - 4	2
	5 - 9	3
	10 - 14	1
	15+	16
Formal Employment Status	Full-time	22
	Part-time	-

The fears of some nurses with participating in HIV care meant there were different levels of knowledge and skills among the case management nurses encountered by clients. One case management nurse summarized the effects as follows:

> Sometimes I just want to take all the cases, right? Because you know you have all the experience around it. So, I had to give a very hard case to somebody…I knew it was going to be a complete mess. And the managers gave it to somebody who just started doing HIV. It's not good for the nurse and the client. (P18)

A preoccupation with 'not messing up,' or rather, 'avoiding trouble,' was widely shared by the public health nurses participating in this study. Further information about the source of fears and challenges nurses experience, and how they shape nurses' decisions as well as tensions in the public health response to HIV/AIDS in Ontario, are evident in the description of the organization of case management, an analysis of current polices and the different steps used for follow-up at the point-of-care across the province.

5.2. Theme 1:

"Avoiding trouble:" Encouraging Conformity to Biosecurity Measures

A major theme in the practice of case management nursing with clients at risk or living with HIV/AIDS is "avoiding trouble." Functioning within a climate of "fear" and "angst," where people can be prosecuted for non-disclosure of their HIV positive status and where forced measures can be implemented in public health to promote partner notification and disclosure, has resulted in the development of nursing care concerned with helping clients avoid trouble. Within this climate, nurses also shared concerns about protecting themselves, and with being perceived as capable of protecting the public from the spread of the virus.

Central to case management nursing practice is ensuring each client understands the implications of "public health law" and "criminal law" for people living with HIV in Ontario:

> I like to show them the difference between public health law and criminal law…So, the criminal law is a criminal law, and there are things that if you don't follow, you could be charged. And the public health law is really the Public Health Act under the Health Promotion and Protection Act…The difference would be the criminal law might say, you know, that you don't have to disclose if your viral load is low and you are using condoms. But we feel in public health, we feel strongly, that you should always disclose and always use condoms, and take the risk down to as low as possible. And obviously that's very general and it does, in the pamphlets [we provide], talk about that the Medical Officer of Health does have the power to *Section* people for not following those directions. So, if you were having sex and not disclosing to anybody, you could get in trouble on two fronts really: criminal and public health law. Yeah, so I just say there is a difference, and one thing I'm going to tell you is what you have to do legally to avoid criminal charges, and the other is what we would like to see you do. (P1)

Nurses' concerns with describing the potential legal and public health consequences related to being diagnosed with HIV are not necessarily related to an endorsement of public policies around the criminal prosecution of non-disclosure of a positive HIV status. The aim of case management nurses appears to be helping clients avoid actions that carry additional personal and social consequences as they attempt to cope with their diagnosis. For example, another case management nurse explains that in counseling:

> I also phrase it in a way that I'm asking them to protect themselves…I want to be their ally too, right? And their healthcare provider as well, and the same for the person they're having sex with. So, I always phrase it in the form of, "You need to tell them in order to protect yourself. There could be legal implications." And I mention to them that I've seen partners charge other partners for not disclosing to the police, and it's a hard thing to go through. And while sometimes those things get thrown out of court, like if it's low risk like oral sex or something, it's still a nightmare to endure. (P18)

A nurse's concern with protecting a client from legal problems is almost always coupled with counseling about public health expectations. Public health expectations include adhering to legal guidelines as well as medical goals and measures for a "trouble-free" outcome. For example, the same nurse added:

> I also talk to them about medication that's available, and stress why it's so important that they take their medication properly and continue their relationship with their doctor. And I do say to people that the people that I see get into trouble are the individuals who stop going to the doctor, or for whatever reason, didn't want to deal with it. (P18)

Both criminal law and public health expectations are carefully explained as part of the counseling provided by case management nurses, and a nurse's interest in helping clients avoid trouble stems from an aim of protecting clients newly diagnosed with HIV from the harm that could result from not following, or *noncompliance* with, either pre-established legal and/or medical directions for HIV care.

Nurses' endeavors to encourage clients to conform to both biomedical and legal--or *biosecurity* measures--is also related to protecting themselves personally and professionally from harm:

> Following-up on a diagnosis can be seen as really emotional or heavy. I think it's a lot for nurses to try and navigate. I think nurses too are nervous about documentation, and what to do if a situation comes up, like if someone says, "No, I'm not disclosing," or things like that, where they might find themselves in a situation where things could go wrong. I guess those nurses might choose to stay in a safer element. (P22)

The potential of having to deal with the emotional and professional burden of managing the consequences of a client receiving a diagnosis of HIV and their noncompliance with disclosure of their positive status for example, are reasons public health nurses appear to be avoiding becoming involved in the case management of people with HIV. Among those nurses who do get involved in HIV follow-up, avoiding emotional and legal turmoil is a reason for making criminal and public health laws clear and encouraging conformity. Public health nurses who have experience with a client's case being brought to court for non-disclosure, brought to the attention of the local media, and/or managed with forced measures in the name of public health, recall such an occurrence in their careers as "a dark time" (P10). One nurse described the emotional burden of a case where things "went wrong" as:

> All those raw emotions! It's in the news, and the public knows about it, and you're just trying to protect them… And at the same time, you're worrying about the client too! Is he okay? Will he self-harm? He's a person! (P11)

Encouraging clients to conform with biosecurity measures has become the main means for nurses to protect their own sense of well-being and personal "safety" along with their clients.

Nurses justify their commitment to encouraging compliance with biosecurity measures as: "Then we've followed-up, and done our due diligence, right?" (P11). "Avoiding trouble" simultaneously refers to avoiding "wrong" doing professionally--in a workplace, a court of law, and in the court of public opinion. As one nurse explained, news stories and *Third Party Reports,* or complaints by members of the public, about clients accused of non-disclosure are not uncommon: "They're not shy here to splash your face on to newspapers, or televise you on the news, and it's happened many, many, many times" (P3). These events lead to questions about the due diligence of a public health unit with regards to upholding a duty to protect the public from the spread of infections like HIV/AIDS. Encouraging each client to conform to the biosecurity measures advocated by a public health unit has become an important theme in nurses' response to HIV/AIDS as it is one of the main strategies available at the point-of-care for helping clients, nurses and public health units to "avoid trouble."

"Avoiding trouble" and encouraging conformity to biosecurity measures is actualized by nurses in case management through: (1) mandatory engagement; (2) following a predetermined pathway; (3) explaining what is expected; (4) making it easy and making sure; (5) judging each individual's ability to conform; and (6) intervening with graduated intensity and forced measures.

5.2.1 Mandatory engagement

The engagement of public health nurses in case management is primarily based on the status of HIV/AIDS as a *reportable infection*. The "duty to report" a potentially infectious disease in Ontario is based on the Health Promotion and Protection Act (HPPA), where it is stated that a healthcare provider who "forms the opinion that the person has or may

have a disease of public health significance shall, as soon as possible after forming the opinion, report thereon to the medical officer of health of the health unit" (R.S.O. 1990, c. H.7, s. 25 [1]). The HPPA (1990) further describes the "mandatory health programs and services" each public health unit is responsible for providing, and these include: "Control of infectious diseases and diseases of public health significance;" and "Health promotion, health protection and disease and injury prevention, including the prevention and control of cardiovascular disease, cancer, AIDS and other diseases" (R.S.O. 1990, c. H.7, s. 5). When public health nurses initiate contact with a client for the purpose of case management, they start by explaining that public health follow-up is mandatory following a diagnosis of HIV/AIDS based on the HPPA (1990).

Across the province, nurses enter into relationships with clients with a similar introduction: "Typically if I reach them by phone, and I haven't met them before in the clinic, I'll identify myself and my role as a public health nurse, and how we follow-up on reportable infections" (P10). While engagement with a public health nurse in a clinic for counseling about HIV/AIDS in the context of sexual health or HIV testing is voluntary, when a test for HIV is reactive, public health nursing intervention becomes "obligatory." At that point, nurses explain to their clients that the engagement of public health with their care is mandatory as it is linked to special legislation. This is made clear in policies for case management that indicate the need for nurses to "Review HPPA" including how it "provides the legal basis for engaging in case investigation and contact follow-up activities for reportable STIs in Ontario" (POL2b). In practice, nurses say:

> I would use a sensitive approach, and state what a public health nurse does, and tell them about the Health Promotion and Protection Act, and how the result comes automatically to public health, and as a nurse, I'm obligated to follow-up with you and make sure you're well, and everyone you're with is well. (P12)

Nurses then generally describe the parameters of the Health Promotion and Protection Act (1990), and the aim of "mandatory engagement" with public health:

> We'll say, "It's a reportable infection," and I always talk about that there's certain parameters that we have to do, that we're mandated by the government to do. So, we talk about those things like: we make sure your healthcare provider knows; they offer treatment; and then part of it is also connecting with people who may have been at risk for getting this infection. I always approach it like, "We know you don't want this to spread, and that's the mandate of public health." (P11)

In essence, each client is informed that a diagnosis of HIV/AIDS means their involvement in HIV care is no longer solely their prerogative, but subsequently lies within the territory of the provincial government*,* by the authority of the HPPA (1990), administered through public health, and overseen by nurses responsible for the case management of infectious diseases.

Case management is subsequently organized around the mandate of the HPPA (1990), namely the "control of infectious diseases" and "health protection," through mandatory reporting of new cases of HIV/AIDS and engagement of nurses in the follow-up of each case. In public health policies and practices for people living with HIV, case management officially starts with the notification of a health unit of a diagnosis of HIV/AIDS. For example, as one policy notes:

> Cases shall be reported using the integrated Public Health Information System (iPHIS), or any other method specified by the Ministry within five (5) business days of receipt of initial notification as per iPHIS Bulletin Number 17: "Timely Entry of Cases." (POL2c)

Across the province, when nurses were asked how case management starts, the response was similar: "I guess it would be a positive lab. It comes in by fax, and the secretary would notify the nurse. We just usually verify that it is a new case" (P1). Another nurse elaborates: "So for HIV, the lab is entered in iPHIS by the data clerk so that the encounter is created, and they let us know that an HIV is coming." Therefore, case management begins with a client's "positive lab" result for HIV. A client officially becomes a "case" when their laboratory result is entered as "an encounter" in the provincial data base used for

surveillance, or *integrated Public Health Information System* (iPHIS), and forwarded to a nurse for follow-up in a public health unit.

Notably, while all people with HIV are referred to as “clients” in case management, in many official policies, several terms are used throughout to define “a case.” In three policies, a case was simply referred to as “the individual” (POL1a; POL3a; POL7a). However, people who enter into the domain of case management are primarily referred to in terms of the reportable infection for which they were diagnosed. In some policies, they are “the index case” an epidemiological distinction used to identify the first documented case of an infection or communicable disease (POL13b). Other terms used include “the individual infected with HIV” (POL1a; POL8; POL10; POL12); “the HIV positive client” (POL1a; POL8; POL10); “the HIV case” (POL1a; POL4; POL13b); and/or “a confirmed HIV/AIDS” (POL7a). Whether inferred or directly referred to in policies or practices, the root of the definition of “a case” in case management appears to be the medical and laboratory parameters for a diagnosis of HIV/AIDS. The connection between “a case” and an individual’s “diagnosis” with HIV/AIDS is clearly described in one policy where case management begins with the “case” definition shown in Figure 4. The “case definition” in

2.0 Case Definition

2.1 Confirmed case of HIV infection:

2.1.1 Children less than 18 months – lab confirmed PCR or p24 antigen in 2 separate samples collected 1 month and 4 months after delivery.

2.1.2 Adults, adolescents and children greater than eighteen months – lab confirmed HIV antibody or p24 antigen.

2.2 Confirmed case of AIDS:

2.2.1 A positive test for HIV infection with confirmation and definitive diagnosis of 1 or more AIDS indicative diseases.

Figure 4:
Case Definition (POL16c)

this policy mirrors the definition for a "confirmed case" on iPHIS, the electronic surveillance system managed by epidemiologists in a public health unit. The conceptualization of "a case" used by nurses in case management aligns, not exclusively but predominantly, with the medical and epidemiological definitions of a case expressed primarily in laboratory terms in a public health unit.

The "purpose" of case management stated in policies is also expressed in terms of a person's laboratory result. As clear in Figure 5, the purpose of case management is "the follow-up of positive HIV and AIDS reports," or follow-up of the virus. The goal of engaging with clients using a *virus-centric approach* is subsequently linked to the HPPA (1990). As further stated in another policy, engagement is "required under the HPPA to decrease the spread of infection" (POL16a). In nursing practice, *mandatory engagement* is mainly conceptualized as the required entry of a person into the domain of public health via their medical diagnosis with HIV/AIDS, for the purpose of containing the spread of the virus with public health methods authorized by the HPPA (1990). The nomenclature used to define "a case" and to describe the purpose of case management portray a client's engagement as both a legal requirement and an extension of a biomedical indicator--evidence of the virus in their body--notwithstanding a variance which suggests "the individual" is also the focus of engagement for public health nurses in HIV care.

5.2.2 Following a predetermined pathway

In Ontario, the "management" of cases also centres around the virus and the goal of controlling its spread. As one public health nurse explains, "Each infection has its own policy" (P13). Within the Policy and Procedure for each infection are the steps for how a health unit expects it to be managed:

> Upon receiving a new STBBI report, the PHN must complete the necessary steps for case management and contact follow-up, as indicated in the Policy and Procedure for the specific infection. (POL15f)

HIV Case Management Policy

Purpose:

1.0 To describe the methods used in the follow-up of positive HIV and AIDS reports.

Policy:

1.0 To follow-up positive HIV and AIDS reports in (NAME OF JURISDICTION) as indicated in the *Ontario Public Health Standards* (2008, or as current), the *Sexual Health and Sexually Transmitted Infections Prevention and Control Protocol* (2008 or as current) and in accordance with the *Health Protection and Promotion Act* (1990).

Figure 5:
The Purpose of Case Management in a Nursing Policy (POL16c)

Nurses responsible for case management are divided onto teams by a title that corresponds with the reportable infections from the Policies and Procedures that they are trained to manage in practice. In some health units, the nurses responsible for case management with training around a variety of reportable infections, including HIV, are called, Communicable Disease (CD) Investigators or Infectious Disease (ID) Nurses. In other locations, reportable sexually transmitted and blood borne infections (STBBIs) are separated from other communicable diseases reported to public health, and nurses involved in the case management of people with HIV in those health units are subsequently referred to as STBBI or STI Nurses.

It is also common for nurses to refer to case management, itself, in terms of the infection specifically targeted with their practice. This includes, for example, the follow-up of positive HIV test results being equated with “HIV case management.” The division of case management by infection is most evident in nurses’ description of their training. One public health nurse explained, for example:

> So, I learned from the woman who did it before me…I was already doing Chlamydia, Gonorrhea and Hepatitis B case management. So, it was just learning about HIV. (P21)

The organization of case management nursing around the specific infections that a health unit aims to control with public health measures is consistent regardless of the title of the nurse or team.

Nurses involved in case management may be positioned on any of the following teams, divisions, and departments, depending on the public health unit: Sexual Health (SH) Team; Communicable Diseases (CD); the Health Protection Division; Healthy Living Division; Health Promotion and Prevention; the Community and Health Services Department; Clinical Services; and/or Public Health Programs. However, the role of nurses and steps used for case management practice described in policies is in many ways the same. Generally, the nursing care of people with HIV involves following the movements of a client from the time of their entry into HIV testing services, through the provision of post-test counseling, until the completion of a client's and their contacts' engagement with the surveillance system of a public health unit. Therefore, the scope of a public health nurses' follow-up with people with HIV encompasses an awareness of a broad array of:

> …guidelines for human immunodeficiency virus (HIV) infection, including screening; assessment; testing; processing of reactive results; pre- and post-test counseling and case management, including contact tracing; and iPHIS documentation for surveillance purposes for both Sexual Health Clinic Clients and Community Clients. (POL3a)

The domain of case management includes understanding, tracking and engaging clients in terms of their HIV status through the process of screening, testing positive, learning and receiving counseling for their test results including how to prevent the spread of the infection to others and where to obtain specialized care for the virus, and the on-going monitoring of their individual progress with infection control via public health's surveillance system.

A predetermined pathway

The linear pathway or steps in HIV care envisioned for clients in public health policies, and the place where case management is situated along the spectrum of an individual's engagement in HIV care, are reflected in the overall physical organizational structure of a health unit. Across Ontario, a wide variance in architectural details exist across public health units. For example, some buildings are new and built especially for housing a public health unit, while others are renovated office spaces or government buildings (e.g. a defunct prison). Some health units are strategically located in satellite buildings in a city's downtown core near shelters for people who are homeless, and others are in large venues on main roads and public transit routes or next to other government offices, including federal health programs and local police stations. Internally, however, the organization of public health units share common features.

In all health units, the public enters into a waiting area where administrative assistants are often the first to receive a client, and responsible for sorting each case and arranging their encounter with the appropriate member(s) of the public health unit team. A health unit's clinic area is often the most prominent space in that it is the area most open to the public. In a separate area, out of site from the public but in a large room close to the clinic, is typically the space where nurses responsible for reportable STBBIs, including HIV, on the CD or Sexual Health (SH) teams are situated. CD or STBBI nurses involved in case management generally work in cubicles separated by infections but open to communication with other CD or Sexual Health team members. In walled off spaces next to the public health nurses who provide direct care for people are the managers of their team, which are sometimes nurses but can also be inspectors, health promoters, or have other public health backgrounds. In a separate section, and occasionally on a different floor or other building, are the epidemiologists, health promoters, and other public health nurses responsible, for example, for vaccine preventable diseases, nutrition, school health

or “healthy babies” programs. The AMOHs and MOH can be found in private offices on yet a separate floor of a health unit, a different building and/or another city. This configuration with its compartmentalization of team members within a health unit supports the typical one-way flow of a case from an administrative assistant, through a clinic, to case management nurses, into the domain of epidemiology, and in specific circumstances, into the realm of team managers, the AMOH, and/or the MOH for further direction.

A hierarchical order

In this arrangement, case management can be summarized as a segment of mandatory care along a linear pathway between the screening of a client in a clinic and the ongoing surveillance and evaluation of a client’s success in controlling an infection that is reportable to public health. In one policy (POL13b), for example, the segment of HIV care that falls within the domain of case management is:

> To investigate each case report of HIV / AIDS in order to ensure the client is:
> -Properly informed about their infection
> -Connected to appropriate clinical support services
> -Aware of preventative actions required to minimize spread of infection

In effect, *HIV case management* consists of the measures undertaken with a person living with HIV by a public health unit, *between* their visit to a health care provider for an HIV test and the authority of an MOH in that jurisdiction, in response to the individual’s progress in reducing the threat of the virus to the public. The present layout of each health unit reinforces this position, with its compartmentalization of case management nurses in cubicles between the clinical care area and other health promotion and disease prevention teams, and with its social construction of physical space between case management nurses’ place near the “frontline” at the point-of-care’ and the walled-off and/or distant offices of team members responsible for surveillance including those with the most authority over how cases are managed.

Variations in the positioning of case management nurses in public health units across the province mirror changes in the focus of HIV follow-up in public health over time. As one experienced public health nurse reflected:

> Years ago, it was 100% funded by the Ministry, and it was a nurse that didn't even do clinic. She was full time HIV, and that is all she did. And then we needed more help in clinic, so she started going over and started doing half-time HIV and half-time clinic. Over time the position has changed, and even now, it has sort of lost its importance. I don't know if I want to say it was 'important,' but it was a distinctive role and now it isn't. I would suspect it's partly lost its funding, that's part of it, and the epidemiology, and the fact that the nurse used to initially do a lot of support because people were going to be dying. But now they are healthier, and they don't need that much support, it's sort of changed. (P6)

The roles and expectations of case management nurses have shifted over time in accordance with the views of provincial and health unit administrators about the priorities in the epidemic and the needs of a health unit. The roles of public health nurses and organization of case management tend to be restructured around changes in the incidence and prevalence of infectious diseases illuminated by surveillance, and decisions in a health unit about where to place nurses in order to respond.

A previous restructuring trend in Ontario involved the separation of the follow-up of reportable STIs, including HIV, from the follow-up of other infectious communicable diseases (ICDs). Simultaneously, nurses elsewhere raised concerns about an opposite restructuring trend, the integration of STI case management with the management of all other reportable infectious diseases:

> I guess every health unit is different, but they plan on integrating us. So, we'll all be doing food borne [infections] along with the STIs eventually…but my personal thoughts are… that if you spread out all those different cases to the group, your ability to learn becomes diluted, and you're not going to have that experience to get to where our senior nurse is now who is training me to do HIV. Having that background, that sexual health background is huge. Like, it's quite different talking to someone with HIV, or their partner that needs to be notified than it is talking to someone about a foodborne illness. It's a different skill set. (P3)

In some places, the role of nurses responsible for STI case management is viewed as separate from their clinical role in the public health unit's sexual health program, despite the views of the majority of nurses in those units that the two roles are related or fluid. Notable was that neither the decision to integrate the work of case management into the broader context of sexual health, nor separate nurses responsible for HIV follow-up from the sexual health nurses' clinical role appear to be made with the input or in relation to the needs of case management nurses responsible for providing "frontline" care.

In most cases, case management nurses are not quite clear about the reasons behind the current structure of their health unit. The distance of public health nurses from the arena where decisions are made about the organization of case management is evident in one nurse's description of the process involved in restructuring who claimed:

> And this was determined by management that the STIs would go into communicable diseases, so that they would have a bigger pool of people to draw on if there's a big outbreak of something. That was the philosophy we were told as to why we were going to be broken up. (P3)

There are also no guidelines in the HPPA (1990) about the organization of health units, the position of case management in relation to the "frontlines" of care, and the steps to be used by nurses for the follow-up of reportable infections; only the hierarchy for decision-making about programming is made clear. According to the HPPA, the Ministry of Health and Long-term Care (MOHLTC) "may publish public health standards for the provision of mandatory health programs and services and every board of health shall comply with them" (R.S.O. 1990, c. H.7, s. 7[1]), and the MOH is subsequently responsible to the board of health "for the management of the public health programs" (R.S.O. 1990, c. H.7, s. 7[3]). Therefore, what is considered "mandatory" and "optional" in the management of reportable infections, structure of case management, and the involvement of nurses in decision-making is largely under the authority of the board of health and MOH in each jurisdiction (HPPA, R.S.O. 1990, c. H.7, s. 9).

Maintaining order

In practice, the policies and procedures used for case management are created with varying degrees of input from the nurses involved in HIV care. The inclusiveness of nurses in the process of deciding the focus of "management" in policies is dependent on the approval of the manager and MOH. According to one nurse, "For years I did the policies for case management and they would go through the manager and anywhere else they had to go" (P2). Similarly, in another health unit:

> It was us who did it, and this is going back almost 20 years. Our old AMOH was really quite great at sitting and ensuring that frontline staff had input in policy. It might not be that way now. But [the policy] still stands... So now it's all kind of laid out in there. So, it's good for people, because they can just look things up. "Okay, so I found this, tried this, and I've gone nowhere. Okay, I'm going to look to see what the policy has to say." And the nurse in training has the two manuals for clinic, the Policy and Procedures for case management, and then works with you until you see they are comfortable with clients and they feel confident…We'll go through the orientation checklist and make sure that all these 100 points were covered. (P14)

In some health units the nurse responsible for the case management of people with HIV is also responsible for writing the Policy and Procedures manual, while in others, a member of the case management team who no longer provides direct care is appointed as responsible for the maintenance of the team's policies. In general, the responsible nurse documents the steps used in practice as policies, and the final format is based on the approval of a manager and MOH. Policies are also arrived at by collecting the guidelines in use at other health units and adopting the practices that fit best with the needs and concerns of the team.

Therefore, the final content of *Policies and Procedures* for case management reflect: the latest "priorities" of the Ministry of Health and Long-term Care and boards of health; the practice issues and solutions discussed among nurses, managers, and the A/MOH; and the decisions that are approved for practice by the MOH and preserved through their documentation as guidelines for nurses about how to "do" case management

(P17). The guidelines, or agreed-upon measures for case management, are passed down to the nurses who provide HIV care through the orientation and training of each nurse. "Checklists for policies and procedures," "cheat sheets" or *scripts* for counseling, and "flow charts with how to follow-up" (P9), as well as "shadowing" and "mock interviews" (P14) are techniques used in training to assist nurses new to HIV care to learn the guidelines for case management and implement them accordingly in practice. After their initial training, nurses might also return to the guidelines in policies to support their decision-making as new issues arise. In these ways, the policies offer a predetermined pathway for nurses to follow in their practice; as explicated by one nurse, "If they are pregnant, do this. If they are not, then this. So, it's all laid out in that sense" (P9).

The primary focus of nurses in the public health response to HIV and guidelines being implemented in the "management of cases" are shown in Figure 6, the Policy and Procedures for case management of one health unit. In another document created for public health nurses, the follow-up of reportable STIs, including HIV, is illustrated as a "process algorithm" showing three similar measures common to all STI case management: the completion of education/counseling; identification of sexual contacts; contact/partner notification (POL12a). As one nurse explains: "We see, really, STIs as the same, only HIV you go a step further" (P13). For example, counseling people who test positive for HIV about the duty to disclose to future sexual and needle sharing partners is one "extra" step that is unique to HIV case management.

The steps for case management

In order to complete the *management* of HIV, five steps appear to be consistently followed in health units across Ontario: (1) Verifying a positive laboratory result; (2) Contacting the testing clinician's office; (3) Contacting the index case; (4) Partner notification; (5) Entering surveillance data.

Management of Cases

Primary focus of HIV/AIDS case management is to:
- Counsel regarding ongoing transmission risks;
- Counsel regarding duty to disclose to future sexual partners and needle sharing partners;
- Carry out partner notification;
- Link the case to appropriate resources and treatment; and
- Offer testing for other STIs, hepatitis and tuberculosis where appropriate. (POL2c)

Figure 6:
The Management of Cases in a Nursing Policy (POL2c)

Step 1: Verifying a positive laboratory result.

The first step of case management is usually to verify that the laboratory result received by the public health unit represents a new case: "That would be one of the first things: confirm, confirm, confirm" (P17). Nurses "start by logging on to iPHIS" (P2) and checking whether or not the test result matches the criteria of the "case definition" used for HIV/AIDS. One nurse described the process of verifying a positive laboratory result as:

> We just usually verify that it is a new case. It may be an indeterminate result, right? The secretaries don't want to deal with trying to decide that, so she gives it to me, and I go on iPHIS and look it up, and look on our old files to see if there isn't a similar name, and make sure it's an actual new one. Usually at this point, the nurse would also call the doctor, just to kind of start the process…If it's a closed case, one that's already been counselled, we wouldn't do anything. (P1)

Case management subsequently proceeds as follows: "Sign into iPHIS, get your files, and while the program assistant comes around the corner and delivers and picks-up new and old cases, (start) calling docs, calling clients, doing entries" (P2).

Step 2: Contacting the testing clinician's office.

The second step of case management is to "contact the physician's office" or the person listed on the laboratory report as the healthcare provider responsible for ordering the HIV test. Case management nurses are expected to contact the ordering healthcare

provider by telephone or, in a few health units, by faxing a letter containing a checklist for the healthcare provider to complete. The aim of this step, as one nurse explains, is "to confirm, and find out if the client has been notified, and ask a bunch of different questions like if they know some of the risk factors, before you get started" calling the client (P16). Figure 7 illustrates the guidelines for follow-up with the testing clinician as they appear in the Policy and Procedure manual for case management in one public health unit.

Nurses verify that the demographic information on the laboratory report received from the healthcare provider is correct and complete, and request information about the client's risk factors for HIV/AIDS (i.e. a social history including the types of sexual contacts or experiences sharing injection drug equipment in the past). Nurses also ask if any medical treatment was provided to clients co-infected with a reportable disease, and whether or not a client has been notified of their positive test result(s). Nurses request this information to help them prepare for the next step, their follow-up with the index case.

2.0 Client follow-up

2.1 If the infection was not diagnosed at the Public Health Unit Clinic, the staff member will contact the physician's office for more information about the case including:

- -Additional demographic information;
- -Signs and symptoms;
- -Risk factors;
- -History or receipt or donation of blood, blood products, or other body materials.
- -Laboratory testing that has been performed;
- -Treatment if any;
- -Contacts who are known to the physician;
- -Social circumstances;
- -The physician's plans for referral to specialized care;
- -Other relevant information.

2.2. The staff member will discuss notification of the client with the physician. If the physician has not yet informed the client and wishes to do so, the Clinic staff member will wait the agreed upon interval prior to contacting the client.

2.3 After the agreed upon interval, the staff member will contact the client and arrange for a visit to the Health Unit or home visit for counseling.

Figure 7:
Guidelines for Contacting the Ordering Physician (POL10)

In nursing practice, for example, the conversation with the healthcare provider who ordered the HIV test might include:

> Well, why they tested, the reason, and are they aware of their test result? And, what are the next steps? So, for us in particular, and the patient themselves, are they going to be referred? Are they having any kind of issues as far as support needed? If the education is done or not done, that would be a big step for us too, and what we're going to be doing. Are we doing the partner notification? (P3)

Enquiries are made about whether or not the client was referred to an Infectious Disease Specialist or other service provider, any follow-up was completed with people who might have been exposed to the infection from contact with the client, "and then if we [nurses] are going to be responsible for contact tracing" (P1). These subsequent questions help anticipate the kinds of additional counseling or support nurses might need to include when counseling the index case to ensure they continue along the predetermined pathway from testing for HIV to receiving the medical treatment needed to control the virus.

Step 3: Contacting the index case.

After verifying evidence of the virus on the laboratory report and ensuring the index case was notified of their HIV positive test result, the next step in case management policies is to follow-up with clients, as shown in Figure 8. In relation to the sequence of steps for managing a case, one nurse said, "Usually, that's when we call the client, when we know they've been told. That's our main thing" (P1). The focus of the third step, contacting the index case, continues to be virus centric. The priority is "to let them know that you have tested positive for the HIV antibody and that means you've got the virus, and this is what it means" (P4).

Utilizing the demographic information shared by the testing clinician, nurses say, "We call every single case. Unless, they are lost to follow-up, we will speak with them." An example of a call to a client and the measures taken to protect their privacy were explained as follows:

PUBLIC HEALTH NURSE [PHN] FOLLOW-UP

1.0 PHN contacts index case after discussing details with physician. PHN documents attempts made to contact index case by telephone and letter. If unable to contact case, discuss with program supervisor as to course of action.

2.0 PHN will review the following issues with the client and document in the client record:
- 2.1 Nature of infection
- 2.2 Transmission risk behaviours including sexual practice, injection drug use, tattooing, piercing, receipt or donation of blood or body organs
- 2.3 Other STI testing – syphilis, Hepatitis B & C, TB, chlamydia and gonorrhea
- 2.4 Hepatitis A and B vaccine if not immune and indicated
- 2.5 Partner notification plan – case of PHN
- 2.6 Legal issues
  - Consistent condom use for oral, vaginal and anal intercourse/contact exchange
  - Disclosing HIV infection to all sexual partners
- 2.7 Other risk reduction behaviours
  - Never sharing sex toys
  - Using clean needles, equipment and straws for drug use (needle exchange)
  - Prenatal HIV testing – follow up to prevent spread to infant
  - Never share razors, toothbrushes, scissors or other personal hygiene tools
  - Availability of Post Exposure Prophylaxis drugs for up to 72 hours after an act of unprotected intercourse (go to nearest ER or consult with Infectious Disease Specialist
- 2.8 Referral to local addiction services or PHN for further support
- 2.9 Regular medical and Infectious Disease Care Program follow-up

3.0 PHN assists index case to trace contact(s) using the following time frames:
- 3.1 from previous negative HIV test if one is available,
- 3.2 from a particular exposure, or
- 3.3 as far back as the client can remember starting with the most recent contacts.

4.0 If contacts are anonymous, strategies are explored with client as to how contact tracing might occur.

5.0 PHN advises index case of importance of partner notification and consequences of failing to notify contacts.

6.0 PHN offers condoms and harm reduction supplies as indicated.

Figure 8:
Policy for Public Health Nurse Follow-up with an Index Case (PO13b)

> So really our approach is the same with every client, whether HIV or chlamydia. We say who we are. We verify who they are. And then we'll say, you know that it's confidential information that we want to talk about. Then we ask them to verify their surname and date of birth. And we'll go forward from there. (P3)

When introducing themselves to an index case by telephone, public health nurses first confirm they are speaking with the client, then explain that the “nature of the call” is the case management of their HIV positive test result. Then, as one nurse adds:

> …we’ll let them know that we’re going to talk about “how to keep you and other people safe, and we’re going to talk about how to get treatment, and we’re going to talk about your legal obligations.” (P1)

The aim of the first phone call is to ensure the client is aware of their HIV positive diagnosis and risk to others, and to arrange an appointment to meet, in person if convenient, to discuss the guidelines for managing the infection.

The “nature” of a first follow-up telephone call to a person newly diagnosed with HIV was described by one public health nurse as follows:

> Well, typically I would say, “Well I understand that you saw Doctor so-and-so, and had some testing done. And public health has been notified that you tested positive for HIV.” And I will say, “And you've been informed of that, is that correct?” And then I will say that, “Public health has a role, in terms of HIV, to ensure that you understand your diagnosis, and that you understand how HIV is transmitted and not transmitted, and to make sure that you’ve been referred to the care and supports that you need. Do you have time that you can talk with me?” And then you know, 50% of the time they'll say, “No, my kids are here,” or “I’m on the bus,” you know, and so I will negotiate a time that we can talk. (P5)

The priority of public health nurses’ follow-up with an index case is to engage them in counseling about their risk factors, risks for transmission, the contacts potentially exposed to the virus, the duty to disclose their HIV positive status with subsequent sexual and needle-sharing partners, and how to obtain support and treatment to reduce the legal and medical risks of living with HIV/AIDS.

The priority in counseling is to discuss what is of interest to 'public health.' The focus in counseling on the public health unit's predetermined priorities is most evident in one nurse's description of what is discussed with clients:

> Yeah, so I would call them, and I would review the information needed for HIV surveillance. I would review the post-test counseling that's been offered by the physician with an emphasis of, "Have you been referred to specialist care?" And we're lucky to have a specialist clinic in town. So, "Have you been referred to care?" And if they haven't been, then we will do it. But a big part of it is the partner notification, collecting the names, review of safer sex expectations, and disclosure. Of course, we review, you know, tear up your organ donor card, don't be a blood donor, and all of what can transmit and what can't transmit HIV. We review all the health teaching for sure, but the public health emphasis would be on disclosure, safer sex and partners. (P5)

The content that is considered essential or deemed extra in the follow-up of a person with a positive HIV result is dictated by the health unit's policies. As explained by a different nurse about her recent experience in counseling:

> We hit briefly every major point I wanted to get out just in case he didn't come to see me in person. So, disclosure, legal implications, reason for testing, abstaining, and then we had the partner notification discussion…Yeah, we mostly touched on everything, um, following the guideline mostly about what's a priority now to talk about, and then what can come later. (P16)

In a virus-centric approach, ensuring an index case is made aware of how to obtain medical treatment and prevent transmission, as well as their duty to disclose and notify all partners potentially exposed to the virus is viewed as "essential" to public health nursing follow-up with an index case.

The emphasis in counseling on the medical and legal measures a client should take to protect themselves and the public, are a reflection of expectations on public health nurses to focus on medical and legal risks and consequences, or biosecurity concerns and measures, in their follow-up with clients:

> As a minimum, not necessarily with the health care provider, but when we're talking with the client, we would hit certain parameters mostly to do with the educational piece, partner notification and disclosure. The bottom line, drilled into our heads, is that we have to get to that eventually, be it at the first call, second call, third call… (P3)

Despite having training and an interest in engaging clients in counseling about a broader array of topics in the HIV response, nurses' follow-up with clients is shaped by a pre-established consensus captured in the Policy and Procedure manual of a health unit about what is "essential" to discuss when engaged in case management. The "parameters" of counseling are established according to the hierarchical order outlined in the HPPA (1990), operationalized in the various processes of decision-making in a public health unit, and preserved in the content that remains as guidelines in the policies used in nurses' practice. Therefore, the experience of nurses when counseling clients of feeling "always under the pressure of what the minimum is that has to be done" (P2), can be viewed as an extension of the hierarchical structure delineated in the HPPA (1990) and subsequent boundaries established around nursing care by the way the legislation is currently interpreted and operationalized across the province. The organization and policies presently in use in public health appear to be compelling nurses and clients in Ontario to feel obliged to follow a predetermined pathway based on "certain parameters," namely biomedical and legal concerns, when meeting to discuss how to "go forward" after a diagnosis of HIV/AIDS.

Step 4: Partner notification.

In the policies for case management, it is clearly stated that public health nurses are obligated to ensure each index case is counseled about the "importance of partner notification and consequences of failing to notify contacts" (POL13b). Discussions with clients about partner notification are linked in practice to contact tracing and disclosure counseling. The importance of contact tracing, partner notification and disclosure counseling for informing partners of clients of their potential risks for HIV is understood in terms of its medical value. For example, in practice, clients are told that notifying a contact of their potential exposure is:

> …very important because the infection could continue to spread to other people especially if that person happened to become HIV positive and does not have any idea. That's a really high-risk time for transmission. So, one of the ways we prevent the spread of the infection to other people is by letting them know and explaining where they can get tested. (P21)

Clients are made aware by nurses that, "what we're trying to do in public health is reduce the rate of infection, and the highest risk time of people transmitting HIV is when they don't know they have the infection" (P21). Informing people of a known potential exposure so that they might feel compelled to engage in screening and other measures to help prevent the transmission of HIV is viewed as an effective means of controlling the spread of the virus.

Contact tracing, partner notification and disclosure counseling are therefore considered essential to the follow-up of reportable infections in public health, because they are viewed as medical and "ethical and legal responsibilities." In one policy, it is written:

> Public Health has ethical and legal responsibilities to inform known persons potentially exposed to a communicable disease. There is also a legal and ethical obligation to protect the confidentiality of persons infected with a communicable disease (HPPA). (POL16c)

One strategy used by nurses to fulfill the ethical-legal obligations of a public health unit is to counsel clients about the following medical and legal consequences:

> Usually what we will tell them is that, "It is very important that any current or future sexual partners are notified of your diagnosis, because if you were to not notify them, and later they found out you are HIV positive, it's possible, apart from public health, that person could go to the police and there could be a criminal investigation. That wouldn't be instigated by public health, but it is possible. "So, in order to avoid that, because the last thing we want to happen to you is for a criminal investigation to take place, it's very important that you notify all your partners." (P5)

Public health nurses undertake their "ethical and legal responsibilities" by encouraging clients to conceptualize contact tracing, partner notification and disclosure as a means of avoiding a criminal investigation into their moral and legal conduct. The concern of a public health unit with the moral conduct of clients and decision to mandate partner notification and disclosure is grounded in concerns about consent and an assumption that

a contact's right to know their risk outweighs the risk of harm to individual cases in sharing their positive HIV status. In practice, nurses explain, for example: "I always approach it like, 'We know you don't want this to spread, and that's the mandate of public health. You probably would have appreciated it if someone mentioned it to you.' We kind of go down that road" (P11).

Therefore, contact tracing, partner notification and counseling clients about the need to disclose their HIV status are medico-ethico-legal concerns, or biosecurity measures, included in case management to "reduce the rate of infection" of HIV/AIDS. In the Policy and Procedure manuals for case management, the process of contact tracing and partner notification is defined as "the process of identifying relevant contacts of a person with an infectious disease and ensuring that they are aware of their exposures" (POL12a). In this process, the role of a public health nurse is to:

> Obtain full names of all sexual and needle sharing partner(s) who can be identified including last known address and telephone numbers or profile names on website. All partners prior to diagnoses (or last negative test) must be notified by public health regardless of notification by index case. (POL2b)

The strategies used at this step of case management depend on the guidelines in place in each health unit and the clients' situation. As one nurse explains:

> So, with Chlamydia and Gonorrhea, for example, if the client says, "I will notify my partners," we leave it at that. But with HIV, we collect partner names with all new diagnoses. So even if individuals say, "I want to tell my partners," we say, "Great, fair enough. You go ahead and do that, but let's negotiate. In one week's time, I'm going to call the partners to ensure that notification has taken place and to answer any questions they might have." Not all health units do that as well. Some health units, even with HIV, leave partner notification up to the individual. (P5)

A nurse from a different health unit also stated, "Our AMOH actually wants names. He'll push it for Gonorrhea, Syphilis and HIV. He won't push it for Chlamydia," and clients are given the opportunity to notify the people at risk, "but then we want to talk to them ourselves" (P4). In practice, nurses describe the options to clients as established by their individual health units in the following manner:

> I just try not to be too pushy about it. I just try to explain to them that it is our obligation to follow the Act [HPPA, 1990], and that we do need to notify people. In the case of HIV, you can notify your own partners, but I need to also confirm that you did that. Now whether you tell me, you give me their information, or whether you give my information to your contacts and they call me, we usually prefer one or the other. (P1)

Clients who opt to inform contacts on their own are provided further counseling about what a public health unit expects will be included in the process of partner notification, as shown in Figure 9. Generally, the role of a case management nurse is to ensure that all contacts are notified in a manner consistent with a health unit's guidelines, or rather, provided information deemed important from the perspective of a public health unit, regardless of who assumes responsibility for the task: the testing clinician, the case management nurse, or the client.

From a public health nursing perspective, the decision about who will notify a client's contacts is a matter of "safety." As one nurse observed, "Sometimes they're worried that the person is going to figure out it was them and there's going to be a backlash and they might get outed." (P6). Nurses will then explain to clients the measures in place to help protect each client's identity and protect them from undue harm:

If the client decides to notify their contacts on their own, they will be advised of the importance of contact notification and the consequences of failing to notify contacts.

They will be supported in how to notify contacts. They are advised to provide the following information to their contacts:

- -Inform the contact that the client has HIV, the nature of the disease and methods of transmission;
- -The contact should be tested as soon as possible, and abstain from sexual Intercourse until appropriately tested;
- -Testing is available through their family doctor or the PHU at the Clinic.

If the client decides to notify their contacts on their own, the Clinic staff member follows-up with the client at the next visit to ensure that the notification has occurred and offer further assistance to the client.

Figure 9:
Guidelines provided to an Index Case for Partner Notification (POL10)

> First of all, we only tell people that they may have been in contact with HIV, and that we offer testing, and then explain how they can get tested. We never connect a name to it. And sometimes we suggest the contact tracing might actually be done by a nurse that doesn't even know who the index case is, other than their phone number. (P11)

However, in verifying the notification of partners and whether or not disclosure has occurred, it can be difficult to maintain control over the confidentiality of the client when there are only a few contacts involved. In response to clients' concerns about a nurse's ability to help preserve their anonymity, nurses agree, "Yeah, that is challenging, but what we have to be is honest and say, 'There may be the possibility that a person may figure out that it's you, but we will never confirm that. It won't come from us'" (P5).

Nurses are subsequently resigned to the current reality in public health practice that partner notification and disclosure can be "scary" for clients as these measures create the conditions under which they may lose control over who is aware of their HIV positive status and what is done with the information. As one nurse proclaimed, "But unfortunately right now, that's what we're working under, the Health Promotion and Protection Act. Whether it's right or wrong, it's there for a reason" (P1). When public health nurses "give clients the opportunity to do their own contact tracing and negotiate" how contacts will be informed, they are understood to be trusting the domain of case management to clients and implementing strategies that will "empower the client to take control of their health" (P9). From a public health nursing perspective, allowing clients to notify their own partners is viewed, in part, as a way to allow people with HIV to take the measures they need to protect themselves from undue harm while participating in the case management process of protecting the public: "Whenever they feel they can safely notify the partner they can do so and then just let us know" (P10). Clients are described their options in *disclosure counseling* for similar purposes. When clients are counseled about their duty to disclose their HIV positive status, they are told, for example:

> Like, you don't have to tell your minister. You don't have to tell your boss, but it depends on your job. If there's no risk to not telling people, then you don't have to tell anybody. And you know, you should consider telling your dentist and your doctor, just because of health reasons. And we refer them to CATIE, and we always refer them to HALCO for the legal stuff, because I'm not a lawyer. So, "I'm not going to interpret this for you, but you need to read this information and be aware that there are times when you could be charged, whether they catch HIV or not." It's kind of scary. It's for their protection, that they need to understand this. (P1)

Clients are provided information about when disclosure is optional and essential, along with links to resources. These efforts are meant to support each individual's ability to make decisions about when to disclose their HIV status in a manner that will promote their own safety "ethically and legally" while they endeavor to protect the health and safety of members of the public from the risks of transmission.

As such, the measures used for contact tracing, partner notification and disclosure counseling represent how case management may focus on an "individual" client but is primarily driven by a virus-centric approach and predetermined goal of controlling the spread of HIV. "Right or wrong," the reasons and measures cited in policies and practices in Ontario for engaging each client with HIV in the process of mandatory disclosure, identifying contacts, notifying them of their risks, and providing names for verification by a health unit can be summarized by one nurse who declared, *"*Like you know, it has nothing to do with the person. This is just an infection, and we're going to manage it" (P9). The anticipated outcome of this step, of ensuring with different degrees of force that all contacts of an individual are notified of their potential exposure to HIV/AIDS, is health protection: "We're doing this to protect the public--the 'bigger' public" from harm (P2).

Step 5: Entering surveillance data.

According to case management policies, "HIV cases may be closed and filed once a case has received HIV counseling, and all reachable contacts have been notified and

ideally tested, and the iPHIS entry is completed" (PO2b). Therefore, the fifth step in case management is to enter data collected about the case and their contacts into iPHIS, the integrated Public Health Information System. The information about cases and contacts entered into iPHIS is "sent to the Ministry for statistical purposes and identification of potential outbreak situations/disease trends across the province of Ontario" as "required in the HPPA" (PO2b). From a policy perspective, completing the required documentation and closing a case on iPHIS for surveillance purposes marks the end of a public health nurses' "encounter" with a client in the process of HIV case management.

When a laboratory result is first received and added to iPHIS by an administrative assistant, it is marked "open." After completing each step of the case management process, nurses are expected to indicate the outcome on iPHIS by choosing from among five other options that best describes the end result or "encounter status" when HIV follow-up is finished as shown in Figure 10. In practice, HIV follow-up with a case can be considered "complete" when a nurse determines:

> Well just basically that they know what they have, how it's not transmitted and how it is transmitted; that they know about disclosing so they don't get themselves in trouble legally; and that we get the contact information; and treatment. So, there's like four things really. (P1)

Encounter status:
- Closed, follow-up complete
- Closed, untraceable
- Closed, lost to follow-up +

Date to reopen, search again
- Open (use only if case management in progress)
- Open, referred to other PHU
- Open, referred to MOHLTC

Figure 10
Encounter Status on iPHIS (POL2b)

In terms of contacts, “as soon as we've notified them and told them where they can get tested, and how frequently they should get tested, then we close the contact, and then we link the contact on iPHIS to the index case” (P5). Subsequently, when a public health nurse has exhausted all efforts to verify a positive HIV test result, ensured clients are aware of their diagnosis and counseled, completed contact tracing, and confirmed all known partners were notified of their potential exposure to HIV, the official role of a public health nurse involved in case management is concluded: “So when that's complete, then I would document in our electronic documentation system, and then I would document on iPHIS, and then I would close it” (P5).

Like case management, iPHIS is organized by cases, under which there are unique fields for each reportable infection. Under each infection, the fields requiring completion, or designated as “mandatory” in order for a case to be closed, are exactly the same for each case. As a result, nurses have developed intake forms (electronic, paper, or fax forms) and counseling forms (worksheets or flowsheets) to capture and document the information in case management that is to be entered into the surveillance system. A form used in case management to document information about clients typically contains spaces for demographic information, checkboxes to identify content covered in counseling, a separate area to list information about contacts, and a section for comments or “nurses' notes.” As several nurses claimed: “It exactly matches iPHIS. That's where we developed it from. And this is to make sure we have covered everything we need to in post-test counseling” (P4). Subsequently, the forms created by nurses to guide the case management process largely reflect the requirements in iPHIS for successfully completing and closing a case with an additional space for “nursing” notes. A case can be closed when all required fields marked on iPHIS with a “red diamond” are updated. In effect, the public health surveillance system is updated by nurses as a last step in case management

practice to help complete the process of mandatory engagement and reporting of a client's status by a health unit.

Nurses' documentation on iPHIS is subsequently an essential part of their care and is used to communicate information that helps public health practitioners understand the progress of clients in controlling the spread of the virus along the predetermined pathway from screening to treatment, and track their risks and success or failure in preventing the transmission of HIV as they cross jurisdictional boundaries:

> We go into iPHIS to look at the notes from Health Unit B, and if they've got nothing in there, then we have to contact them. And I'm going to say, "Can you send me your hard copy notes, because we need to know what you talked to this person about." So, we use iPHIS. We use it a lot. (P4)

As such, the obligation of nurses to enter surveillance data about each individual client and their contacts is another biosecurity measure linked to a concern with a client's progress within the context of public health's broader goal of containing the spread of the virus and protecting the "bigger" public from harm.

A nurse's decision about the amount of "additional" information to share when completing the documentation for case management can be traced to case management nurses' concerns with protecting both their clients and their selves from harm, including avoiding "legal" trouble. Nurses' preoccupation with protecting clients from harm was explained by one nurse who stated, "There's such a stigma with HIV" (P9), and another nurse who described the reason documentation is minimized on iPHIS by their team as:

> …some areas are not secure, I guess program secure, so that other people in different programs might be able to see it. So, I put very little on it. I may put bare minimum things like, you know, "All sexual contacts notified according to client," or something important like that. (P18)

The trend of filling in "everything that's got the diamonds" and minimizing all other information collected in the nurse-client relationship on iPHIS, is aimed at minimizing the risks to clients and nurses, particularly if the records pertaining to a case were to be subpoenaed. Specifically, the decision to minimize the amount of information shared in

documentation on electronic and/or paper records, is linked to a concern with demonstrating "due diligence" in a court of law:

> At this point we are doing a narrative, [but] we're trying to change that--condense our notes to an action-response kind of thing. That's coming from our "Documentation" nurse specialist. I think it's for legal reasons. Less narrative, less "I will do this" and it's not done, like "I will follow-up in 2 days." Things like that we put on a worksheet, not an official document. (P12)

Additionally, in many health units, the worksheets with nurses' notes are subsequently "shredded" after the information is transferred into iPHIS (P17). Regardless of the method of documentation, the underlying decision about whether or not to expand nurses' notes or share nursing concerns uncovered through counseling in iPHIS is largely related to legal issues surrounding case management practice, namely the risk of being involved in the criminal prosecution of a client.

For example, legal concerns are evident in the decision by all participating nurses across health units to create forms with *checklists*. The purpose of developing a form with checkboxes next to detailed descriptions of each pre-determined step of case management, and aligning the content with iPHIS, is to provide clear evidence that each step was followed and case management was completed "as required" by a public health nurse. As described clearly in the excerpt from the policy of one health unit:

> Due to the possibility of future legal proceedings, it is essential to document counseling given to HIV reactive clients on the HIV Case Management Nursing Form concerning the guidelines for informing partners of their HIV status prior to penetrative sex or sharing of needles. They have a legal duty to tell their sexual partner(s) they have HIV before having sex if there is a risk of transmission. (POL3a)

The importance of creating nursing forms with extensive checklists in HIV case management as well as completing the records required for epidemiological purposes on iPHIS, was described in further detail by the following nurse who noted:

> HIV is probably the only thing different from the other STI stuff, that we actually make sure we have a paper file for it as well.…But the only reason for that again is for the potential to have to take that record out of the office. No one gets arrested for Syphilis. So, it's very different for people with HIV, because

> of the potential for legal issues. We can't take our computer out of the office and say in a courtroom, "Yeah, we did." And you can't remember 10 years later what you talked to a specific client about if you didn't document it in that detail. So, if you had to be taken to court, you would want that…So that was the strategy at that point. We changed it [referring to the HIV counseling form] to make it better. (P2)

Similarly, another nurse explained that documentation practices vary in case management for people with HIV, "because some of us have been to court for cases of non-disclosure before;" nurses maintain more detailed notes "about all the fine points for the counseling" on the back of the form with checklists and enter only "the pertinent points into IPHIS" (P3). In other health units, iPHIS is used as the main documentation tool and a paper copy of the data entered into iPHIS is printed and attached to the form for legal purposes: "We do our notes on iPHIS, then we print them out, so they're on the [client's] file" (P4).

Within nurses' descriptions of the various methods used to document case management nursing care and enter surveillance data in iPHIS, is a common experience of feeling obliged: a) to help ensure a health unit is in compliance with its HPPA obligations for reporting HIV to the MOHLTC; and b) to clearly communicate the "status" or degree to which both the client and the nurse have complied with biomedical, epidemiological, ethical and legal expectations written in public health polices by the end of their "encounter."

5.2.3 Explaining what is expected

A major part of nurses' work in case management is subsequently dedicated to explaining to clients what is expected after a person receives a diagnosis of HIV/AIDS from the perspective of each health unit. As one nurse summarizes:

> You know what? When I talk to them, I say to them that, "Public health expects you to--and I do say that it is 'public health' that expects you to--disclose to any sexual health or needle sharing partners. We expect you to wear condoms to protect anyone that you might be putting at risk. If you don't, I don't know what's going to happen, but people have been charged. People have been splashed all over the news, because the criminal code, it's very grey." I tell them, "People are charged with assault, charged with non-consensual sex, and you could get into trouble." I don't talk to them much about Section 22s.

> That's only if it comes up. I have said that, "If you're caught not disclosing or you have not, that the Medical Officer of Health can take further actions," but I just leave it at that. (P4)

In counseling, *educating* a client largely involves making each individual aware of the behaviours a person with HIV/AIDS is expected to follow based on the policies and guidelines developed in each public health unit for case management. In a counseling session, nurses claim that "[i]f the education is done or not done, that would be a big step for us" (P3). As described by one nurse, when educating a client, "basically, we cover as much of this [information] as we can from this HIV positive counseling checklist, and that's just going through test results, and knowledge of HIV transmission, meaning of test results--just review that" (P12).

The checklists on the forms created by nurses for case management "partly serve as the guidelines" to follow when engaging a client in health teaching during a counseling session (P16). Typically, nurses bring their forms to meetings with clients and review each topic. A sample of a checklist for health teaching on a form used for case management is shown in Figure 11. Whether by telephone or meeting "face-to-face," nurses follow a similar procedure: "[W]e have our sort of checklist—it's more general stuff and then specific to HIV," and often start with the topic of "'transmission' and try to leave 'disclosure' until the end" (P12). Alternatively, nurses who are "comfortable" with the content on the form, generally those with more experience, say they "do the same thing too--highlight this sheet" but they "don't necessarily go through that hard checklist. You might bounce all over as you're talking about things, but you kind of address all the important things, like all the guidelines" (P9).

Therefore, an aim of health teaching is to try to ensure that clients are "really clear about—I'll call it *obligations*" (P3). According to one nurse, a result of feeling the need to focus on obligations is that "a lot of counseling is like, 'Don't do this!' or 'You must do this!'" (P7). *Counseling* is generally conceptualized as a meeting to provide clients and contacts

Health Teaching (Tick box)
Reviewed transmission & educated re: HIV infection (i.e. not diagnostic of AIDS)
Provide specific guidance re: avoiding HIV transmission. Protect others from sexual secretions, blood and other bodily fluids.
Medico-legal requirement to disclose their HIV status to potential sexual or drug equipment sharing contacts.
Client able to verbalize an understanding of this [medico-legal] requirement.
Advised no blood/organ, tissue, sperm or breast milk donation.
Advised not to share personal care items (i.e. razors, toothbrushes).
Discussed benefits of treatment and follow-up and maintenance of optimal health, including lifestyle modifications and empowerment.
Reviewed how to clean blood spills.
Encouraged to complete STI testing.
Discussed avoidance of activities that increase transmission risk of toxoplasmosis and enteric pathogens (i.e. hand washing, healthy eating, use of gloves).
Persons with HIV should inform their HCP and consider informing other HCPs (i.e. dentist).
Disclosure to friends, family, workplace
Reviewed safe sex/safer drug sharing practices (i.e. needle exchange program).
Literature provided

Figure 11:
A sample of a Health Teaching Checklist used for Counseling (POL6)

with education about the rules to follow for "good health" (P21). The "education piece" includes "as a minimum," information about risk reduction, treatment, notifying contacts, and disclosure (P3).

Rules for good health

Risk reduction.

Often the first topic nurses educate clients about is the meaning of HIV, how it affects a person's body, and the risks of transmission. When a public health nurse is involved in administering an HIV test, education about the virus and its implications for case management begins at the time a client is informed of their positive HIV test result. The information a client is provided by nurses at the time of learning they tested positive for HIV was described by one nurse, who explained:

> When you first come in you say, “Listen, I have some news. It's not the news we wanted to hear. It's not the best news,” you know things like that. “Unfortunately, you did test positive for the HIV virus. Your result was positive.” And then usually, that's kind of all they will hear. We talk to them about what it means to be HIV positive, you know, like: “This is what is happening now in your body. The virus is in there, and it's going to replicate itself. And the goal of treatment is to slow down that replication. When it replicates itself, your immune system is going to become depleted, because it's going to make HIV cells instead of T cells. So, the goal is to stop that process, or at least slow it down.” (P4)

At the time of receiving a positive test result, nurses provide minimum counseling as they are concerned about the amount of information a client is able to absorb. The goal of starting with a discussion about the nature of the virus and raising awareness about “what is happening in their body” when infected with HIV, is to help clients understand how treatment and other prevention measures can help reduce the impact of the virus. For example, the same nurse would continue by leaving a client with information that public health has determined is most important for them to know at that juncture:

> “Now that you are positive, you are expected to disclose your status to any sexual or needle sharing partners. Do you understand this?” That's probably as far as we’ll go, because they're probably not able to listen anymore at that point. (P4)

The “education piece” at the time of receiving a positive test result is focussed on making a client aware of the biomedical risks of living with HIV and their ethical-legal obligations around the duty to disclose their positive HIV status in situations that might put others at risk.

When clients are contacted by a public health nurse after having received a diagnosis of HIV/AIDS, counseling in case management begins with education about the bodily and social changes a client can expect as a result of HIV infection, along with the measures recommended in public health to mitigate the risks of harm from HIV for themselves and others. The “education piece” when meeting a newly diagnosed client was described by a nurse as follows:

> If they were coming in and they were already aware of their diagnosis, I would start off by saying, "So, we understand that you are positive for HIV. I just wanted to talk to you a little about things that might change now that you know that you have this diagnosis, and how that might affect your life. So, we know it's associated with sex, and that there's some things that might change there. I want to talk to you about some knowledge I can give you about your sex life, and how that might change with partners, and if you have a current partner and/or casual partners, how you are going to manage that depending on what's going on in your life. And, just about other health things, because it is a chronic illness, so it's going to affect other parts of your health." And then, you know, we would talk about those other parts of health and how it's going to affect those categories of life. And then kind of break it down so that you're not overwhelming them all at once. And so here we go, like with sex, you know, "HIV is spread through these fluids. When you are having sex, this is where your riskiest behaviour is, these behaviours are not as risky and then the less risky, although they all carry some risk of transmitting the virus." (P9)

An important topic in health teaching is educating clients about the importance of behaviour change to manage the spread of the virus through their bodies and to their partners, followed by a description of the behaviours in sex that are considered high and low risk for transmission.

Each client is educated about the specific behaviours that should be adopted in sexual relations to protect their partners and themselves from harm. For example, as one nurse suggests, the next step in counseling involves "trying to educate them that oral sex is a safe alternative, and definitely in a hierarchy of risk, it is safer than unprotected anal sex" for preventing transmission to a partner (P5). At the same time, it is made clear that with "condomless" oral sex, "you can pick up Gonorrhea and you can pick up Herpes, and when you have a coexisting STI, you can get sicker, and you are more likely to transmit HIV to others" (P5). Nurses might then explain:

> Our point of view is that if there is any risk, the condoms are there for protection. But that's also to protect them against other infections. So, we think that condoms should be used for oral, vaginal, and anal sex. (P3)

Included in a discussion about the behaviours that clients are expected to follow for safer sex, is the need to use condoms. In many cases, "the big issue for them is using condoms" (P5) and while in some places nurses say, "We don't really expect people to be using

condoms with oral sex" given the low risk of transmission from this behaviour, clients who test positive for HIV in other jurisdictions are told that for vaginal or anal sex, "Well, we would say you have to. Really, you have HIV and it could spread anally or vaginally" (P6). The rules vary among health units, but "[f]rom a public health standpoint" (P2), educating clients with HIV uniformly emphasizes risky behaviours along with "the behaviors that the Medical Officer of Health is requiring" (P5).

Treatment.

Counseling also includes educating clients about the benefits of treatment. The aim in discussing treatment is to increase a client's awareness of the ability of medication and specialized care to help suppress the virus and help reduce long-term risks of harm:

> Yeah, we provide counseling in a general sense, I mean not going into all the medications available or anything, but just to give them a sense of all the developments in HIV care, and how different it may be from what they have heard. And we mention that if you're cared for, there's no reason you're going to die from HIV. (P12)

Mainly nurses emphasize with clients that "treatment is often effective and people with HIV can live long, healthy lives…that as long as it's kept managed with medication, you can live as long as someone without HIV" (P18). The emphasis in education about medical treatment with a case or contact is on the ability of medication to reduce the biomedical risks to themselves, as well as help prevent the spread of the virus to others:

> If we do talk about treatment, then we do talk about prevention, like what are the advantages of being on treatment for prevention: how getting on treatment reduces your viral load which is proving in science at this point that it can prevent the spread of HIV to other people. And so, the advantage of being connected with treatment early is it can keep you healthier, and it can get you connected with the physician that is the expert early so that they can help you out with some of these things. So, there's more information about treatment as prevention, and it's important that [clients] get that. (P21)

The goal of discussing treatment in health teaching is to both help clients understand how it is important to "keep them healthier," and how medical treatment could be used to help them protect the health of their partners. However, little information is provided about the

availability of Post Exposure Prophylactic (PEP) treatment for contacts or Pre-Exposure Prophylactic (PrEP) treatment for long-term partners as most health units did not provide medications or prescriptions for these treatments, and few had guidelines regarding how to manage clients who potentially qualified for PEP or PrEP other than to refer people to the nearest emergency department. Treatment information was provided to women who tested positive for HIV "if they're childbearing age," including education "about pregnancy, and that you can still have a healthy baby…you just have to follow-up with your health care" (P1). Therefore, treatment is explained as an option for people with HIV, but education about treatment involves highlighting the importance of "having to follow-up" with a healthcare provider, a specialist, or go to the hospital in order to keep healthy and reduce the health risks of HIV for others.

Notifying contacts.

When educating clients about the importance of contact tracing and partner notification, nurses point out that in public health, "We need to talk to all contacts. That's the rule" (P3). Cases are provided with information about the choice they are expected to make regarding partner notification:

> So, I would just say you can either notify the person yourself, or if you want someone to notify them confidentially, where we don't use your name, we don't connect it in any way to you, we just tell them that they're a contact of HIV and need to get tested, they have that option. (P21)

When contacts are notified, they are also informed of what they "need" to do along with the behaviours a public health unit "expects" them to take upon learning of their potential exposure to HIV. In practice, for example, one nurse explains:

> I would call them and let them know that they may have been a contact and give them all their options for testing: like where [to go], and the availability of point-of-care and Anonymous testing, and all of that. I tell them if they're comfortable going to their own family doctor, by all means. But I also tell them that it's very important that they don't have any unsafe sex until they are tested and aware of their own status. We just say you may want to test now and then again three months from now. (P5)

In addition, as described by another nurse, each contact is told: "They may not necessarily have it, but it is important that they do get tested. They need to know. If they do have it, you know, they can get started on treatment." (P6). Therefore, the "education piece" for contacts involves a list of options and actions contacts "may want to" take and "have to" adhere to once they are told they are a potential risk for spreading HIV. Education around contact tracing and partner notification involves making sure all contacts of clients with HIV understand the behaviours for testing, treatment and safer sex in public health guidelines for protecting their health and the health of others.

Disclosure.

Similar to the other "educational pieces" in health teaching, nurses' counseling on the topic of disclosure is centred around behavioural guidelines for clients as shown in Figure 12. Each case is provided with an additional list of behaviours they "need" to undertake in order to satisfy legal obligations related to the duty to disclose. Nurses review a list of behaviours with clients that includes "the guidelines about who you will have to tell," including who "for their protection and for your protection need to know" (P1). Public health nurses would explain, for example:

> "[I]n terms of notification, you know, we need to talk to you about who you will need to notify and also who you don't need to notify. And, also, about informing future partners if you're going to have sex. Inform all your needle-sharing and sexual partners." That information we try to relay first: "And if you don't, there might be legal consequences of not doing so." (P8)

Disclosure counseling also includes education about the importance of condoms: "And so we recommend to everyone that they use condoms…to disclose and to wear condoms" (P22). After completing health teaching about recommended behaviours related to disclosing, nurses provide clients with a list of situations where clients are not expected to disclose. When educating clients about their obligations around disclosure, public health nurses include information about behaviours that are "safe." As one nurse explains, "It is

HIV COUNSELING FLOWSHEET

☐ **Disclosure**

YOU ARE REQUIRED to inform all your past, present and future sexual partners that you are infected with the HIV virus. This information must be provided to your sexual partners before any sexual activity; A latex condom must be used for each and every act of such sexual activity; and you must advise your partners that condoms may sometimes break; and advise your partner to seek medical attention immediately if the condom breaks and to have regular testing for HIV.

☐ **Sharing of Injection Drug Equipment**

YOU ARE REQUIRED to inform all you past, present and future injection drug use/drug equipment partners that you are infected with the HIV virus. Never share needles or drug equipment for any purpose, including snorting and injection drug use or tattooing. Clean injection/drug use equipment is readily available.

Figure 12:
Checklist for Disclosure Counseling on an HIV Counseling Flowsheet (POL10)

"more important to know that the big thing is, they don't have to tell everybody" (P1).

Clients are first educated about the duty to disclose at the time they are diagnosed, and then "reminded" if they test positive for additional STIs thereafter. In terms of a "dual diagnosis" and how clients are reminded of the need to disclose their HIV positive status, one nurse said:

> We've had plenty of that here: clients say they tell their partners, and then at the other end, the contact says, "No, they didn't tell me." It becomes, "He said, she said. She said, he said." So, part of what we may say to them is, "Part of why we are asking if you disclose, and why we're following up with partners, you know, the *disclosure piece thing,* is that, if we are also able to document that you are aware, and if we actually talk to them too, that's good for you." So, the rationale is "your protection." (P3)

From a public health nursing perspective, health teaching on the topic of disclosure is viewed as an additional means of increasing, evaluating and documenting a client's awareness of the behaviours that will reduce their risk of exposing themselves and others to harm, and subsequently a "good" way to enable clients to avoid trouble. According to one nurse:

> I'll talk about from a public health perspective this is what we recommend. Failure to do so here has led to different kinds of charges...and that it's in their hands. And we write that they have been informed, and that we've talked about these things, and that they have voiced understanding. (P21)

As shown in Figure 13, the forms used to guide health teaching often include a checkbox for nurses to signal their completion of health teaching with a client about the "actions and concerns" of Public Health in Ontario around disclosure. After providing education, nurses are expected to indicate their completion of an assessment of each client's knowledge of the behaviours that indicate compliance with the duty to disclose within the "current legal climate."

☐ **Client verbalized an understanding:**

***Current Legal Climate:**

Our actions and concerns are from a public health perspective; However, clients also need to be aware of legal considerations. The Supreme Court of Canada addressed the issue of HIV disclosure with the Cuerrier Decisions in 1998 and more recently with the Maboir decision in 2012. Clients should be referred to the HIV/AIDS Legal Clinic of Ontario (HALCO) for information or advice pertaining to HIV disclosure and the criminal law.

Figure 13:
Guidelines for Disclosure Counseling on a Health Teaching Checklist (POL14)

5.2.4 Making it easy and making sure

A number of measures have been developed by case management nurses to make compliance "easy" and "make sure" biomedical and legal obligations are understood and achieved. These strategies are notable in the relations nurses describe when explaining their follow-up with colleagues and clients that have become normalized in HIV care.

For example, case management practice includes strategies to make it easier for primary care clinicians to fulfill their reporting obligations. In many jurisdictions, testing clinicians "don't proactively do that," and in a number of health units case management nurses have developed a "reporting form" they fax to their offices to assist them. The fax

forms contain a checklist with the surveillance information required for each case in iPHIS, and subsequently help nurses “capture all the information that we want” in a way that is most convenient for the clinician (P8). In sending the request to fill out the fax, one nurse says, “So we're just hoping that they've done their own assessment and identified some of the risks that we’re looking at, complete the reporting form” and have it faxed back to the public health unit for the client’s record (P12). A different nurse explained: “We have timeframes” and “[i]f we are unable to obtain information from the healthcare provider within five days, then we would put in a phone call to the doc” to try to obtain the information needed to continue with case management (P3). In some health units, the process is as follows: “If we can’t get them on the phone, which often happens it seems, then we say that we’re going to fax over a reporting form for them to complete” (P12).

Along with “making it easy,” nurses use additional strategies to “make sure” that the steps of the case management process will be completed. For example, an additional use of the fax form is to help ensure the counseling provided to clients by testing clinicians is consistent with the counseling guidelines of a public health unit for people with or at risk for HIV/AIDS in Ontario. As one nurse says, “So it’s a checklist…This form lays out everything that we do for counseling and then makes sure that they do it” (P9). The range of reasons for using a fax form was summarized by one case management nurse who explained:

> Yeah, sometimes I use a fax form…If I talked to the doctor’s office and I know that it's an older infection or the patient has just changed jurisdictions, then I’ll likely send out a fax form. Sometimes they use the fax form because it has a whole counseling section that they need to fill out, especially for a doctor’s office where they seem pretty uncomfortable about doing the counselling, like “I don’t know what to say to this person” or “I don’t know what to tell them.” Sometimes I use that form and say to them that these are points that you can go through when you're talking to them about their diagnosis. Sometimes it's like, “Well, I've been a doctor for 20 years and I've never had a patient before who tested positive, you know, and I only booked half an hour.” So, I try as much as possible to reinforce that this is or can be a serious diagnosis for people, and it’s important to really help or support them in any way we can.

> But at the end of the day, you can't control the way someone is going to act. (P22)

Nurses created the fax form to enable clinicians to fulfill their counseling and reporting obligations. It is also used by nurses to identify and address gaps in the HIV follow-up provided by a testing clinician. The content on the form helps reiterate the knowledge related to HIV follow-up each public health unit believes is “essential” to cover with new cases, and the checklists provide a method of determining the extent to which a clinician was able to introduce or reinforce the teaching required by a public health unit in their counseling.

Being proactive in “reminding” primary care providers of provincial reporting and counseling guidelines has become an important part of the role of case management nursing as an increasing number of primary care clinicians are preferring to pass on their responsibilities for HIV follow-up to public health nurses. According to one nurse, at the beginning of the epidemic in Ontario, the healthcare providers who ordered the screening test would complete most of the follow-up counseling with the people who tested positive for HIV in their clinics as well as counsel partners: “Once upon a time, years ago, it would have been like that. And now, no one wants to” assume responsibility for HIV follow-up in primary care (P13). While it may not be the case across all jurisdictions, nurses are also finding themselves increasingly obligated to “tell people their results” (P18) and “refer someone to the infectious diseases clinic because they haven’t been referred by a community doc” (P5). As a last resort in making sure the steps for case management are successfully completed, nurses will go as far as to “do for” colleagues and clients the tasks that are mandated in public health policies to make sure “essential” requirements are met.

Double checking

Public health nurses have also developed the practice of “double checking,” or

checking the work of colleagues and the steps taken by a client are completed as required. Often the result is the double "doing" of tasks to verify, or "make sure," that case management is progressing in a manner that is consistent with public health policies. For example, nurses' first step in the process of case management is to check the work of the administrative assistant who entered the laboratory result in iPHIS:

> My first step would be to search iPHIS for the history to make sure nothing gets missed. We look on iPHIS to see if there were any other STIs like Hepatitis C. That would be step one, really. And then we normally call their healthcare provider. (P2)

In the words of another nurse, the rationale for double checking is that "sometimes it helps to have more eyes to look at things to catch any mistakes" (P18).

For similar reasons, nurses might also check that the work of the testing clinician has been completed as part of the second step of case management. As one nurse claimed, "Yeah, and sometimes the doctor will go through intensive medical counseling with someone and do some partner notification, and then we'll sometimes double check things" (P22). For example, all nurses said they double check that clients have been notified of their HIV positive test result. As one nurse revealed, an important aim for nurses in contacting the testing clinician as part of the second step in case management is to double check that the healthcare provider has informed their client of their diagnosis:

> It's basically a courtesy call. Often, we just check if they have told the person and ask when they are planning to do that? Which, most of the time they have and if they didn't, then we can talk about what their responsibilities are as far as follow-up and reporting…So, next, we either call the doctor back to confirm [when it is done], or we have the doctor ask the client to call us. (P1)

The impetus of calling the testing clinician "sometimes" twice to make sure the client is aware of the diagnosis is to prevent mistakes and avoid trouble, "because there was an incident when we called the client, and they didn't know" (P8). According to another nurse, in "situations where doctors have told me they've been informed and they haven't, and I've been the one informing them" a client became suicidal, and "that can be a nightmare"

and "so it's always good to chart that you asked the doctor" (P18). As described by a nurse at a different health unit, calling physicians to double check that they fulfilled their medical obligation to inform a client of their test result involves:

> So, it's just checking to make sure that I'm not calling this person who has no idea, right? I don't want to be walking into that situation. So, I would be making sure, "Okay, do you have an appointment scheduled for them? When is that? I'm going to call you a week after, or a day after, however that works out, or could you call me after that person presents to their appointment and let me know that they have shown up and that everything has been communicated to them and how that went?" (P21)

Nurses double check that primary care providers complete their medical responsibility to provide a client with their diagnosis in order to make sure it is safe to call the index case. Double checking the work of the testing clinicians is undertaken by nurses to help protect both nurses and their clients from undue harm as the case management process proceeds to the next step.

"Double checking" is also an important part of nursing follow-up with each client. Across the province, nurses have integrated a strategy of "double checking" partner notification is completed to make sure HIV follow-up with a client is complete. As made clear by one nurse, "They can certainly inform their partners, but we will also inform them" (P6). It is common in practice to double check that a contact has been informed by insisting that the client ask the contact to call the nurse to confirm they have been notified of their potential exposure to HIV, "and if we don't hear back from them, like say in one week, then we are going to follow up" (P4). One nurse summarized the rationale for double checking the efforts of cases to notify contacts as follows:

> Let me just clarify, they are often very comfortable to tell us that they've done the notification. They will say, "Yes, I notified them, I notified my partner. But that's just to get us off of their back. So, we do the verification part, which has become a new thing for us. It's like a punitive thing, in my opinion, but it is what it is. We were just concerned that contacts weren't being notified, that in some cases we knew that they weren't being notified. So, it was just a way for us to make sure to protect the community, the public, that these people have the right to know that they could be at risk. (P8)

Despite beliefs that it is punitive, double checking whether or not a case actually notified all contacts of their risk for HIV is a strategy integrated into case management nursing practice to avoid potential medical-ethical-legal consequences associated with erroneously assuming the task was completed. The aim of confirming a client has fulfilled their obligation to notify contacts is to avoid trouble by making sure all efforts were made to protect the public from harm.

Accommodating

Public health nurses have also developed strategies for accommodating clients. For example, across the province, clients are offered several options for where to meet for counseling by case management nurses. As summarized by one nurse:

> I've gone to the doctor's office and the local AIDS Service Organization, and we did go to a client's home once. He was very ill and mobility was an issue. So, we had to go there. And the hospital if necessary. Other than that, it's here [in the health unit] mostly. We'll meet them wherever they wish to meet, really, if it's a private spot where we can communicate with them. We try to make it easy and attainable for them. (P11)

In the words of another nurse, "We try to make it whatever works for them" (P10). In some health units, normal practices are altered to ensure nurse-client encounters for counseling take place. One nurse provided a description of how the health unit standard of practice for informing clients of their HIV positive test results was changed to accommodate clients for the purpose of counseling:

> We actually only used to give results in person, but we've had a lot of people not come back. So now, if we get a hold of them, we try to get them to come back to the clinic. If they won't or if they don't, then we will tell them on the phone. (P4)

Accommodating clients by altering certain "rules" at the point of care is a strategy initiated in case management to address non-compliance and make it easier for nurses to complete the steps of HIV follow-up with clients.

Nurses also make follow-up with public health guidelines for HIV case management more convenient for clients by adjusting timelines for completing certain

steps. Client's concerns are often accommodated to facilitate the process of partner notification. According to one nurse:

> We ask them, "What is reasonable?" And, you know, usually you come up with a time frame, that they'll suggest and if you're happy with that, then you go with it. And then we will leave it a bit before we contact that person. (P3)

The timeframe for completing partner notification can be negotiated in order to increase a client's likelihood of compliance. Clients are also given options as a means of encouraging their compliance. Another nurse explained that to complete the step of partner notification:

> Another option is that I give the client my name and number and they can give that to their partners, and their partners can call me. Then they can be in control. (P2)

In practice, nurses might also offer to do the partner notification for the client in order to ensure it is completed. All nurses agreed that if a client is concerned about the reaction of a contact or partner with whom they had a relationship, "particularly if it's been a bad experience, [and] they do not want to notify them, we would do it for them. As long they can get us the contact information, we would do it for them" (P1). Nurses are also increasingly assuming responsibility for partner notification as a means to protect clients who, in the current legal climate, prefer to remain anonymous. Providing clients with space to negotiate and options at the point-of-care is a way nurses accommodate clients while simultaneously promoting both the client's and nurse's adherence to public health guidelines for progressing on the predetermined pathway from testing to treatment in the process of HIV follow-up.

The needs of a client's contacts are also accommodated in the process of case management for a similar reason: to *make it easier* to achieve biosecurity measures and goals. For example, several options are tried by nurses in order to reach a contact as a means of facilitating partner notification as well as a contact's engagement in screening for HIV. As a nurse in one public health unit described:

> So, for partners, yeah, we would follow-up if they have information for their partners. If they have phone information, we're going to try to reach them by phone. If they frequent the clinic, but we can't reach them through the clinic, we'll do what we'll have to by phone. And in the case that we can't find people, and we can't get hold of them by phone, then we'll go out and try to find people. We go out into the community, we've done that. And just try to touch base however we can. And that's educating them that, "You might have been exposed to this infection. These are the risks. These are the main ways you can get it. If these are some of your risk behaviours, you know, we really recommend you getting tested." And if I'm on the outreach van, I'll say to the others, "Do you want me to do the follow-up right now?" We try to bring them into the clinic, but if we can meet them somewhere with the van, if we can get to them, I've done that before too. (P9)

Nurses have been granted the autonomy to extend the typical boundaries of HIV care at the frontlines in order to ensure contacts are informed of their risk of exposure to the virus, notified of their need for testing and if necessary, referred to treatment. Similarly, nurses are allowed to alter the normal procedures at the point-of-care around testing available to the general public at a health unit in order to accommodate contacts concerned about their HIV status. According to nurses, when a person is "named as a contact of a sexually transmitted infection, like HIV, it doesn't mean that they necessarily have it, but it's important to get tested [and] so we try to help arrange it that they can get tested ASAP, you know, in the clinic quickly" (P6). From a public health nursing perspective, it is "essential" to make testing more convenient for people with a known risk for HIV as a means of ensuring that the "bigger" concerns in public health about protecting the public from harm are "quickly" addressed.

5.2.5 Judging each individual's ability to conform

Public health nurses are expected to report the status of a client's progress along the continuum of care in HIV follow-up, first in iPHIS for surveillance purposes, and then to team managers and the A/MOH for their professional judgement and feedback regarding the outcome of a case. In nurses' own words, the case management process is "always about a judgment" (P3). The position of case management on the "frontlines" of a public health unit means that public health nurses are the healthcare professional in the HIV

response initially responsible for assessing and documenting the extent to which individuals, in their professional judgement, "have done their duty" in fulfilling public health and legal obligations after receiving a positive HIV test result (P2). In particular, public health nurses are expected to report any cases to a manager and an A/MOH that appear *not* to be doing "their duty," and considered a possible risk to the public.

Risk assessment

Nurses' assessment of each client's potential risk begins with the collection of demographic information. As shown in Figure 14, the "demographic history" of a client provides important clues as to an individual's risk factors for noncompliance and potential risk to others. For example, nurses are taught to use information collected about their "birth country" and "sexual orientation" to determine whether or not a client is a member of one of the high-risk groups identified through public health surveillance as "priority populations." As outlined in one policy, the groups with the highest "risk factors include MSM, African Caribbean Black, First Nations, IDU, Female partner of Persons at Risk" (POL3a). Information about a client's "employment history," "current sexual partner(s)," and "children" can help a nurse begin to identify potential risks an individual might represent to significant others.

A risk assessment in case management also includes collecting information from testing clinicians and clients about signs and symptoms of HIV/AIDS. All case management Policy and Procedure manuals refer nurses to the *Canadian Guidelines on Sexually Transmitted Infections* issued by the Public Health Association of Canada (2016) for a list of biomedical indicators and risks related to HIV/AIDS (PO12a). Nurses are expected to use the available guidelines to help identify signs and symptoms and their relevance for each client in terms of their risk status. An example of the biomedical indicators of HIV used by public health nurses to identify a client's potential risk is shown in Figure 15. Together, the assessment of a client's demographic history and history of

DEMOGRAPHIC HISTORY: This area assists in capturing and highlighting potential risk factors for HIV acquisition/transmission.

Birth Country: Record country client born in.
Other Countries Residing in with dates: Record countries client has resided in and the duration dates if applicable.
Date Arriving in Canada: For clients that now reside in/travel to Canada indicate date arrived.
Employment History: Record significant employment roles for client, assess/provide health teaching for potential HIV acquisition/transmission. Advise client to review with their professional body for any practice recommendations/restrictions. Check if applicable, client referred to their professional college for further infection reporting and any practice recommendations/restrictions.
Sexual Orientation: Indicate client's sexual orientation, Heterosexual - opposite sex partners, MSM - men having sex with men, Bisexual - partners both male and female, WSW - Women having sex with women, Other - specify.
Current Sexual Partner(s): Obtain client's marital status/current sexual partners as part of contact notification assessment/and PEP- Post Exposure Prophylaxis assessment.
Children (include age): identify children of client, assess for potential exposure contacts i.e. Vertical transmission.

Figure 14:
Guidelines for completing a Demographic History on an Intake Form (POL8)

recent illness is used by nurses to identify where each individual might be situated along a spectrum of risk: from low, medium to high risk. A final judgement about each client's risk is reserved until the remaining steps of case management are attempted.

Following their initial "intake," public health nurses continue to collect information in their interactions with clients about each individual's ability to comply with the process of HIV follow-up and conform with health teaching. Subsequently, public health policies also include guidelines that can be used to "assess client barriers and readiness to change" (POL2b). The following is one example of a list of indicators for determining when

Assess client for risk factors, and signs & symptoms

HIV signs and symptoms (2-4 weeks post-exposure):
-fever/malaise
-sore throat, fatigue, headache
-nausea/vomiting/diarrhea/loss of appetite
-lymphadenopathy
-thrush/oral ulcers and/or genital ulcers
-arthralgia or myalgia
-rash
- >5 kg weight loss

- Acute/early stage HIV symptoms develop in about 70% of HIV infected people and generally last 2 to 4 weeks.
- Approximately 3 weeks after initial infection, the p24 antigen appears in the blood, and remains present for about 3 weeks. As the p24 antigen level declines, antibodies to HIV begin to appear. This is termed seroconversion—the interval when antibodies are first produced and detectable, and this immune response causes the flu-like symptoms of seroconversion illness.
- The HIV viral load rises quickly in the early stages of infection; this is a highly infectious period in the progression of the disease.
- Clients must always be informed about the 12-week window period where they might test negative for antibodies. If there is a suspicion of HIV infection and non-reactive blood results, the client should be retested at 12 weeks after potential exposure.
- Risk to sexual partner is greatest after the eclipse phase (0-11 days after infected) and especially in the 1rst three months of initial infection with HIV (viral load is higher in 1rst three months of contracting the virus).

Figure 15:
Biomedical Guidelines used in Case Management for Risk Assessment (POL3a)

"ongoing follow-up may be required" as described in one case management policy shown in Figure 16. Behavioural indicators are used to assess "the client's willingness to change practices" and potential ability to engage in "behaviours in the future in order to reduce their risk" (POL8). The demographic history, history of signs and symptoms of illness, and behavioural risk factors are reviewed to arrive at an overall impression, or *judgement*, of

Ongoing follow-up may be required. PHN should consider history of:
- Continued substance abuse
- Involvement in prostitution
- Knowledge deficit related to HIV infection and transmission
- Lack of consistent address
- Missed appointments
- Failing to utilize appropriate services
- Notification of risk behaviour (i.e. named as contact)

Consult with program supervisor regarding course of action in these situations.

Figure 16
Reasons for Ongoing Follow-up with a Case (POL13b)

each individual's fit within a category of risk. An example of the criteria used for categorizing a client as "high" risk from the guidelines in one policy is shown in Figure 17. A client may be categorized as high risk as a result of their nationality, sexuality, biology and behaviour.

In practice, a nurse's judgement about a client's risk in public health is typically expressed in terms of an individual's demonstrated willingness and ability to conform with the steps of case management and biosecurity measures advocated in case management policies and practices for "good" health. For example, a nurse might report and record their overall assessment of an individual's ability to conform in the following manner:

> Like, "I've met with so-and-so. We've talked about it. They're going to the infectious disease specialist. They're going to the AIDS Service Organization. They have a really good understanding of disclosure. I don't think it's going to be an issue." Or, "They seemed to balk a bit about disclosure." Because I've had people say, "Well, if I tell people, they're not going to have sex with me." So, then we explore that for awhile. "That could be very, very possible. So, how would you handle that? What could you do about that?" But if I really feel they're probably not going to disclose, I will let the MOH know that I have a feeling that they may not disclose. The MOH just wants to know if they are going to be an issue. (P4)

A public health unit is particularly interested in identifying clients who may have "issues" conforming to public health guidelines, and the assessments completed by nurses in the

process of case management support further decision-making about how to respond when a client is judged to be noncompliant and presents as a risk.

Epidemiology of HIV

High risk factors:
- unprotected repetitive anal/vaginal intercourse
- sex with an HIV-infected partner
- sharing IDU equipment with someone who is HIV-positive
- multiple and/or anonymous sexual partners
- sex trade works and their contacts; homeless; street youth
- MSM
- African Caribbean Black
- First Nations
- acquisition of other STI, e.g. syphilis; hepatitis B or C
- children born to mothers with known HIV
- women who are represented in the above groups or engage in high-risk activities with them (i.e. share needles or other drug equipment and/or engage in sexual activity)"

Figure 17:
A High-risk Category used to Assess and Classify a Client's Risk (POL3a)

Providing updates and reports

The Policies and Procedure manuals for case management provide clear directions for nurses about when and where to forward information about a client who is judged as presenting a risk. In each health unit, "[t]here's certain parameters with every disease about when to consult" (P3). Variations exist across health units in Ontario about the frequency with which nurses are expected to provide updates or consult about cases. However, the same hierarchical order in the steps for reporting and decision-making are outlined in each policy for nurses to follow. At the start of case management, it is expected that the administrative assistants will "Notify the Program Manager and HIV Lead PHN of all HIV reactive results" (POL3a). Then, at any time in the process of case management,

nurses are expected to forward information first to the team manager, and then as necessary to the A/MOH when a case appears to be presenting a "challenge" to usual policy and practices. The hierarchical order for reporting "challenging" cases is commonly written in policies as follows:

> During the case management process, PHNs will provide the Manager, Clinic Services or designate with updates on challenging cases and review cases as needed with the Manager/MOH. (POL1a)

In case management practice when an issue of non-compliance arises, such as when a client with HIV tests positive for a new STI for the first time, the process as explained by one nurse involves:

> I'm going to make [the manager] aware that I've done the follow-up teaching, I've collected the partner names, there hasn't been any resistance, the client is willing to give partner names. If everything goes well, then it's left at that. But, if there is a subsequent, so another STI, at that point there is a possibility that the AMOH will consider issuing a Section 22 order. (P5)

The purpose of providing updates is primarily for a manager to be "made aware" of issues surrounding a case and how a case has been managed. Then, a case is brought to the attention of the manager and MOH for further *direction* only when additional measures may be required to encourage a client to cooperate.

In a few health units, additional strategies for sharing information and arriving at judgements about a client's progress in case management are implemented. For example, in a number of health units, all HIV cases are discussed regularly at team meetings. An example of the procedure in policies with this variation is as follows:

> During the case management process, Public Health Nurse (PHN) will provide the Program Manager with updates on the case. All HIV cases are discussed at weekly case review with the Associate Medical Officer of Health (AMOH), Program Manager and team. For any challenging cases, PHN will consult with Program Manager and AMOH as needed. (POL8)

At a team meeting, one nurse explained, "we all sit and say, 'These are what people's thoughts are so what do we take from that? How can we all collectively come to

agreement? Are you all okay with this plan?'" (P22). With regards to each "challenging" case:

> We have discussions about can't, or *willing versus able* kind of thing. So, in the case of someone who isn't going for follow-up, or disclosing, or whatever it is, is it that they can't do it? Or they're having trouble doing it? Or are they truly not doing it? You know what I mean? Are they not willing to or are they actually having trouble not being able to do it? And if that's so, how do we best help that? (P22)

The purpose of the meeting is to assess the details of each case and arrive at a consensus, or "collective" judgement, about the level of risk posed by a client with HIV and the "best" course of action to help a nurse mitigate a risk with a client.

In some health units, "mandatory reporting to managers" is also expected with all HIV cases, and this involves forwarding managers and the A/MOH a summary about each case as part of the typical process of case management (P8). According to one nurse, the process of keeping a manager and MOH of a health unit updated with a case's progress can subsequently involve a number of internal measures:

> We usually bring it to a case meeting…once a month. And they want to make sure that everything has been done: that they are aware of their diagnosis; they're notified; we've talked about transmission, harm reduction, risk reduction, legal responsibilities; and they are aware of how to access treatment. The contacts are identified and referred [for testing]. And IPHIS is updated. And if they're referred, I'll usually put where they are planning to go and which doctor. And it's a nice summary for the manager. They have access to this summary sheet. (P12)

In lieu of "summary sheets," some managers and A/MOHs are updated by email. Often, communication about cases with A/MOHs travels indirectly from the point-of-care nurses through team managers. According to one nurse, for example:

> We email our manager, who sends the message to our director, who changes it to their words, and sends it to the MOH. And then it'll go back to the manager and then any feedback will funnel down to us. Eventually that's how we will get wind of it. We just look to inform him really that there are public health concerns but we're handling it. It's really just letting them know. (P11)

In other jurisdictions, an A/MOH will receive their updates via iPHIS. The process for reporting the status of a person with HIV through iPHIS is as follows:

> If we have any issue, we go to our manager first. And then she would go to the Assistant Medical Officer of Health for any timely things, like if we might need a Section. But every time we get new cases, we summarize them. It goes onto iPHIS and the AMOH looks up stuff on them. We just write a little email message to him saying, you know, "We've gotten this client," and we give him the client's number on iPHIS so he can go look it up, and we say, "This is what's happened. We've counseled, but we don't think he'll be a problem. He seems to have a good understanding." Or, "Yeah, we might have a bit of an issue…Yeah, this one is a problem." So, we send a little message. For HIV, he wants to be kept abreast. (P4)

Common across the province is the reporting of information about HIV cases from nurses at the point-of-care of case management to their managers, and then to an A/MOH for the purpose of ensuring authorities are "kept abreast" of the status of each individual with HIV in terms of their conformity to the health unit's guidelines. Typically nurses forward summaries describing their assessment of a client's "issues," their professional judgement about whether or not the case poses a "problem," and the assessment criteria upon which their professional judgement is based.

The purpose of reporting cases is primarily to ensure that "everything has been done" at the point-of-care by the nurses managing the case (P12). Providing managers and A/MOHs with summaries is a method for case management assessments and efforts to be reviewed, or judged, in terms of their alignment with public health unit policies. The practice of reporting, whether mandatory or not, enables health unit authorities to assess nursing judgements. The summaries of the strategies and outcomes in case management help managers and the A/MOH "keep abreast" of the due diligence of nursing practice decisions at a distance from the point of care. Simultaneously, follow-up on the work of nurses at the point-of-care helps demonstrate to the public that nurses in a health unit are fulfilling their "due diligence" in the management of people with HIV as specified in the

HPPA (1990). The use of reporting as a means for nurses to demonstrate "good judgement" was evident in the statement of one nurse, who explained, for example:

> We would only bring something to the manager if they ask, or if there was a concern, or complaint, that someone's having unprotected sex and there's a potential Section on the horizon. Or it might be something that we've tried all of our secrets on, and we can't find him or her, and then we might go to the manager and say, "Look, you know, we have tried this, and this, and this, and this, and haven't been able to find the person. I am closing it. Can you think of anything that I haven't thought of?" And that's probably more for our own sake. And then we would document it, that we reviewed it with our manager and the AMOH before it was closed. (P13)

Nurses send managers and the A/MOH summaries about cases and work together as a team to address concerns or complaints in order to be able to confirm as a team and document that all available strategies are "tried" before closing a case. The final judgement about whether or not it is "safe" to close a case is made by managers, and if necessary, the A/MOH; "like if there's ever a case management issue, usually the ultimate decision comes from our AMOH" (P8).

Therefore, a hierarchical order is traversed to arrive at a judgement about a case's risk to the public and deciding how to respond to cases that pose a potential "problem." The overall process was summarized by one nurse as follows:

> If there was any concern, I would go to my supervisor and I would take my direction from my supervisor. "Where do I go with this information? How do I approach this? What's our stance on this?" And if there was anything that [the manager] is uncertain of then we go up to the next level...it would be our director, and I've gone to the AMOH before with some issues too just for her expertise in public health. I mean, as a team, we usually have a really good discussion, but it does come down to if the AMOH says, "No, we need to this," or "I think this is where we need to go," that's where we're going to go with it, whatever the management team decides to do. (P21)

Information about each "challenging" case is forwarded along a linear pathway that corresponds with the hierarchical organizational structure of a public health unit. A client's willingness and ability are judged step-by-step of the case management process by nurses, and nurses' assessments and actions are reviewed in a stepwise manner through a line of authorities that correspond with the compartmentalization within the

organizational arrangement of a health unit. While the roles and expectations of nurses are made clear in case management policies, the expectations of managers and the A/MOHs are described the Policy and Procedure manual of only one health unit, and it appears as shown in Figure 18.

Manager:

- Advises staff regarding case management and problem solving
- Holds regular case consultation meetings to discuss challenging cases. PHNs document the recommended course of action on client chart.
- Refers cases to AMOH as needed
- Ensure that all policies and procedures are up to date and followed
- Reviews files periodically for quality assurance
- Ensures the development and implementation of a training program appropriate to the needs and responsibilities of the team
- Ensures that program policies related to HIV cases are followed

A/MOH:

- Provides consultation for difficult cases
- Provides advice to program staff including manager and community physicians if required
- Considers appropriate public health measures to be taken for protection of the public
- Decides what public health measures need to be taken for difficult cases
- Determines if a Section 22 order is necessary
- Issues Section 22 order under the HPPA when required (POL16d)

Figure 18
Roles and Expectations for a Manager and the A/MOH

Notable is that the members of a public health unit with the greatest authority over a case are often situated at the greatest distance from the point-of-care. Subsequently, the public health unit official making the final judgement about a case's risk and determining how to intervene, is often physically separated from the point-of-care and typically arrives at decisions without having met a client or their at-risk partners. The purpose of following a "chain of command" is to review nursing assessments and

practices, and to ensure that the measures undertaken with clients by nurses at the point-of-care are, in the judgement of the A/MOH, the “best” measures available for mitigating risks and “problems” posed to the public by people with HIV.

5.2.6 Intervening with graduated intensity and forced measures

A case is judged as “difficult” when an individual appears to be “unwilling or unable” to comply with the steps of case management or health teachings related to risk reduction. Therefore, the predominant role of public health nurses in case management as it is currently conceptualized is to identify individuals infected with the virus who pose a risk of transmission and then implement measures to encourage compliance with “transmission reduction methods” (P5). After the normal steps of case management have been implemented, nurses are expected to initiate additional measures with “graduated intensity” when clients continue to pose a risk to others. The practice of public health nurses in responding in a stepwise manner, with graduated intensity, is described by one nurse as follows:

> So how things are playing out in our jurisdiction right now, if somebody gets a new STI following their HIV diagnosis, we will call them and we will do some more intensive counselling. First of all, I will have attempted to get whatever information from the testing physician about the new STI to make sure that they are aware of the diagnosis, have been treated, and so forth, so that I have that information in hand. And then I’ll call the individual and do what we call, I don't know, *first step counseling* for lack of a better term. And what I will say when I call is, “We received a new report of syphilis, and we’re also aware that you are HIV positive, and sometimes, when we get a new report, a new STI, sometimes it’s indicative that you’re not consistently practicing safer sex, and can we talk about that? Can we talk about how you are keeping yourself and others safe?” That’s when sometimes you’ll get people who don’t want to talk to us. And this is the form that I’ll use for those situations, when I’m calling someone who has been coinfected. And I’m going to go through the health unit has concerns where the client is not using transmission reduction methods: enhance client’s knowledge, reviewing how HIV is transmitted and perhaps barriers to them using safer sex strategies. So, it’s a two-pager, and fairly intense. So what we tell them, and that's a first incidence of an STI following their initial diagnosis, we say that we need to make sure that you understand how HIV is transmitted, and we collect partner names, and then we tell them as gently as possible, again we want them to see us as supportive, but we do tell them, “If you were to be diagnosed with another STI in the future, our Medical Officer of Health may choose to issue something called a Section

> 22 order, which would require you to take certain measures under the Health Protection Act to keep yourself and others safe." So, we do tell them that this is what could happen…The AMOH would say, "This is the third STI for this HIV infection. Draft a Section 22 order." I would draft it and then it would go to the manager and the AMOH for review. (P5)

Nurses engage clients in minimally intrusive approaches as a "first step," which includes dialogical methods such as reviewing health teaching, and then increase the intensity of engagement with clients who "resist" by exerting more pressure in counseling to conform. Increasing the intensity of engagement involves warning clients of the power of public health authorities to use more coercive measures, and if necessary, reporting the case to the A/MOH who may issue a Section 22, Section 35 and Section 102 order to force compliance if required.

The threat of Sections

An A/MOH has the power to issue an order under the authority of the HPPA (1990). The name of an order corresponds to the "section" of the HPPA (1990) in which the details of the power granted to an MOH are described. For example, in Section 22 of the HPPA, it states the following:

> **Order by M.O.H. re communicable disease**
>
> **22** (1) A medical officer of health, in the circumstances mentioned in subsection (2), by a written order may require a person to take or to refrain from taking any action that is specified in the order in respect of a communicable disease. R.S.O. 1990, c. H.7, s. 22 (1).
>
> **Time**
>
> (3) In an order under this section, a medical officer of health may specify the time or times when or the period or periods of time within which the person to whom the order is directed must comply with the order. R.S.O. 1990, c. H.7, s. 22 (3).
>
> **What may be included in the order**
>
> (4) An order under this section may include, but is not limited to,

(g) requiring the person to whom the order is directed in respect of a communicable disease that is a virulent disease to place himself or herself forthwith under the care and treatment of a physician;

(h) requiring the person to whom the order is directed to conduct himself or herself in such a manner as not to expose another person to infection. (R.S.O. 1990, c. H.7, s. 22 [4]; 1997, c. 30, Sched. D, s. 3 [2]).

An A/MOH may follow-up with a Section 35, and request "a judge of the Ontario Court of Justice" issue the order "where a person has failed to comply with an order by a medical officer of health in respect of a communicable disease that is a virulent disease" (R.S.O. 1990, c. H.7, s. 35 [1). Failure to comply with the advice of an A/MOH following a court order can result in further legal consequences such as a Section 102, "requiring the person committing the contravention to take any action that is, in the opinion of the judge, necessary or advisable for the purpose of reducing the likelihood of a continuation or repetition of the contravention" (2007, c. 10, Sched. F, s. 21). Typically, orders are served as a letter from the MOHLTC to the client in person by the public health nurse, other member of the health unit, or a bailiff, and outlines the "circumstances" or behaviour(s) of concern the order is addressing, along with the frequency with which the index case is to report to a public health unit for mandatory assessment and counseling. As described by one nurse, "Usually we counsel them: 'Do you attend your medical appointments? Take your treatment? See the specialist?'" and after reiterating and reinforcing public health teaching "then we'll be monitoring them, we'll touch base with them at 6 months, and then ongoing counselling for life…unfortunately, whether they want to hear it or not" (P3).

As shown in Figure 19, in addition to helping serve the order and engage the client in counseling, the public health nurse's role in implementing a Section 22 order includes reporting the client's progress: "then it's always you're connecting with the AMOH: 'Okay we're getting this far, or we're not getting this far,' and he might say, 'Okay continue again

Enforcement of Orders:

The Sexual Health program staff members responsible for follow-up of the case/partner will also follow up with the order to determine whether or not the individual has complied with the order within the required period of time (as outlined in the order).

In situations where there is non-compliance with an order the file must be brought to the attention of the Program Manager, Program Director, and MOH to determine further action. At the discretion of the MOH, legal consultation may also be sought to determine appropriate action.

Follow up of Section 22 Orders:

All Sexual Health staff who have served a Section 22 order to a client will complete [an outcome summary form], and normally submit this completed form to the program manager within **2 weeks** of serving the order. A copy of this form is to be printed off and placed within the client's record. Staff will inform the program manager immediately of any repeat infections or ongoing contraventions of the order.

Figure 19:
The Role of the Public Health Nurse in Enforcing Orders (POL7a)

for another few sessions and see what happens'" (P2). The intent of engagement continues to be:

> They know what is expected of them, and they also know about failure to comply. It's written on the order. So initially we say that subsequent STIs could result in a Section 22. Then, once a Section 22 is actually issued, failure to comply with a Section 22 can result in a Section 102. That's when a person is brought before a judge, and the judge dictates, you know, steps that they would have to take. And we have done a few of those as well. (P5)

The goal of gradually increasing the intensity of the measures used in case management practice is the same at each increment: "To find out how we can make sure that [the client] does what he's supposed to do and not get into trouble, really" (P4).

Decisions about when to issue a Section and how mandatory follow-up is defined once the order is issued are based on the judgement of an A/MOH about the individual's "needs." The timelines and actions nurses are expected to implement in the management of cases therefore tends to vary across heath units in relation to the viewpoints of the

A/MOHs in each jurisdiction. This is clear in the description of the decision-making process in the account of one nurse who explained:

> Yeah, we haven't had any [Sections issued] for a while. So, with the new AMOH, the tide has shifted on the rigidness. Because ultimately, you know we gather all the information and give it our manager, and she would say, "I have to meet with the AMOH and see if a Section is going to be issued." And it's really their call. If he says, "No," obviously we say, "Okay." (P14)

Policies do not reference scientific literature to support decision-making around the application of a Section in practice. According to public health nurses, "There isn't a lot of guidelines" (P13); "Our policy is [the client] gets called forever. The HPPA says that it's infinite, because of the disease, but all health units do it completely differently" (P14). One nurse, explained, for example, "The section is there forever, but not necessarily the follow-up" (P13). In terms of using Section 22 orders to enforce compliance, one nurse said, "We have had quite a few in the past, but, well, I think we would tailor it to each situation: What's the circumstances of the case? What do we know about this individual?" (P6). Another nurse elaborates: "I guess each person is a little different, as you know" (P12). Decision-making is done "case-by-case:"

> So, with the Section 22 in our jurisdiction, the expectation is, "Disclosure to all partners of your HIV status and sex with a condom." Whereas I think some health units will say, "Disclosure always, but if you disclose then condom use can be negotiated." But then again, it's case by case. Because when somebody has had ten STIs following their HIV diagnosis, okay something's not working here. Something's not working [and a Section might be issued]. Somebody who is using condoms consistently for anal sex, but not using them for oral sex, and has an undetectable viral load, we likely would not Section them. But again, it's up to our AMOH, and it's case-by-case. (P5)

The boundaries of nursing care are shaped by each A/MOH's beliefs about the meaning of a client's behaviour and the "best" way to respond to it. The stance most public health units have adopted is shown in Figure 16, an explicit or implicit policy of engaging with clients using the "least intrusive, most effective approaches" to encourage risk reduction behaviours.

For any case where a person may be posing a risk of HIV infection to others, non-coercive measures must be implemented to decrease or eliminate the risk posed. The "least intrusive, most effective" approach to intervention should be followed. A Section 22 order under the Health Protection and Promotion Act (HPPA) is only to be considered as a last resort when less intrusive measures have failed.

High Risk Client and Actions that may be taken

-CD investigator will consult with the program manager and AMOH
-Contact client within 5 business days to schedule in person counseling session with CD investigator if feasible. If not feasible, counseling can take place over the phone.
-Counseling session is documented on "Re-counseling Form." **Minimally, discussion focuses on disclosure and encouraging the use of condoms and barriers during sex if the risk is related to sexual behaviour.**

Issuing a Section 22 order

-Non-compliance is reported to AMOH. Evidence of non-compliance can include:
- -Further evidence of unsafe practices (sexual or needle sharing)
- -Engaging in penetrative (oral/vagina/anal) sex or needle sharing without disclosure
- -Failure of case to follow through with plan i.e. unwilling to meet with CD investigator, follow up with HCP
- -Refusing counseling
- -Case refuses to name sexual or needle sharing partners so that partner(s) can be notified of exposure
- -AMOH/MOH may issue a Section 22 order under the HPPA. If the AMOH signs a Section 22 order it may be served either in a counseling session or sent via regular mail.

The CD investigator should follow up, when possible, on cases after orders are issued to ensure they comply with the specified time periods for those items in the order that have a time frame attached (e.g. naming contacts or attending counseling). Follow-up is specific to the individual case and the context of the order.

At a minimum, the CD investigator will attempt to contact case or health care provider 6 months after an order is issued to assess if they are managing the order's requirements. This should be discussed with program manager prior to attempt to discuss what information is required. Attempt at least two phone attempts to the case and if unable to reach the case or information provided needs to be verified contact health care provider.

Figure 20:
Guidelines for Non-compliance in a Public Health Nursing Policy (POL2c)

Intervening with graduated intensity.

In summary, *case management nursing practice* in Ontario predominantly

appears in public health policies as a series of increasingly intrusive steps public health nurses are mandated to follow under the authority of an A/MOH granted by the HPPA (1990) to ensure that people with HIV are made aware of and comply with a set of predetermined biomedical-ethical-legal measures deemed essential for protecting themselves and others from the threat of the virus. The intensity of case management practice is increased in response to a client's "failure to comply" with the ideal steps of HIV follow-up. Each public health unit has its own criteria for how much time and space nurses and clients are allotted to demonstrate conformity with the expectations of the A/MOH before the intensity of engagement in practice is increased.

The graduated measures and timelines nurses are expected to follow when completing the first 5 steps of case management are clear in most health unit's policies. Across the province, the policy for client follow-up is similar: "We call them first. No phone number, no answer, we'll send letters. Actually, we have this HIV follow-up form. It's like an algorithm" (P7). In Figure 21 is an example of an algorithm nurses follow in one jurisdiction or decision-tree, highlights the deadlines for clients to respond, or "lines drawn" in the case management process that signal to nurses when it is time to take a new course of action. The actions at each new step on a decision-tree increase in intrusiveness, for example, from a phone call to a home visit. One nurse describes how the timelines are implemented as follows:

> You look up in the policy how many times to call, which is like three tries over three weeks, and then we send a sort of a generic letter [that says], "I have an important health issue to discuss with you. Please call us at this number." We use texting now too. Each office has a phone they can use for texting, so then we might just send a text message and it says right on the bottom, "Please do not answer this text. Call." There's an order then: three tries, and then a letter, and then a text, and we give them three weeks to respond. And then we do one more call. It's in the policy. Now if it's chlamydia, we close them off at that point. If it's syphilis or HIV, we don't just close them off. Then we might try other strategies, like a home visit or let's send the Outreach Nurse to see if they can find this person or whatever. (P4)

PHN will follow-up with all new HIV/AIDS Cases once HIV/AIDS notification form is returned.
→
Attempt to contact client within **72 hours** via phone, email or letter
→
No response after **2 phone** calls or email, send letter and a response date of **maximum 2 weeks** from the date the letter is sent.
→
No response to letter by requested response date, home visit will be made within **1 week.**
→
No one home, leave letter. If no response after **5 days** to letter, consult Manager.
→
If client lost to follow-up, send lost to follow-up letter to HCP, Close on IPHIS: "lost to f/u."
→
When client has been reached, advise of result, provide HIV positive post-test counseling, complete partner notification, offer HIV package of resources, chart, close file once f/u has been completed, close on IPHIS.

Figure 21:
Timelines guiding Nurses' Actions in HIV Follow-up (POL4)

The timelines and actions taken with a client when a Section 22 is ordered also reflect a process of intervening with graduated intensity. As explained by another participant:

> So, here's our Section 22 policy, which we basically adapted from one of the major public health units in the province. We only had one before, and it was a few years ago. So, when this one was issued, we did quite a bit with the individual as far as negotiating different timelines. We discussed it with our MOH, and he gave a timeline for when he was supposed to disclose to his partners that he had HIV. And actually, we almost Sectioned him, and our MOH said, "Let's give him one more chance." And we did that again, and we met with him a lot. He had some problems with contact tracing--he had a very "bad memory" problem. So, we had to go back, and it was painful how many times we had to go back and meet with him. He kept saying that he was going to do it, but he never did it. And it was the requirement that [his partners] would contact us, and then we would know. And we never pressured him. We gave him a lot of chances. We were very diplomatic with him. We tried and tried. We tried to put everything in place to prevent the worst from happening, and the worst thing that could happen, did happen. He just had to do what was right. I remember he called us, after the Section, he started giving us some names and then got taken to jail. He was charged. It was just nasty all around. (P11)

Decisions about which measures are the "least intrusive and most effective" as a case progresses are grounded in the collective decision-making process of a health unit and

ultimately based on the individual judgements of an A/MOH about what is and is not acceptable behaviour for someone with HIV in Ontario.

Case management begins with nurses following pre-established steps and timelines when attempting to reach and first counsel a client, and proceeds in accordance with subsequent timelines and actions as determined in consultation with the team manager and A/MOH as necessary, to encourage a client to comply with the goals and measures required by the public health unit for completing the management of a case. According to one nurse, the amount of force used is meant to reflect the intensity of the threat perceived:

> We get very few clients who are resistant. Some do, yes, and if they are resistant, we have to use more forceful measures like, for example, home visits, if they don't respond to our phone calls or letters. You know, "I just went to my healthcare provider. I've already told him information. They know, so I don't need to tell you anything." We get those clients, and we appreciate that, and we understand that, but there is information that we need to get. So, they will just cut us off. So, we send letters, and we text them, and we call, but we still need to verify partners. Like if anything, we just want to know partners. We'll go to their house, we'll drop off a letter, and say you need to come, or call us. And if they don't respond, then we have to do another letter, *more threatening* letter as you may call it, you know? We do regular mail, then we do registered mail and sometimes we'll throw in a Section 22 message that, "If you don't respond to us, you know, this may result in a Section 22." So eventually they call us, and we talk to them, and ultimately, we can close off our case very cleanly. (P8)

The plans for clients, including when to intervene with *forced measures*, or strategies that may be "threatening" for a client, vary according to the A/MOH's views about when forced measures might be effective for helping complete a case as "cleanly" as possible.

When an A/MOH believes a person at risk or living with HIV/AIDS "poses a risk to others," a Section may be issued to increase the consequences of non-compliance. Clients are typically ordered to report to a public health unit and engage in an evaluation of their behaviour with a public health unit "for life." Any "violation" of the order is managed with increasing coercion including threats of legal proceedings. Alternatively, as shown in Figure 22, when compliant, the A/MOH may grant a client greater time between mandatory meetings and space to exercise more freedom to practice "good" behaviour prior to re-

engaging with a public health nurse for an assessment and counseling. The management of HIV/AIDS largely involves the management of the behaviour of people at risk or living with the virus to contain the threat of transmission to the public.

Concerns regarding non-compliance:
If, during the counseling of the client, the Clinic staff member becomes aware that the client is not likely to comply with the advice given and poses a risk to others, the Clinic staff member will notify their Manager. The Manager and the Clinic staff member will consult with the Director, and options will be explored, including the issuance of a Section 22 order…

Clients who are issued Section 22 orders will be followed up on an ongoing basis at the following frequency:

An initial visit in one month; then
Every two months for one year; then
Every four months for one year; and then
Annually thereafter.

More frequent follow-up may be required based on the risk perceived by the Clinic staff member and the presence of any risk factors…

Should the Clinic staff member become aware of any violation of the Section 22 order, or the client come to the attention of the Health Unit for any of the reasons of this policy, the Manager and Director, Medical Officer of Health and Health Unit lawyer will be consulted regarding further action including using Section 102 of the Health Protection and Promotion Act.

Figure 22:
A Timeline related to the Compliance of an Index Case with a Section 22 Order (POL10).

The role of case management nursing in the HIV response in Ontario, therefore, is to direct people at risk or living with HIV along a pathway to “good” health. Based on these results, the parameters of “good” health reflect the medical-ethical-legal stance of a public health unit and is dictated by the measures deemed as essential by an A/MOH for protecting the public from harm. Public health units and nursing care are organized around a virus centric goal of controlling the spread of HIV or “disease containment.” The successful “completion” of a case is largely measured in terms of a client’s ability and willingness to engage in “transmission reduction measures” or “good” risk reduction behaviour. As a result, *engagement* in the current model of public health care in the HIV

response in Ontario is a form of behavioural control. Public health nurses involved in case management are expected to provide direction to each individual newly diagnosed with HIV/AIDS and assess and report a client's progress or compliance with the behaviours public health deems as essential for "good health." Progress in the HIV response is conceptualized in medical and epidemiological indicators as suppressing the spread of the virus and reducing the threat of HIV to the public.

As a virus centric approach, case management nursing is described in public health unit policies as a series of tasks. The main tasks of case management include following people infected with HIV through a linear pathway or set of steps from screening to treatment as a means of helping control the internal and external spread of the virus through the bodies of individuals infected with HIV to others, and simultaneously, helping clients, nurses and public health authorities avoid medical, ethical and legal consequences or "trouble" associated with the spread of HIV. The focus on medical, epidemiological and ethical-legal concerns, or "biosecurity" in the public health response to HIV/AIDS, means nurse-client engagement is mandatory and public health nursing is preoccupied with "making it easy and making sure" all individuals with HIV and their contacts in the province are educated about the risks of living with HIV in Ontario. The outcome of each case is entered into a provincial data base for electronic surveillance. People with HIV are monitored "for life" to assess the likelihood of their compliance with "transmission reduction measures," and each individual living with HIV lives under the threat of increasingly intrusive measures being applied by the A/MOH of a public health unit to contain the threat the virus and their behaviour poses to the public.

5.3. Theme 2

"Living with a Client for a While:" Collaborating with Clients to Meet their Needs

Public health nurses across the province may adhere to a virus-centric approach in their follow-up with people who test positive for HIV in Ontario. However, when asked, "What

is the goal of case management nursing practice?" the response was not an expression of biomedical or security indicators. Across health units, the goal of case management with people affected by HIV from a nursing perspective was similar: "It's support. To let them know they are not alone" (P8). At the point-of-care, case management nursing practice is constructed around a people-centered approach and can be conceptualized primarily in relational terms: "So, it's really just a time for us to talk, and give them support, aside from all the stuff that I have to get" (P8) (See Table 3).

Table 3

Comparison of different Social Constructions of Case Management

Medical-Epidemiological Management	**Balance**	**Nursing Management**
Public health policies (treatment cascade)	Source	Nursing practice (point-of-care)
Biosecurity	Approach	Relational
Disease specific, virus-centric	Concerns	Comprehensive, client-centred
HIV follow-up	Definition	Living with a client for a while
Task-based	Response	Dialogical
Positive HIV lab result	Case	Person who tested HIV positive
Undetectable viral load	**Goal**	**The client feels supported**
Direction	**Steps**	**Collaboration**
1. Verify lab result		**1. Learn the client's story**
2. Contact clinician's office		**2. Start where the client is at**
3. Contact index case		**3. Share mutual concerns**
4. Partner notification		**4. Match information to needs**
5. Enter surveillance data		**5. Facilitate connections**
Not notified or linked to treatment	Incomplete	Unable to reach and counsel
Engaged in medical treatment	Completed	Engaged in obtaining quality of life
Diagnosed, in medical care, undetectable	Indicators	Aware of options and coping
Fixed, objective	Outcomes	Variable, subjective

Case management nursing practice includes risk assessment, educating clients about risk reduction and engaging clients in specialized medical care, but the meaning of "engagement in HIV care" as articulated by nurses is perceived less as an objective outcome, and more as a subjective process and qualitative measure of the nurse-client relationship. Rather than disease containment, the goal of engaging clients in care is to help them "feel better" about their options and potential of living with HIV. For example, one nurse described the criteria of a case that "went well" as:

> If I could engage a client; if I could gain their trust. If I could engage them to a point where I could teach them all the things that they need to know and that they left feeling better. I think that's a big thing, that if people leave after they speak with me and feel better, I've done something. So, it might not be everything on that checklist, or it might be just a portion of things just for now. But if I can engage them and I can get them to see me as someone they can talk to without judgement, without a power balance, without any sort of fear, and they feel better after talking with me, then that's successful. (P9)

Alternatively, "the opposite" of success in case management according to nurses is a lack of mutual engagement: "I think it would be if I couldn't reach them. If I felt like I couldn't engage them, or if they were resistant to wanting to open up to me, then I would feel that that wasn't successful" (P9). *Engagement* from a public health nurses' perspective means:

> …to establish a relationship and try to meet them face-to-face. That's what we want to establish. Because in HIV you want to establish with them that you can have some trust. Because that's huge, right? It's a huge diagnosis for them, and they are going to have a lot of care. And that's the case management piece. (P11)

The "case management piece" is conceptualized by nurses as engaging *with* clients and not necessarily engaging clients *in* a predetermined linear pathway from testing to treatment.

As one nurse explained, "I understand what those [biomedical indicators such as CD4 counts and viral load] all mean and how it equates to a person's health outcomes, but at the end of the day, it's not really my business. For sure we want to counsel people about keeping track of those and what they mean for the long term" (P22). However, when

guided by a goal of "supporting the client" as opposed to "disease containment," the practice of engagement can be traced to different set of actions and indicators. Care is not geared specifically towards specialized medical follow-up and efforts are undertaken by nurses to be non-judgemental. Follow-up in case management from a public health nursing standpoint was conceptualized as 'living with a client for a little while:'

> If I have somebody who's really engaged, and they're going to follow-up, and I'm going to be more involved with their life for a little while, I may do a little more informal conversation, or I'll offer them some written information--if they want it, alright; if they don't, they don't. But I'm going to make myself a resource more in that sense, if they're open to that. (P9).

In terms of contacts of people with HIV, the aim of nursing is also to be seen as a resource and non-threatening: "It's just so that they have that information at hand and what they do with it is kind of up to them. That's important, I mean I don't think it's fair to give them this news and then force them to get tested. Maybe they're not ready for that, and you just have to accept it" (P22).

At the point-of-care, nurses' emphasis in the HIV response is to "try to come at it from a caring perspective," which centres around the client's needs and concerns, mainly "how I can hopefully help you and support you" (P21). A client's progress on the linear pathway from screening to suppressed viral load is not an essential outcome. A measure of progress, or a "good" outcome of engagement is a client's ability to identify and progress towards their own personal goals after learning about their risks or diagnosis with HIV. In the words of a nurse, the desired outcome of being "involved in their life for a while" is envisioned as:

> I guess when you feel they're comfortable sharing some of their concerns with you, and when they're starting to open up a little bit and maybe identifying some of their own issues; feeling good they can identify some of the things they want to achieve. And that they might even use you as a sounding board, and they're asking you for advice--well not advice but maybe guidance--information for their own knowledge. Maybe it's helping them to--well it's making them realize, you know, "somebody cares, and somebody's watching." (P6)

Success is a measure of engagement with a client in a relationship, or *relational care*,

such as when "you give them an opportunity to share their experience and they feel okay about it" (P12). As another nurse further elaborated:

> I think it's that with the client we have *some kind* of engagement. It doesn't have to be high-functioning, or a high level of involvement, but the fact that they are asking a few questions, that they have some kind of sense of what they are in for, and that this [engagement] is something they are going to need maybe--help, over and over--whether it be from us or from somebody else. (P3)

The goal for nurses in the HIV response is to "have some kind of relationship starting to build," (P2), that "is hard to measure" but is a feeling "they trust us in our case management…they come to know us" (P3).

Public health nurses concede that, "yes, of course the treatment piece is huge," but success is more a matter of respectful, mutual engagement and support (P14). A caring approach was described by one case management nurse, who explained:

> I find if you show people that you care about them, the first thing shouldn't be, "You've got to get treatment." The first thing should be talking to them about how they can make it through this difficult time. (P10)

The goal of public health nurses that emerged in interviews is to help clients consider and cope with "what it all means; 'What's your future?'" and involves "letting them know that we're going to support them and are here to answer questions. We may not have them, but we'll try and find the answers, or look for the people that can help" (P11). Engagement in nursing care guided by a goal of the client feeling supported is linked to a narrative that is nearly imperceptible in the guidelines written in the Policy and Procedure manuals across the province, but traceable in nurses' description of a different set of strategies adhered to in their practice: (1) Learning a client's story; (2) Starting where the client is at; (3) Sharing mutual concerns; (4) Matching information to needs; and (5) Facilitating connections. In this section, each step will be described in turn.

5.3.1 The steps of case management from a nursing perspective

Learning a client's story

While carrying out the steps in the policies, public health nurses aim to learn a

client's "story." As one nurse explains, "We'll ask, 'So what was the reason for testing? What was their story?" (P10). The "investigation" starts from the moment a person's file is received. In the words of one nurse, "So I would look in their file and see what kind of counseling we've done and what the scoop is, you know, has this ever happened before with this individual?" (P6). Another nurse elaborated:

> So usually I look through the labs. I first want to check to see if there's anything I can see off the bat. And I'm just looking to see if there's an early marker [of HIV e.g. a reactive P24 antigen test result] and if this might be a new infection for the person. Sometimes there's a little identifying info on the paper, like it might say this was for travel, if there were any symptoms, things like that. Sometimes there's little codes on it, and sometimes there's not, to see where the person was tested. Was it at the doctor's office? Or the hospital? Or did they come from our clinic? Then usually I'll put the phone call in. If it's at the doctor's office, I'll call them. If it's from the clinic we have their file. I usually check that to see: Why was the person tested? Did they get their diagnosis yet? What are some of the risk factors or the things we know off the bat about them? In our unit, what we do is track symptoms. We look to see when they presented if they had any complaints. Later, we use all of the stuff we know to kind of time the infection to a certain extent: we look to see whether it's a new case or a chronic case. So basically, at this point, I'm just trying to get as much info as I can to get a picture of what might be happening with the person, and then sort of take it from there. (P22)

An important first phase of case management nursing is gathering information from the client's chart and testing clinician about "what brought this person in for testing" and "get a sense from the doctor or whoever it was, who they are and why they may have come through" (P21).

Part of learning a person's story also involves attempting to understand what was already discussed and decided with regards to a client's case, including "What is their plan and how they're going to act on the results" (P11). In addition, nurses call the testing clinician to find out if "there was something going on in particular," and to "kind of get a sense from that physician, and getting a sense of that physician, of their comfort level" with managing the situation (P. 21). Therefore, part of the public health response for case management nurses involves learning not only whether or not clients have received information about testing and treatment but following-up with how clients have been

treated by others and whether or not they are coping. "If the person came to clinic first" then nurses explain that they "usually have a conversation with the nurse who saw them. . . to see, 'How did that conversation go? Do I need to do any follow-up with them? What was the story?'" (P21). If the public health unit receives a 'third party complaint' by phone, "say someone calls in, we say, you know, 'Why would a person call in? What's your take? What's your practice? What are you thinking?' because they could be a jealous lover, it could be an enemy, you never know. We do go out of our way to find out what the client has to say" (P13).

When public health nurses speak with clients, they start with open-ended questions, "to kind of open the door" to dialogical engagement and learning about a client's situation (P11). Examples of open-ended questions may include: "So, how are you handling the diagnosis? Where are you with getting support? Whether it's coming from the family--maybe you've discussed it with them? Or maybe not? How about through your medical support? Where are you at?" (P10). Nurses further claim that making a home visit has a greater purpose than "tracking down" a client. A home visit can be "very enlightening" and one aim is also to "see what's going on in their world" (P13). According to one case management nurse:

> And sometimes, well, I've been in some pretty frightening places, and you walk in and see how a person lives. It makes you think, "How could they possibly make it to an appointment?" (P13)

The first step of case management based on interviews with public health nurses is to ascertain each client's story in order to understand what conditions may be impacting a client's ability to cope and to "start where they are at" when engaging *with* clients in care.

Starting where the client is at

While public health nurses typically take the lead in contacting a client newly diagnosed with HIV and their partners, the steps followed for case management tend to unfold in relation to the client's responses to questions. Across health units, nurses agreed

that "follow-up doesn't have to occur in these exact steps: first call the doctor, then the client…Every case is different" (P13). Another nurse added:

> I find that with HIV that you can't be like, 'Okay, step one, now step two, all the way down the list.' Sometimes step one might be step five, or a mix in-between. Everything will be covered, but like yeah, it might not happen that way. (P14)

From a nursing perspective, the role of the case management nurse is to centre the follow-up around the client's story. Engagement *with* clients start with efforts "just to kind of get a bit of feel for the case. You know, it could be someone who was diagnosed 20 years ago, and it's like, okay, let's see where they are at then" (P14). Engagement *with* clients rather than engaging clients *in* a predetermined pathway to "good" health in practice means, "We try not to follow the [counseling] form. We make it a discussion" (P14).

The process of dialogical engagement with a client typically begins with an open-ended question and continues with identifying and addressing their concerns. As one nurse explained:

> I always ask them how they're doing. "How are things going? How are you doing?" Where are they at, at that moment? And then I explain my role and ask what some of their expectations might be, and then how we're going to help kind of navigate through it. (P11)

Decisions about what care to provide are centered around each person's unique situation, which may vary. In the words of another nurse, "Sometimes when we call them, they really want to talk and they have a lot to say, and sometimes people feel they've already been supported" (P22). Often, the decision about which issues would be discussed with clients depends primarily on nurses' assessment of a client's questions, knowledge and situation, including which topics were already covered in counseling with the testing clinician:

> It really depends on how supportive the testing health care provider has been to them. In cases where they're tested at a walk-in [clinic], they don't get a whole lot of anything except they just get the result. So, in cases like that, they're looking for a lot of information. So, in that case, the first call is just about wrapping your head around it, how are you doing, going through the process of what's going to happen going forward. And then the second meeting is checking-in on their understanding, and then going over all those educational pieces that are nice to do if they're open to it. People can be in like two different

> camps: "It's not a big deal," they're on medicine and it's okay; and the other one, you're dying, "I'm going to die tomorrow. How could this happen? How does it happen?" And there's lots in-between. You never know what you're going in to. (P2)

When engaging with clients in care, public health nurses both try to anticipate and attempt to create space for counseling about the variety of topics related to living with HIV that may be of interest to clients.

By "showing them a lot of respect when they come, and not being in their face or asking them a lot of questions, they can choose really what they need to discuss" (P11). One rationale for starting with a client's concerns, or "starting where a client is at," was described as follows:

> Because that's your big concern, especially over the phone, "How are you doing?" And we try not to come across too "power-over" kind-of-thing, because to me, I think that's when people might be the most fragile, before they've had a chance to talk to us. They just know they have it and many don't really know anything else. (P1)

Public health nurses are also finding that "people understand a lot more about it now," and the reason the process of case management is not "fixed" in a specific order and content is to accommodate people with any questions they might have about managing HIV without leaving them "overwhelmed" (P1). One nurse elaborated:

> I try to get an assessment of their knowledge base—some people are very knowledgeable and some people aren't—to get a sense of like am I just going to tell you stuff that you already know or where can I help you in this? "Have you been doing any reading? What has happened with you since you got this diagnosis? So, first off, do you have any questions?" (P21)

Starting with a few open-ended questions is viewed as a means of sensitively "opening up" space for ongoing mutually respectful engagement with a client. Respectful engagement involves "avoiding assumptions" (P22), and "overall, being non-judgemental" and "listening and not making comments" (P1).

Nurses believed that, "You know, when you have talked to them a little bit, and maybe developed a bit of a rapport, and gotten to know a little bit about them, you sort of feel a bit of empathy, right?" (P6). Another nurse explained, "So we just work with

speaking about their emotions and trying to understand what they are most concerned about" (P8). Learning a client's story helps establish the conditions for understanding, or "empathy," and starting where they are at enables nurses to engage clients on topics that are a priority in their lives in the process of promoting public health. Leading with questions such as "Were you expecting the results? How are you feeling?" (P8) or "Any immediate concerns? How are you coping?" is a strategy used at the point-of-care by nurses to create opportunities to respectfully share information (P1). The potential benefit of "learning a client's story" and then "starting where they are at" was described by one nurse as:

> So, if this is the best way to beat an STI, but you're going to practice here, then we might as well meet them there. There's no sense in talking about, "Thou shalt!" sort of thing. We can offer education about where you're at, that these are the strategies that you might need to put in place. (P11)

The goal for nurses in engaging with clients using these tactics is to tailor educational, emotional and social support to clients' needs. Therefore, from a nursing perspective, case management in Ontario involves "using a harm reduction approach" (P10), meaning, "Okay, we acknowledge they're going to 'do this,' so how can we help you to do it more safely; so not to belittle them, or tell them, 'you can't do that,' but suggest what can be done to do it more safely" (P11).

Sharing mutual concerns

The incorporation of a people-centred and harm reduction approach into the practice of case management involves engagement in conversation around a variety of different scenarios of concern to clients while discussing the issues of concern to a public health unit. According to public health nurses:

> It's kind of fulfilling what we need to get for our mandate in public health, but just in a way that best serves that person. At the end of the day, there are a bunch of questions I need to ask and I'll try my best to get them answered, but if someone is really upset about their diagnosis or whatever element, then I'll divert the conversation to what they're feeling or what they really need. Do I make sure I check off every single box for the risk factors? No! I'm asking them a bunch of questions,

> and addressing, I guess, what they are more focused on. If they say, "Yeah, I think I really do need to take more time, I really need to talk to somebody, or I really need to exercise--whatever it is, whatever they are telling me is a priority for them--then kind of balancing that against what I need to collect. (P22)

The direction of care with clients "just depends on the scenario," and to maintain a "balance" in case management, nurses say they "always try to answer their questions" in the process of providing information deemed important from a public health perspective for protecting the public (P22):

> Actually, at the first meeting, that's one of the things we say too: "We're not going to leave you on your own. We're going to make sure you get the care you need. We're not going to just tell you, and that's it. We're going to make sure you're okay"…"How are you doing? How are you coping with it? How are you sleeping?" Have you told anybody? Who have you told? What are you thinking?" and that sort of thing. And then again, we'll go through the checklist. (P4)

In practice, fostering mutual engagement, or a sharing of mutual concerns, is a strategy used to help clients "feel supported" when engaging with a case management nurse.

Public health nurses encourage the sharing of mutual concerns by trying to maintain a dialogical relationship when offering information about guidelines and services available to support people with HIV/AIDS:

> So we would already have this, the lab information, and we would fill in the reason for testing, and talk about these things [on our checklist] at some point, you know, depending on what their needs are. I do say, "There are a lot of things I need to talk to you about, but if you want to ask me questions, just stop me at any time." We really try to use the principle of client-centered care. They're the driver of their care. There are certain things we need to get through, but we try and do it with them feeling that they are in control of it, right? And that we are advocating for them. (P10)

In nurses' experiences, "there's a huge range" of issues that might be a priority for a client who is newly diagnosed with HIV (P5). One of the main concerns of clients is "the disclosure piece and talking to future partners and current partners" (P3), or "Who do I need to tell?" (P4), and "Am I going to pass this on to my child? Am I going to pass this on to a family member?" (P10). In the words of one public health nurse:

> A lot of the conversation is just letting them know that their life is still normal. "You can still have a job. You can still hug and kiss you know and do everything you do with your family, eat off each other's plates and drink from the same glass. But if

> there's a blood spill, or an open cut, this is what you should do to manage it…You don't have to notify your family if you don't want to. You don't have to notify your friends, until you are ready. It might be helpful to notify your friends, because they could be a good support for you, but only notify the people who are going to be supportive to you, not who you'll have to support." So, things like that. "Oh, okay. I thought I would have to notify my employer and it would affect my job." (P8)

Clients' "biggest concerns" also include how they can maintain employment (P3), how to access medication (P18), the ability to have children (P1), how to optimize health through nutrition (P6), family members' reactions (P11), and stigma (P9).

A broader conceptualization of the public health response appears to exist within the intimate spaces of the nurse-client relationship where information sharing is not limited to descriptions of the biomedical and behavioural changes expected of clients:

> The doctors will focus on medical treatment, CD4 counts, viral loads, and TB testing, but for nurses it's the 'overall health' that's important: spiritual needs, nutrition, sleep. One question some clients ask is, "How long will I live?" but we 'break the bubble" of fears. "It is a chronic infection, and not just medicine is important. HIV doesn't define you." (P19)

While not well accounted for in the policies or documentation criteria on iPHIS and other forms, the role of public health nurses in case management tends to involve discussions of a number of personal and social issues:

> When you meet them, we do not just focus on the HIV, but we talk about a lot of other things too: family, your hobbies and your interests, and you know, we have a lot of clients with kids. Like the last client I saw, he was so distressed…And it turned into a conversation about his friends, his, you know, his life, his parents--all the factors which were causing him stress. Not just the HIV, because he said, "I can deal with the HIV actually, I know I can get it treated. I have friends who support me. I know the face of HIV has changed, so actually, I can kind of deal with this now, but the job, and you know, my mom..." It just gives them a chance to talk about other things that they haven't been able to talk to about with other people. (P8)

Nurses working in rural public health units shared additional issues that impact their clients' personal and social wellbeing:

> They may be having anonymous sex with clients at bathhouses or meeting people online. Here we see that a lot: a lot of MSM who are living as 'hetero.' Many go to bigger cities where there's bathhouses for sex with other men but are married here to a female. Even when we are meeting with them, you know like if they refer to being in a marital relationship, or a heterosexual relationship, we will still ask further, you know, do you also have other relationships? Many have never disclosed that,

> especially to a health care professional, because that’s their life, “their other life” that they don’t really discuss. So, it’s huge. (P11)

In other public health units, the issues clients shared with nurses might be similar or different, but the process used to engage in dialogue around mutual concerns was generally the same:

> I guess it depends on the client. I mean, sometimes people are managing well and it’s less of an involvement. And sometimes people at first are hesitant to talk about any information, and then when you are kind of assessing with them what their needs are, you find they have a lot to say or have questions. Sometimes people have questions that I can't answer, about medications, insurance, or stuff like that. Then we can take some time, you know, and I can get some answers and get back to them. And sometimes we might try to arrange for them to come in and give them an opportunity to sit down and say, “Okay, obviously there's been some difficulties, so let’s start off with some of the things you want to accomplish right now. Like what are your top 5 goals? I’ve for sure done that with a few patients just to say like if they have complex issues, like mental health or addictions issues, I’ll say, “Okay there's a lot going on right now, so what are the top three things that you might like to get done for you?” (P22)

The counselling provided by public health nurses appears to address a combination of biomedical, personal and social issues of concern to clients, and suggests that a more comprehensive approach to case management exists at the point-of-care than accounted for in policies. Case management nurses tend to include strategies that promote dialogical engagement to identify and understand the intersection of all three and their impact on clients’ ability to cope, “so it isn't just, ‘You must... You must...You must;’ no, it's a conversation” (P5). Subsequently, the nursing care offered at the ‘frontlines’ of the public health response in Ontario, although relegated to the margins of public health care, appears to be less about “avoiding trouble” and more about finding ways to work together with people as “allies.”

Matching information to needs

Public health nurses draw from a variety of sources of knowledge to provide support and comprehensive care in case management. In the words of one nurse, “once everything is sorted with the doctor’s office and they’ve told the client we are going to call,

well, actually we then do more research, and try to educate ourselves on anything the client could possibly need" (P16). "I always think of us as 'information brokers,' said another nurse (P13). One of the most important roles of a case manager from a public health nursing perspective is "to be more like a support, and kind of address questions that maybe other clinics can't answer," and the work of case management is "sometimes just a matter of filling in the blanks a little bit after they've gotten their diagnosis" (P22).

Public health nurses involved in case management described their sources of information as follows:

> We had a very basic knowledge of the clinic before we went into STIs, and then a very good basic knowledge of STIs before we started HIV. And we have done a ton of our own reading, and our own research. (P13)

The sources of literature attached to policies to guide case management practice are primarily medical and epidemiological in content and mainly provide information about methods of HIV transmission, risk factors, and risk reduction measures. There is relatively little information about how to provide personal and social support in the guidelines for case management practice. Those that exist are either educational material collected from community agencies, at conferences, or created by nurses in the process of following-up with clients.

Nurses match this information to clients' needs by "gauging" what information might support the client "where they are at." For example, when determining what care to offer a client at the time of learning their diagnosis, one nurse explained, "I would probably say, 'You do have HIV. I'm sorry to have to tell you,' and then I probably would wait...wait to see their expression on their face and gauge how they are reacting to that, and kind of go from there" (P6). The process of gauging a client's reaction and responding to their needs then continues throughout the process of case management. As one nurse explained:

> When you ask the questions about what they know, it sort-of evolves from there. You find out what they understand. You ask them, like, "How do you think you got this? Like, "Where do you think this came from?" And the discussion can evolve from there. (P3)

The case management process subsequently involves the use of probing questions to identify and then match information to meet clients' needs. This is evident in the following description of one nurse's counseling:

> So, then I'll ask them, "So, did the doctor talk to you about what next? What you need to have done? Did they talk to you about viral load and other tests for looking at how healthy your immune system is? Did he talk to you about treatment options, and what the plan is there?" Just getting a sense of how far the physician got with them, and then if they say, "I don't know. I just got blood taken," and they don't have any idea what happened, then I'll say, "Well I imagine what he was testing for was to look for how much virus is in your system and how your immune system is faring against that virus. And then that information will help him to refer you and make decisions about treatment options." And then I'll talk to them about where they can go for treatment and talk to them about the different locations. And often I'll talk to them about transportation: "Are there any barriers? Do you have a car? Are you working, and do you have drug benefits?" and those kinds of things that they'll need to know to manage in the future. (P21)

The question and answer approach tends to evolve into a form of relational care. A public health nurse will continue using the "standard questions and approach, and depending what the client wants, that may change" (P22). Another nurse elaborated:

> Because you can ask them, "Hey, how's this going?" and they might bring up, "Hey, what about this?" If their big thing is, "Look, I'm still sharing needles," I'm going to talk to them about that. If it's the drug use portion that's more important to you today, then I'm going to focus on that. And if you had a client you couldn't touch on all this [information on the counseling form], because you can't always get everything in on one shot, it's okay; it's that ongoing communication that's really important. (P7)

A relational approach enables public health nurses to help cover the counseling topics expected of a public health unit, as well as to identify and support clients with medical, emotional, and social issues unique to their experiences with being diagnosed and living with HIV.

A *relational approach*--or gauging a client's response and matching information to meet their needs--involves efforts to avoid being "pushy" (P5). In the words of a nurse,

“That education piece is a lot to digest, so we try to gauge it with how the client responds--we cut it up” (P11). “Cutting it up” as a tactic in practice means:

> You can’t do too much all at once, just little bits, and checking-in all the time to see how they’re handling that, and to see what they understand too. You know, you can say a lot, but they might not be getting it, especially if their head is somewhere else, you know. You just have to be always mindful of that--where their head’s at--because it’s hard, you know….So you want to take the information available, and simplify things, and for them to know that there’s good stuff, and we’ll go through it step by step, and we’re here for you, and you know that we’re going to be supporting you as you’re going through this. (P17)

Sensitively matching information to clients’ needs means that “essential” topics public health nurses are expected to discuss such as partner notification and disclosure may not necessarily be broached “until we can build a bit more of a relationship” (P17). This was clear in the description counseling by one nurse who said:

> It was all client led and it wasn’t the first conversations we had about it. It came up later. So, I said, okay, he has this partner, and this was kind of his concern right now. So, then I asked him if he thought about how he was going to tell them, and we went through the advantages and disadvantages, and I said, “It’s tough, obviously to have the conversation.” But he decided, the client decided, that he was going to tell her himself, and we have this guide from CATIE [the Canadian HIV/AIDS Treatment Information Exchange] about “How to tell your partner,” and I went through it with him. (P16)

Public health nurses’ practice of case management also includes examples of identifying and addressing topics of interest with clients that were not well accounted for in policies. For some nurses, “the immigration cases, sometimes they are a little more tricky” since perceptions of HIV, access to medications, and types of available services may differ across countries, and nurses agreed, “you need to just be able to help them work through that” (P3). Also, one nurse explained, “lots of people test HIV positive through their immigration screening and their main concern is, ‘Is this going to affect my immigration?’ and a lot of time I don’t have answers to some of their questions, so I refer them to HALCO, which is the HIV and AIDS Legal Service” (P18).

A number of public health nurses also had to learn how to help clients who are

incarcerated in prisons navigate health and social services. From a case management nursing perspective, one nurse said:

> “It's not an ideal environment, but…if need be, depending on what the client wants, I follow-up with confidential health information often in with their personal property…to get them the package of information about the resources in the community throughout the province, because we don't always know where they are going to be going after, what they will need, and what are their next steps when they get out. (P3)

Public health nurses have also had to learn how to support people with precarious housing, no health card, and needing to find ways to afford medications. As one nurse elaborated:

> Well, we end up doing a lot of social work, right? It's crazy, some of the things you're trying to learn. It's not something I've been trained in. So, when I first started doing this job, you're thrown into this ‘uninsured world’ and just trying to get people healthcare, or all these different things, including trying to find doctors who will see patients that might not show up for appointments…Now we do see a lot of guys strung out on crystal meth, and so sometimes we take on that social worker role trying to get people into care. (P18)

From the standpoint of nurses in the public health response:

> We don't say to someone who is in a situation like that, “Okay, let's get you an appointment.” They need food. They need clothing. They need some kind of a house. That's where we would start. They don't need an appointment today--if you live under a bridge, you can't go and take pills. (P13)

Subsequently, much of the work of case management is invisible in the policies and procedures for public health nurses, mainly nurses' efforts to find information and resources to address the wide range of personal and social challenges associated with living with HIV in Ontario.

Nurses rely heavily on educational pamphlets and brochures for information to share with clients: “We have some support pamphlets of services for aboriginals, or if they're interested in nutrition, and these about universal precautions because we're getting a lot of questions around them,” said one nurse (P10), and “it's really these three that we always give” (P17), which include a booklet from CATIE, and handouts from HALCO and the closest AIDS Service Organization (ASO). The information shared with people in case

management extends beyond biosecurity concerns and is largely based on an accumulation of knowledge gained by nurses through experience, handouts designed by community partners, and matching resources to each person's unique needs.

Facilitating connections

In addition to "information broker," public health nurses say another important role of case management is that of "point person." In the words of one nurse, "We're a bit like a point person that has a little bit of work to do" (P11). Along with learning a client's story and centering HIV care around the lived experiences of people with HIV, case management from a nursing perspective involves "facilitating connections." An essential step in working with clients is to "make sure they're hooked up with care" (P4). Public health nurses described several ways connections to care are facilitated:

> We are linked to the provincial AIDS and sexual health information line and that's answered here. And there's the Infectious Disease Specialist, the ASO, CATIE, and our van with the needle-exchange program. Again, HALCO for if they have legal questions--the Canadian HIV/AIDS Legal Network. If they don't have a primary care physician, we will direct them to the Academy of Medicine. And, of course, if it is somebody with children, there are community organizations for that. So, we give them this pamphlet with all the resources, and we offer to refer them to the Infectious Diseases Specialist's clinic. If the client has not been referred by a physician, we can fill out a form for the referral. And we offer contacts standard HIV point-of-care, nominal and anonymous testing. (P5)

Across health units, nurses claimed, "Because we're connected, we really make it our goal to make sure everyone is connected" (P11).

Subsequently, facilitating connections not only involves linking clients to specialized medical care for testing and treatment, but to personal support and social services as well.

> We give them suggestions where they could possibly go. There is a hospital in the next city, where they have Infectious Diseases Specialists, but if it's a client who says I can't get to the hospital all the time, then we'll send them to a clinic in their area where they may not have all those options but they have good clinical care. Or if we know what languages they speak, then we will refer them to a doctor who speaks that language that also can treat HIV. So, depending on what assistance they need, their travel circumstances, where they work, if it's easy to get to from their work, then we'll determine where they might want to go…In our jurisdiction, there

> are very few options, and some clients, they need more nurturing, or more support. So, if it's a client that we know may need a social worker, or more nurturing and support, or a nutritionist, a dietitian, then we'll set that up for them too. (P8)

One nurse also explained, “At the end of the day people don't have to go into treatment, that’s totally up to them; the main thing is that they have that community linkage and someone keeping an eye out for them” (P22). According to public health nurses, clients have a choice:

> So, then we let them know what's out there. Our ASO will do home visits. They will absolutely see them anywhere. The other thing they provide, besides education and support, is they have housing help. They also will arrange for transportation to the specialist in the closest town if that is more of an issue for some people…being able to afford transportation. They have volunteer drivers, so they will take them to those appointments, which is really helpful. (P4)

All public health nurses interviewed across the province expressed the belief that in the nurse-client relationship, the “main role is to connect them” and the main indication that a person’s case was managed well is “that they feel connected” (P21).

The main strategies for facilitating connections are assessment and referral; “So really trying to focus on what the client’s experience is and what their goals are in making those referrals” (P22). In case management nursing practice this means:

> What the relationship really focusses on is getting them in touch with the best person for the support they need. For example, support from the African-Caribbean community, or depending on their demographics, like if it is a gay man than those kinds of things they might need. (P22)

Another case management nurse explained, “Yeah, we just have our resources and know who to call if we need help with something” (P17). For example, public health nurses all claimed to begin a case by assessing and addressing the mental wellbeing of a client when they first meet:

> “How are you feeling?” “Any immediate concerns?” “How are you coping?” “Have you had any thoughts of hurting yourself?” and, if that is a concern, then we’ll focus on that. We’ll just stop right there until that’s dealt with. And we do, we have a crisis line here that we’ll refer them to, and mental health services. (P1)

Case management nurses also facilitate connections by providing options for people to receive support in a way that is convenient by “personalizing it” (P11). Nurses make special arrangements including sometimes offering to escort a client to a service provider if greater support is requested. One nurse shared that in her practice:

> Um, just that they’re always welcome to come in...and that kind of thing. I try to leave the door open, and, you know, “You can always come here for testing,” and we try to get them hooked up with the ASO, if possible, for treatment. The ASO is in the neighborhood, so we can just walk them over there and show them where the building is. Or, what we can do is, for one person I actually did a written referral and sent it in for them, because that’s what they wanted…Or we try to hook them up with our local community health clinic. There’s a nurse practitioner program there that will take on clients. So, we try to hook them up with a healthcare provider there sometimes, so they can have somewhere to call and that they can go to for other issues. And often that helps, because if they’re having other issues, if you can help them out with that, they’re more likely to follow-up with the HIV as well. For example, there’s also a drug and alcohol counseling group there in case they need that. (P1)

Public health nurses facilitate connections to health and social services by creating time and space for people to obtain services in manner that “works best for them” (P21). Another nurse explained, for example:

> And with any contact when I follow-up I make sure that I'm free. If I'm giving someone some alarming news, I want to be free to be accessible. So even to say, “You can come in. I'm here all afternoon if you want to come in. If you come to the clinic you won't have to wait in line. When you come in just go to the front desk and ask for me.” And some people will come in right away, like within the hour, and I’ll just stay a bit later. I don’t feel comfortable calling someone and springing that on them and then saying, “Okay, good luck!” So, they can have an appointment, you know, so they can ask questions and feel comfortable with that. And if I do have to call a contact and I can see that I may not be available, I will make sure that somebody else is there, someone who's really comfortable with HIV testing is working in the clinic. So, it’s like how can we make it more accessible for them? (P22)

Case management nurses incorporate a variety of strategies to make engaging with public health care more convenient and “comfortable” in order help make health and social support services accessible.

Additional strategies used to make clients more comfortable are inviting partners or family members along (P13), meeting people in their homes (P21), offering to meet in coffee shops (P22), doctor’s offices (P6), or hospital rooms (P11), and requesting special

accommodations for people in prisons (P3). The importance of creating supportive environments was explained by one nurse, who said:

> We could meet them in a clinic room, but for me that feels a bit sterile, I think. We don't have a ton of space here so like sometimes we meet in a counseling room. So, there we have a round table and some comfy or couches, just to kind of make it feel like it's less threatening would be the idea. (P22)

Public health nurses help to create non-threatening environment by trying to account "how people learn, and how people feel comfortable talking to another person, and some of it is just time" (P21). While follow-up of all clients at risk and newly diagnosed with HIV is mandatory, the rationale provided by nurses for going to great lengths to meet a person was not only to ensure they were connected to testing and treatment services, but to "reassure them" and provide them with a sense of "connectedness" (P22). The explanation public health nurses give clients for wanting to meet in person is:

> "It's a lot easier to provide information, to give you an idea who we are, and it gives us an idea who you are. You know sometimes it's a lot easier face-to-face. Is that something you would be interested in? We can meet you anywhere that is most convenient for you." And most of the time they will meet us. And often times, after meeting us, they appreciate that we have actually met them in person. It makes it more real for them. And, it makes it more real for them to know that there's someone who actually wants to help them, as opposed to just some person they've never seen before getting them information about an issue affecting them the rest of their lives. That's the benefit of us meeting them. That's why we try to encourage it. At the same time, we won't push it on anyone. We tell them, "This is your choice." (P8)

In other words, nurses say, "We'll meet them wherever they wish to meet if it's a private spot where we can communicate, to make it easy and attainable for them" (P11).

Public health nurses will also make an effort to "take things slow" (P8), "speak slowly" (P22), and in soft, "reassuring" tones (P6) in their efforts "to establish a relationship" and "not lose that connection" with a client (P8). The concern of case management is to promote "that kind of continuity of care" (P9). In a relational approach in the case management process, a nurse will "kind of end it, well it's kind of up to them, you know; but I will ask, 'Do you have any more questions?' and say, 'Feel free to call anytime'" (P1). As one nurse said, "We're closed on paper, but we always tell the client

they can call us back anytime" (P8). Therefore, the nurse-client relationship may continue depending on the needs of a public health nurse *or* the client. However, the follow-up of a case is considered completed "when I know the client is connected to services, [and/or] they know who is available, they know they can access us, they know they can access the ASO for services, and when they are well connected to a clinic" (P11).

By tracing the lines of thinking of public health nurses participating in the study, it appears that case management, therefore, includes a different set of roles and practices in addition to those decided for nurses in Policy and Procedure manuals across the province. Relegated mainly to the private spaces of the nurse-client relationship at the point-of-care, case management involves dialogical engagement that aims to promote mutual sharing of information about what is needed to manage living with HIV. Subsequently, the quantity and quality of case management in the HIV response in Ontario varies not only in accordance to the position of the A/MOH on the type, timing and intensity of public health measures to apply in practice, but also in relation to the degree to which a nurse has the capacity to promote mutual engagement and assess and account for the unique concerns of clients. Public health nurses' work involves encouraging clients to voice their concerns with a goal of ensuring people feel supported in the process of case management. In conjunction with efforts to ensure compliance with the medical and ethical-legal directives of the A/MOH of a health unit, public health nurses incorporate a number of strategies to develop a collaborative practice with people who test positive or are exposed to HIV, such as learning a client's story, starting where they are at, sharing mutual concerns, matching information to needs, and facilitating connections. Case management, as socially constructed by nurses in Ontario, includes relational care, people centred and harm reduction approaches, and creating supportive environments in addition to efforts to help clients "avoid trouble."

5.4. Theme 3:

"That whole dance we do:" Balancing Dual Obligations

The main challenge for public health nurses in the HIV response is how to balance the competing goals and meanings of "engagement" informing case management practice. As articulated by one nurse:

> How do you balance out the risk of protecting other people versus your therapeutic nurse-client relationship? And trusting your client and not damaging that trust with like, "Oh, I need confirmation of every single thing that you do!" versus "I do need to protect the health of these other people?" There's always that balance which is the true challenge. (P9)

Nurses find themselves struggling to balance an obligation to enforce biosecurity goals aimed at protecting the public from the spread of HIV on the one hand, with providing relational care meant to ensure individuals feel supported in case management on the other. In the words of public health nurses, "We try to be kind, but yet knowing that we have something that we have to follow up with because it's reportable" (P11), and "this is that whole dance we do" (P1).

Across jurisdictions, it was believed the emphasis of nursing practice should be on supporting the client:

> I'm going to touch on everything that I have to touch on, but I'm going to do it at the client's pace, and I'm going to do it 'on their page,' and I'm going to let them lead. My focus is not about me and my checklist, but "What do they really need to know?" (P9)

However, in a number of situations, "sometimes you just have to juggle what is the priority: is it maintaining that relationship with the client because you know that they really need you or jeopardizing that?" and frequently nurses find, "the relationship went sour" (P8). For example, one of the most "difficult" situations for nurses is having to balance a need to press clients to provide the names of partners with efforts to support them in their concerns about confidentiality and stigma. The dilemma for nurses is, "It's sort of double obligation! You know, in the back of your head, you're thinking 'contacts, contacts,

contacts' but in the front of your head you are thinking, 'client, client, client'" (P6). The result is a preoccupation of public health nurses with how to (1) combine directional care with relational goals; (2) manage the ambiguities and tensions in HIV care that arise from competing concerns; and (3) generate resistance and innovations in case management practice to improve client outcomes.

5.4.1 Combining relational goals with directional care

Overall, the work of case management nurses in the HIV response in Ontario can be viewed as a combination of encouraging each client to follow the predetermined pathway from testing to treatment established by the A/MOH as the priority for public health while maintaining a supportive nurse-client relationship in the process. In the words of one nurse, public health nurses have a dual obligation that is fulfilled in case management when a client both "understands the infection, and they feel like they have some supports" (P3). The main goal for clients in case management nursing "is support," but providing *comprehensive care* means combining the relational goal of nurses with directions for complying with the medical and legal goals established in public health for HIV care:

> To let them know they are not alone [and] also, letting them know the progression they can make. I'll share cases or other scenarios, like cases where viral load was undetectable with treatment, and they got jobs, and went on to have relationships and families. Just giving them some perspective, or just the knowledge that this is not a life-threatening disease anymore. (P8)

Public health nurses engage in a virus-centric approach but work at the intimate spaces of the nurse-client relationship to support people at risk or living with HIV to achieve their goals for quality of life. Another nurse summarized the balance aimed for in case management as follows:

> Well ensuring that they've accessed treatment, that they are disclosing, and they've gone on treatment and still having a happy, healthy sex life, and safely, and not infecting other people. That's the goal: [a client] can still live a happy life, but without infecting other people. (P1)

In practice, relational goals and directional care are combined in different ways with the aim of accounting for the goals and concerns of each stakeholder involved in the HIV response.

Relational care is meant to establish trust in order to learn what a client values and needs, and account for it. As one nurse explained, “So, we always try to establish a trusting relationship. That's the really big piece, right?” (P11), and case management is considered effective by a nurse when, “I think just seeing some of the most memorable cases is when there’s denial when you talk to them on the phone, and they come to meet you and there’s almost like acceptance, to the point where they just open up, and just share” (P12). Offering both support *and* direction is meant to enable people to accept their HIV positive status and “move on” emotionally, physically and productively as “chronically” different but “happy” members of society:

> My main goal is to reassure them and to see if they need that reassurance. They may know a lot of people who are HIV positive, and they’ve accepted the fact that they are, and they’ve already got a doctor. That’s a lot of people actually. And then you have the others that you call, and they’re just in tears, and then it’s just a reassurance thing. And like usually they’re the people with a lot to deal with--it’s their new normal, right? This is going to be part of your life now. But it’s a manageable illness. Now it is more like a chronic infection. You have it for the rest of your life, but you know you'll adjust to this information. You will move on. You just need to give yourself time to absorb it all. (P18)

Clients find themselves in a category of the “new normal” of “chronically infected” people with HIV and the work of case management nurses is twofold: “We’re here to move you forward: get you in a healthy place and give them hope and let them know there are people with HIV living happy lives” by adjusting to the disease and all the medical and ethico-legal expectations that it entails (P11).

According to case management nurses, the indications of a client feeling both supported and aware of how to manage living with HIV is, “I think when I feel they’ve got all those supports in place and when they’ve got the information” (P17), as well as “knowing that they’ve notified their partner and it went better than expected”(P16), and

finally, “that they are following-up; they have their doctor’s appointment, they met with the ASO, or they have a connection” (P15). Subsequently for public health nurses, case management involves helping clients navigate a number of medical, ethical, legal, nursing, and emotional and social challenges. Arriving at an “acceptable” balance is complex: “And for support, like, ‘It might look like this,’ or ‘It might look like that;’ we might go down this road and all the while knowing that it’s best for the client, it’s the best for the other client [their partner], and it’s best for the public” (P11).

5.4.2 Ambiguities and tensions in HIV care

An “acceptable” balance in case management from a public health nursing perspective means accounting for the different needs of the variety of stakeholders involved in HIV care. It is envisioned by public health nurses as:

> I think it’s just when everyone leaves the process respected, and everyone feels their needs have been met--on both sides too, not just the client, but as far as the team and the services, they worked together. (P10)

However, in its current form, case management nurses believe that often “there isn’t” a balance in public health care. In trying to “juggle” the dual obligations of promoting the quality of life of individuals with protecting the public from the spread of HIV, nurses regret, “sometimes you feel like you might be short-changing one over the other” (P1). The main dilemmas for nurses in case management are related to areas of ambiguity in care, or “grey areas,” that are not well addressed by the accepted policies and practices. Grey areas tend to create tensions in practice and a reluctance of clients and community stakeholders to engage with case management nurses.

Ambiguities and tensions in care have arisen in a number of practice areas. In the words of one nurse, the issue in nurses’ follow-up with clients “depends on what stage of the journey we are talking about,” but mainly what is unclear in the public health response to HIV in Ontario is, “Where do we cross the line as far as being involved with them?” (P10). According to public health nurses, “difficulties” or “grey areas” in policies and

practices include the length of follow up with contacts (P9), how far to "push" a client for contacts' names (P1), the role of public health in monitoring for non-disclosure (P2), the use of Section 22s (P5), and the information that is important to include in documentation in case management (P14). The tensions that arise related to ambiguities, or differences of opinion over the direction of case management, were summarized by one nurse who explained:

> It's just frustrating sometimes with the grey areas. That's the biggest issue--not knowing even something as simple as how often should people be getting tested! Cause there's not even any good guidelines for that, let alone for follow-up. Like, "What do we do in this case?" and "What do we do in that case?" With disclosure? With contact tracing? Well, I think every case is different too, but sometimes you're going by your gut a bit, right? You know, "I really believe this person," and other people, you're like, um, "I don't feel good about this." Probably provincially they would have to look at what are the best practices for follow-up--What works? And what doesn't work? And what's worth doing? And what is not worth doing? And, also, with HIV so different now than it was back in the 80s, what SHOULD we be doing? There are differences even within our team about how hardline we should be. (P1)

The issue for nurses is having frequently to choose one obligation as a priority over the other based on minimal evidence. Practice decisions in complex situations are often based on "a lot of informal discussion with the team and our manager; so it's done case-by-case and usually we've tried to exhaust every method: we'll make all the phone calls, we've gone to their house six times, and we keep going," and the concern for each nurse is, "Like how do you just stop? When is enough, enough, you know?" (P9).

A major issue in case management in Ontario according to nurses is, "We are all different, and some are more aggressive than others in their follow-up" (P1). For example, with regards to 'verifying that contacts have been notified by clients,' a nurse at one health unit claimed, "we still do it, but some health units don't" (P6). In a different health unit, a nurse confessed:

> We are not sure if we should be doing more when verifying if they've been tested. But again, back to the balance of the nurse-client relationship, am I going to stalk you and call you 300 times to see if you were notified and got tested? And if you choose not to get tested, it's kind of your prerogative. (P9)

Yet in another jurisdiction, the nurse explained, “So we do the verification part, which has become a new thing for us. It’s like a punitive thing, in my opinion” (P8). The nurse elaborated:

> But it came out of our meetings with the AMOH. We were just concerned that contacts weren’t being notified, so it was just a way for us to make sure, to protect the community, the public, that these people have the right to know that they could be at risk…Other health units don't do it, but we just adopted that practice, and I think the team in general has mixed feelings about it. Because if the person is going to tell us that they're going to do it, you want to trust them. That's the problem they don't trust them, the health unit. And this whole verification process comes across in a very negative way…We've heard rumblings that there are certain health units that are more punitive and that we and another health unit have a reputation as being more punitive because our case management was more intense. (P8)

Verifying partner notification is one area that a trusting nurse-client relationship and the respect of community partners is sometimes sacrificed in the name of ensuring the public is protected.

Another grey area in case management nursing is “getting peoples’ names and disclosure, that’s often more difficult” (P1). As one public health nurse explained, “I don’t feel comfortable pushing very hard for contacts; I don’t know what other nurses say, but I don’t want to be the police” (P6). Another added, “I would try and see if I could get the name off of them, but if they say, ‘I don’t know,’ you leave it at that” (P21). The dilemma for nurses, or the “dance they do” in balancing their dual obligations is linked to, “I sort of see the important thing as the client who has HIV, and helping them get into treatment, so I don’t want to push them away by making it appear that we just want their contacts” (P21). In many health units, the nurse “would try to get the partners’ contact information, the names and numbers, but certainly if they are going to refuse that” then nurses suggest, “we’re not going to let that be a roadblock for us; we’re not going to ruin the relationship over something like that” (P14). However, in a different setting, “as per our MOH, the client had to notify his wife even though he said they hadn’t had sex in a long time, and it ruined his marriage,” and of concern to the case management nurse was, “and now does he still

come here? I don't know, it probably ruined our relationship with him too" (P7). In those health units, "the MOH's are like, 'No, we need to be as hard line on this as we can be" (P1). As a result, it is common among nurses that "when you do contact tracing or when you talk about this topic, you have that kind of knot in your stomach as to what they're going to say, and how's this going to play out" (P21).

How far to go when contact tracing with clients who say they are disclosing their HIV positive status to their partners is another area of ambiguity in practice that creates "knots" or tension for nurses. There are differences among medical and nursing perspectives about what is the "best" approach to care. As one nurse maintains, "the really complicated ones are like when someone who is already HIV positive and known to us tests positive for let's say chlamydia...that's where it gets grey" (P1). According to the nurse, "If they are disclosing, do we even need to be getting into it with them? Where do we draw the line? You can't really force someone who is disclosing to give contacts. At that point, you're just harassing them, basically" (P1). Another nurse explained the controversy as:

> There's nothing really clear in the guidelines, and management are very adamant [that we verify their partners are informed of their risk for chlamydia and HIV]. Yet, they don't have much experience in HIV follow-up or offer any real explanation why if a person has been HIV positive for 25 years, is on medication and is undetectable, and telling me they are disclosing, how they are suddenly such a high risk when according to science they are not? And then suddenly my issue is that I'm in a position where I have to enforce this decision that I'm not making but it's been told for me to do it. So suddenly I'm in a position where I have to act on behalf of somebody else essentially. And so that's where it can be hard. (P22)

In one jurisdiction, a nurse was relieved when one person living with HIV for years was served a Section 22 for not disclosing to their partners or providing the names of their contacts to public health and "he fought it because he could prove he had an undetectable viral load and our AMOH actually backed down; now he doesn't have to come in for regular counseling, he just has to show his viral load" (P6). In each case, the nurses believed that the stance of the A/MOH and management was to "cover ourselves" so they "don't get in

trouble for not going far enough, like ‘Why didn’t you people call me? I would have gone for testing, right?” (P1). The lack of clear guidelines in public health policies about contact tracing and disclosure counselling is a source of controversy and tension across the province, that frequently results in “disagreements” between nurses, clients, management, and the A/MOH over what constitutes “good” care and *due diligence*, or ensuring that each stakeholder’s concerns are respected (P1; P10).

According to many public health nurses, disclosure counseling and having to monitor a client’s engagement in non-disclosure is controversial: it “is not healthcare” (P10), “it is legal stuff” and “[w]e are not there to interpret the law or give any direction that way. We have our standpoint, like we’re public health: we’re here to protect your health, protect the public” (P2). From a “nursing perspective,” when a client is served with a Section 22 for non-disclosure, it generates tension and fear in case management “that the future relationship with public health is going to be compromised” (P2). In the words of one nurse:

> You have somebody who is working with you, and they’re young, and they’re still going to have sex! Cause they can, and they should, and they’re probably going to get another STI in their future, and you’re creating that negative feeling now for public health. We destroy those relationships, and we drive clients underground. And they may not have any other support. And they won’t get tested now, right? And that’s one of my main struggles as a case manager: as a nurse we wear two hats--that caring nurse working with that person trying to help them with what they are going through, and that investigator side, the public health piece, right? And you know it’s not going to work with most people, and yet the Sections keep going out. (P3)

A sentiment expressed by one nurse was shared by many: “I hated them, I hated serving Sections, I hated being part of the whole thing. I understood it, don’t get me wrong; I don't want to be in a situation where anybody gets an infection, or not knowing they had been exposed to HIV, but it’s a balance! And the conflict goes on, and you know, it’s the nurse that is stuck dealing with it” (P2). It is not clear to many of the nurses how disclosure counseling fits within the domain of nursing, and the ties of case management practice to

threats of coercive public health and legal measures is believed to have a “negative” impact on nurses and nursing care.

From the standpoint of public health nurses, the current policies in place to guide case management practice are particularly problematic with the people who may be less willing or able to conform to the expectations of the A/MOH, “and the problem is that the more risky cases are the harder ones to follow-up” (P1). Organized around a priority of preventing the spread of the disease to the public, the people with the most complex cases can become the least well served by case management. These cases include people with mental health issues (P6), experiencing homelessness (P1; P5), Indigenous people (P7; P9), gay and bisexual men (P7), women with few supports (P6), people who use injection drugs (P13; P14), newcomers to Canada (P8), and people at risk or living with HIV in prisons (P2; P9). In case management, the issues for the people with the greatest needs are often individualized and decontextualized by the need for nurses to emphasize biosecurity concerns. In cases where clients become less likely to be interested in speaking with or meeting a public health nurse, case management nurses have to focus on their obligation to protect the public, or the “public health pieces” considered in policies to be essential as opposed to relational care. One nurse reiterated, “Well we're always under the pressure of what the minimum is that has to be done” (P2), and another explained, “I have certain things that I have to cover, but if they're not that interested in talking to me, I cover what I need to cover: partners, the expectation of disclosure to all needle sharing and sexual partners, and consistent use of condoms for all types of sex” (P5).

The effect for public health nurses of having to function under the threat of using forceful measures is that case management comes to be viewed as “punitive” by both clients and community partners. A number of nurses claim that some physicians and AIDS Service Organizations are generally supportive of case management until “we charge

somebody with a Section 22 and then not so much" (P14). In the experiences of public health nurses: "They're more than happy to speak with us on the phone and help with us in any way they can, but sort of the whole vibe of us, is we're kind of police, right? Which of course, we don't look at ourselves as like that" (P13); and "that's always been a bit of an issue now, I don't know if you would call it a struggle, or tension, yeah tension, between the health unit and our AIDS resource network here, and part of it has to do with our old methods of follow-up, where people are made to feel like pariahs" (P1). The effect of the grey areas in public health policies is that public health nurses are often in a position where they have little to offer the people with the most complex emotional and social needs but the threat of being Sectioned or anonymous testing, and many in case management have begun to question, "So what is the value of what we're doing?" under this current model of care (P13).

5.4.3 Resistance and innovations in practice

Despite attempts to balance different values and beliefs about the "best" direction for care in the public health response to HIV/AIDS in Ontario, public health nurses' decisions are inevitably governed by the priority given to disease containment and protecting the public. In almost every case, biosecurity is valued over the quality of life for people at risk or living with HIV when solutions for addressing grey areas are discussed. Nurses describe having "some leeway" to implement a more collaborative and comprehensive approach to case management at the point-of-care (P12), but experience clear limitations to their autonomy and ability to develop their ideas for a more relational approach to care in practice.

Forms of resistance

One of the main tactics used by case management nurses to better balance the priority given to biosecurity concerns with clients' needs in the current model of practice is to create more time and space for people to voice and address their own concerns. One nurse explained:

> So, sometimes to maintain the relationship, we just have to take the client's lead and trust that they'll do what they say they're going to do. They're not malicious, they want to do the right thing. It's just a matter of time, which we appreciate, so we let them have it. (P8)

By listening to and "exploring" individual's concerns, public health nurses help create space for new narratives and possibilities for how to proceed in case management to emerge (P22). Many nurses will then "contract" or "negotiate" with clients about how to integrate their unique needs and interests into a public health care plan, and these strategies provide people affected by HIV with more options in case management follow-up. For example, for clients who are "reluctant" to provide public health with the names of partners:

> We will let them tell their own partners. They'll say, "I want to talk to this person first," and that's fair. "Fine." So, we would just contract with them: "You're going to tell your partner by two weeks? Just give me a date. When are you going to tell them? I will wait for that date before I call them, or have them call me once you've told them, cause then we'll know that you told them." There are different ways you can contract with them, you know, it really depends on the individual. (P1)

Creating space for clients to voice their concerns and time to comply with the "expectations" of an A/MOH, are two ways nurses try to create new possibilities for arriving at a "fair" balance among competing priorities in case management practice.

Another tactic used by case management nurses to be seen as "fair" is to distance themselves from the goals and actions used in public health that conflict with their professional values and beliefs. How nurses see their role in the public health response as separate from that of medicine and epidemiology is clear in one nurse's description of the different priorities being proposed by the AMOH for case management follow-up in their jurisdiction:

> [O]ur AMOH is an epidemiologist who is very interested in very different aspects than we are. For people who use drugs, he wants to know more about where you got that filter, where you used it, who gave it to you, did they store it in their pocket, and where did the needles come from; whereas we are looking at more, like, who are your partners, do you need help to talk to them? So, there is really a different emphasis that we are moving towards. It's an enhanced surveillance in a way with

> this particular group. So that's what he'll be looking at specifically with each case whereas we will be looking more at the whole picture. (P13)

Many clinical examples were shared where nurses made it clear to clients that the "expectations" of the A/MOH and epidemiology in a public health unit were not "nursing ideas." In situations where nurses feel obliged to participate in surveillance or threaten the use of more coercive measures, they will "say something like, '*Our line in public health is* that you always inform your partners prior to any penetrative sex" (P18). A number of nurses will further separate themselves and their work from the "punitive" measures being imposed in a public health unit by pointing out the specific origins of the "ideas;" for example, one nurse shared how she makes it clear to clients that, "I'm here to support to you, but for my manager, this is what's required" (P6). Nurses separate themselves from the coercive measures used in public health, because when "we tell them that this is what could happen [e.g. a Section for non-disclosure], that's when people then think, or say, 'You're criminalizing HIV,' and we're not, but yeah" (P5).

In the current medical-ethical-legal environment, case management nurses additionally employ a tactic they call, "good cop, bad cop" to distinguish the stance of nurses from "the powers that be" (P14). Nurses have adopted this tactic to minimize their role played in the use of coercive measures, and to demonstrate their alliance with clients. When serving a Section, some case management nurses say, "I guess I would sort of play 'the good cop, bad cop' kind of thing, that it comes from our MOH and I'm not quite sure what my own philosophy is on it, but he is 'pretty hard-nosed'" (P6). Another nurse explained the limitations of case management nurses in preventing the issuing of a Section and how the "good cop, bad cop" tactic aims to preserve their ability to engage with clients in relational care when it is issued:

> That's not our role. We just collect the information. I once said to a guy, "You won't be sectioned," and then the manager and AMOH went and sectioned him. And it was repealed. So. Well, that was a long time ago, but still, "whatever they do, is what they do." We have to do a kind of "good cop, bad cop" thing then, because we're

> going to continue to talk to them, right? We would have to call him every 2 months for 6 months, and then yearly, and we're the ones who are going to have to make that call. (P14)

"Good cop, bad cop," like creating space and time for clients to voice and address their unique concerns, are measures used by public health nurses to resist the colonization of case management practice with a single narrative focussed on "disease containment." These tactics aim to ally nurses' work with efforts to illuminate and account for "the holistic" concerns of people affected by HIV in case management.

Other forms of resistance in case management include refusing to enact the orders issued by a manager or A/MOH and advocating for "a policy change" (P14). These tactics have met with various levels of success in promoting support for alternative viewpoints in public health units. On a few occasions, the nurse might be "listened to" (P8), and in many other situations nurses' and clients' concerns are not enough to influence a shift in practice or policy. Subsequently, case management nurses appear to believe they have few options but to comply with the decisions of an A/MOH. The boundaries around their ability to promote greater understanding and accountability for addressing the emotional and social needs of clients are most clear in the following attempt of one nurse to resist an MOH's order:

> I brought in the doctor instead and said, "I don't feel comfortable doing this." And he said, "No, you say to her she has two choices: Number one, she can tell him and you will be there with him; or number two, you will tell him." It had some repercussions at the end and the client blamed me. It's a very difficult role. At the time when all this went down, I said to the MOH, "I don't think you should put a nurse in the middle of that anymore. I think it should be you or my manager that gets in there and tells them." I did a year away--I was team leader and I did a year away from case management. I heard he did it again to another nurse. Yeah, they don't like to get involved. (P4)

Decisions in case management are made at a distance from the point-of-care and inevitably based on the prerogatives of the A/MOH. While there are inconsistencies in the rationales given for decisions about when and how to apply graduated measures across public health units, the limitations on the autonomy of public health nurses to establish the

parameters of case management policies and practices does not seem to vary: “And we told our manager that we would like to sit down at some point and have a conversation about our AMOH’s decisions, but for the most part it seems like it's always the way it's going to happen, like that hasn't varied a whole lot, with my cases, anyway” (P2). According to nurses in another health unit, “if we were to say we want it changed, the AMOH would say, ‘Well get some information, do an environmental scan and bring it back,’ and everyone does it ten different ways so there’s no way that that’s going to help make any difference” (P14).

Innovations in care

A number of innovations have been suggested by public health nurses to help address grey areas and resolve “heated arguments” around issues in case management where “people think differently” (P18). However, the development of innovations by nurses at the point-of-care are also largely governed by health unit authorities and priorities. For example, one health unit created an orientation package, and another compiled a “toolkit,” to promote more evidence-informed decision-making. One nurse explained:

> It came from the fact that when I started here, I was not given consistent information. How some nurses practiced varied from others. For the process of counseling and making a referral there was no policy, and I was getting conflicting information and I didn’t like that. And certain other people, how they answer the phone, and triage, it just wasn’t done consistently, and so I felt there needed to be a bit more. So, my manager agreed to have me do something. (P10)

The ability of public health nurses to develop their ideas is subject to managerial and A/MOH approval. In practice, the result is the limitation of new ideas in case management to those that closely align with preestablished goals and emphasis on biosecurity.

The innovations shared by case management nurses in this study were all aimed at expanding the ability of public health units to engage clients in relational care. These initiatives are mainly in the early stages and involve outreach such as greater use of social

media and texting for communicating with clients, a survey to understand the sexual health needs of rural youth, and establishing a regular presence at shelters and youth drop-in centre to pre-emptively build relationships with people from hard-to-reach populations. The rationale for these interventions in the words of one nurse is, “like how do you get better at client relationships? Well, it’s by getting out there and meeting people, and trying to get trust going” (P22). Other innovations aim to increase clients’ access to services such as setting up “warm transfers” to make connections more seamless between the health unit and the local ASO, and nurse-led community-delivered PEP and PrEP through the support of an academic institution.

Notable is that all of these innovations are being developed separately. They are limited to particular health units, governed by its internal hierarchical structure, and compartmentalized by the one-way flow of information through versus across public health units. In this vertical organizational arrangement, nurses’ relational concerns and innovations are siloed and the status quo with its virus-centric approach is fundamentally maintained. There appear to be no policy or practice initiatives in development with nurses in case management to address collective concerns identified at the point-of-care about clients’ “difficulties” with contact tracing and surveillance, stigma, Sections, prosecution for non-disclosure, or clients’ needs for greater emotional and social support, financing for medications, employment, housing and food security.

As a consequence, case management nurses find that despite efforts to be supportive, they are frequently “made out to be the ‘bad guys’” (P1). Initiated under the constant threat of public health law and criminal law, the strategic efforts of nurses to establish trusting relationships, promote dialogical engagement and develop inclusive practices are generally considered by clients and community partners as tactics for “snooping in your business and giving you a hard time” (P1). The effects of a hierarchical arrangement and lack of mechanisms for collaborative policy and practice development

within and across public health units are the "loss" of information sharing, limited possibilities for scaling up relational approaches in HIV care (P2), the dominance of one viewpoint guiding case management practice, the invisibility of much of public health nurses' role in official policies and procedures, and a perception of public health practices as "disrespectful" (P5). Case management has developed a reputation in many jurisdictions as being problematic and relations with clients and community partners are largely unidirectional, meaning "mostly we make referrals" (P22). The impact of an unequal emphasis on a biosecurity approach aimed at protecting the public from the threat of HIV in the public health response was summarized by one nurse as:

> Well, you know, we just kind of keep our heads down, because we know we're mandated to do it. Somebody has to do it. And I do agree, there have been some horror stories! And that's the problem, those horror stories just keep coming up instead of the good stuff. (P1)

Despite the existence of different goals and indicators of success in case management, and a variety of possible approaches to public health nursing care, the priority in the public health response to HIV in Ontario is biosecurity.

The efforts of case management nurses to implement strategies to better account for the unique personal and social conditions affecting clients' feelings of "being supported" are frequently undermined by the threat of coercive medical and legal measures issued in practice. Mandatory involvement in surveillance, threats of Sections and the participation of public health units in the prosecution of clients for non-disclosure of HIV are believed by nurses to be "driving people underground." Nurses' attempts to resist and develop more collaborative approaches in case management are limited by the authority granted to the A/MOH by the HPPA (1990) to determine the structure and policies of a public health unit. As it is currently organized, case management nurses, and their relational goals and ideas, are relegated to the margins of the hierarchy of decision-making. All clients are expected to comply with the biosecurity measures prioritized by

the A/MOH, and their complex needs are simply accounted for in nursing practice with extra time and space to conform at the "frontlines."

In summary, three themes were identified in the analysis of the policies, practices and organization of case management nursing across Ontario that describe the complexity of the work of public health nurses in the HIV response: (1) "Avoiding trouble:" Encouraging conformity to biosecurity measures; (2) "Living with a client for a while:" Collaborating with clients to meet their needs; and (3) "That whole dance we do:" Balancing dual obligations. The complexity of case management nurses' work is related, in part, to the commitment of nurses to providing "holistic" or comprehensive care. The primary goal of case management from a nursing perspective is for the people at risk and living with HIV/AIDS to feel supported. In order to accomplish their goals, public health nurses engage clients in relational care to help understand and account for the physical, emotional and social concerns of each person exposed to or newly diagnosed with HIV. This process of engagement involves learning a client's story, starting where the client is at, sharing mutual concerns, matching information to needs, and facilitating connections.

However, the efforts of public health nurses to develop strategies in case management to account for the personal and social conditions that create challenges for people affected by HIV are not apparent in the policies that guide the HIV response in Ontario. The official policies and procedures in case management are instead centred around biomedical, epidemiological, and legal goals and measures. In the "official" model of care, public health nurses are expected to focus on engaging clients in testing and treatment, and the overall goal of case management practice is to help individuals achieve and maintain an undetectable viral load and prevent the spread of HIV to the public. In this approach, case management nursing practice is viewed as involving six steps: mandatory engagement, following a predetermined pathway, explaining what is expected, making it easy and making sure, judging each individual's ability to conform, and intervening with

graduated measures. These steps represent a historical shift in the public health response from an emphasis on compassion when there was no medication available to offer people at risk or living with HIV to a focus on behavioural control. Case management nurses are now preoccupied with educating clients about the risks of transmission and monitoring their ability to comply. Engagement in risk reduction measures is monitored and enforced with public health law and criminal law.

The priority given to medical, epidemiological and legal goals and measures in case management policies has resulted in ambiguities and tensions over the limited time and space available to support clients who are unwilling and unable to conform. Few options have been developed to assist the people with the most challenges, such as gbMSM, indigenous people, women with few supports, newcomers to Canada, people with HIV in prisons, people with a history of injection drug use and clients struggling with mental health and stigma. As a result, case management nurses are frequently positioned in the centre of controversy or disagreements among different stakeholders in the HIV response about “where to draw the line” when following-up with clients? At the centre of case management nursing care is a “battle for truth” about what constitutes “good” practice and due diligence in the HIV response: disease containment or collaboration where each stakeholder’s goals and needs are heard and respected?

“What we are taught in medicine . . . is a very biomedical model, that your responsibility ends in making the diagnosis and prescribing the right care. If it ends there, poor people will die. People in difficult social situations will die.”
~Dr. Joia Mukherjee, Partners in Health

CHAPTER 6: DISCUSSION

The ‘battle for truth’ over the priorities of the public health response identified in this study of case management nursing is not unique to Ontario. Since the onset of the study, the Canadian Foundation for AIDS Research (CANFAR, 2018) released a new national strategy called, *Ending the HIV Epidemic in Canada in Five Years: It’s Time to Act*. According to the document, we have the “knowledge and tools now to end the epidemic in Canada,” and what is required to improve the outcomes of the public health response is a more coordinated effort to “dramatically scale up testing options, prevention, and access to and support for treatment” (CANFAR, 2018, p. 3). The recommendations are based on the consensus of a multi-stakeholder working group comprised primarily of “doctors and [public health] scientists” who envision the end of the epidemic strictly in biomedical terms, “where new infections are rare” (CANFAR, 2018, p. 3). The recommendations align with the global campaign to “end HIV” (Krishnaratne, Hensen, Cordes, Enstone & Hargreaves, 2016), and targets introduced by UNAIDS (2014) and adopted by Canada to achieve 90-90-90: 90% of all people with HIV will be diagnosed, 90% will receive antiretroviral therapy, and 90% will achieve an undetectable viral load by 2020 (Rogers, 2015). The projection--the end of the HIV epidemic by 2030—is based on the achievement of a single biomedical indicator and has subsequently received criticism for its failure to adequately account for the structural drivers of the epidemic and their impact on the willingness and ability of people to engage in testing and treatment for HIV (Husbands, 2019).

Similar to the findings of this study, a biomedical goal and knowledge are considered “essential” in the latest strategies to end HIV, while knowledge and action

aimed at addressing the emotional and social impacts of the disease appear to be secondary in the management of the epidemic (UNAIDS, 2019). For example, the “knowledge and tools” cited in the document published by CANFAR (2018) as essential to the HIV response relate to risk reduction and new technologies for HIV testing and treatment, namely point-of-care rapid tests, PEP, PrEP, Treatment as Prevention (TasP), and evidence from clinical trials demonstrating that achieving an undetectable viral load with sustained use of HAART can make the virus “untransmittable” (U=U) and reduce the rate of new infections in a population (CANFAR, 2018). While the authors acknowledge the impact of stigma and other sources of structural violence on the persistent numbers of new HIV infections in Canada, no knowledge or evidence is provided to explain how social and structural issues will be addressed (Husbands, 2019).

In their discussion of an alternative approach to infectious diseases management in *Reimagining Global Health,* Farmer, Kim, Kleinman and Basilico (2013) suggest that “[b]eyond the direct experiences of individuals are social, political, and economic forces that drive up the risk of ill health for some while sparing others [which] some have called structural violence” (p. 9). The forces believed to be affecting the rising rates of sexually transmitted and blood borne infections in Canada include social determinants of health such as income, employment, gender, culture and ethnicity, unstable housing, access to health services (PHAC, 2018c), and stigma and discrimination related to racism, sexism, colonialism, heteronormativity and homophobia (PHAC, 2019), many of which were identified as issues relevant to the lives of people in Ontario affected by HIV in this study by case management nurses. Little discussion is devoted to describing the impact of these social determinants of health on the quality of life and wellbeing of people living with the virus in the strategies to end HIV, or how they might be resolved by TasP alone (Evans, Bennett, Croston, Brito-Ault & Bruton, 2015; Husbands, 2018)

The goal of this study was also to identify strategies to better engage people at risk and living with HIV in testing, treatment and support services. The objectives were to describe the experiences of case management nurses in public health units across Ontario and better understand how public health policies shape the boundaries of nursing care and client outcomes in the public health response to HIV/AIDS. The findings provide evidence of two different sets of goals and measures operating within the public health response to HIV in Ontario, and their impact on the definition of case management, including how it is organized and operationalized across the province. These findings provide evidence of different possibilities for conceptualizing the management of HIV, and the power of discourses to frame the goal and priorities of public health policies and practices in the HIV response (Dorfmann, Wallack & Woodruff, 2005). Subsequently, the description and critical reflection on the links between the discourses, policies, processes and outcomes of public health nurses' work in HIV case management help understand how it might be possible that public health authorities would consider declaring an end to the epidemic while social and structural issues remain a problem for people at risk or living with the HIV. The study also offers insight into the potential consequences for people who are unwilling or unable to conform to efforts to scale up the current response to HIV as recommended in the new national strategy by CANFAR (2018).

At the core of the "battle for truth" in the public health response to HIV in Ontario are two separate discourses guiding case management that are similar to those central in the debate about how to end HIV: a medical-epidemiological discourse tied to a biosecurity approach and goal of disease containment and a nursing discourse linked to a relational approach aimed at promoting mutual respect and social support for people exposed to HIV in the management of the epidemic. This study demonstrates how each discourse is linked to a different set of priorities, knowledge, and skills in the public health response to HIV and often compete for time and space within the practice of case management. The

main finding is that the public health response to HIV is predominantly shaped by and perpetuates a culture of fear, and the preoccupation with "avoiding trouble" among public health nurses could be traced to the hegemony of a medical-epidemiological discourse and biosecurity approach with a singular focus on preventing the spread of the virus to the public in the current policies. A biosecurity framework has led to an emphasis in public health care on establishing and enforcing "rules for good health and ethical conduct" in the management of HIV, and the suppression of the capacity of nurses to document and develop strategies to account for the emotional and social concerns of clients. The findings suggest that the singular goal of disease containment in public health policies for case management is contributing to a lack of attention and resources being directed into efforts to address social determinants of health and the structural drivers of HIV in public health practice that may be linked to the persistence of HIV among people from "priority populations."

The emphasis on biosecurity in the public health response in Ontario appears to place a greater value on protecting the "uninfected" public than on addressing the concerns of the people living with HIV/AIDS. A singular goal of protecting the public from harm has resulted in a focus in case management nursing on risk management: assessing each client's level of risk, providing risk reduction education, identifying individuals who are "noncompliant" with risk reduction measures, and implementing forced measures with graduated intensity in an attempt to ensure people who pose "potential problems" conform to the behaviours expected of them by public health units. This approach is resulting in a number of ambiguities and tensions in case management practice in areas such as contact tracing, partner notification and disclosure counseling where the singular focus on "disease containment' appears to be failing to adequately account for the complexity of living with HIV. Nurses believe the limited time and space for responding to the emotional and social concerns affecting clients in the current policies for case management are

impacting their ability to maintain trust, confidentiality and supportive relationships with people at risk and living with HIV and sustain clients in care. The thesis of this study is that the hegemony of a medical-epidemiological discourse in public health care is contributing to the marginalization of the concerns of people who are unable or unwilling to conform to risk reduction measures to manage the virus. Strengthening the capacity of case management nurses to develop a relational approach to address conflicts at the point-of-care related to the current neglect of emotional and social issues impacting people with HIV may be an important starting point for improving the outcomes of the public health response and helping end the epidemic. The findings have implications for future research, policy, and practice in the areas of governance in the HIV response, public health nursing and infectious diseases management.

6.1 The Conflict over the Domain of Public Health in the HIV Response

Specifically, the findings of this study demonstrate how the organization of the public health response around a singular goal of disease containment is resulting in a decontextualized, virus-centric approach to the case management of people at risk and living with HIV in Ontario despite awareness that HIV is both a medical and a social issue (Barker, 2012; Elbe, 2009; Farmer, 1999; Foth, O'Byrne & Holmes, 2016; Gupta, Parhurst, Ogden, Aggleton, & Mahal, 2008; Hargreaves, Delany-Moretlwe, Hallet, Johnson, Kapiga, Bhattacharjee et al., 2016). In, "The History and Challenge of HIV Prevention," Merson, O'Malley, Serwadda, and Apisuk (2008) summarized the medical and social context of HIV care and predicted from a global health perspective that a "combined approach" will be necessary for the HIV response to be effective:

> The HIV pandemic has become part of the contemporary global landscape…Successful responses have addressed sensitive societal factors surrounding HIV prevention, such as sexual behaviour, drug use, and gender equalities, countered stigma and discrimination, and mobilized affected communities; but such responses have been few and far between. Only in recent years has the international response to HIV prevention gathered momentum, mainly due to the availability of treatment with antiretroviral drugs, the recognition that the

> pandemic has both development and security implications, and a substantial increase in financial resources brought about by new funders and funding mechanisms. We now require an urgent and revitalized global movement for HIV prevention that supports a combination of behavioural, structural, and biomedical approaches and is based on scientifically derived evidence and the wisdom and ownership of communities (p. 475).

The results of this study make clear that the public health response to HIV in Ontario is predominately structured around biomedical and behavioural approaches to care (Kilty, 2018; O'Byrne, 2019). The preference given to a medical-epidemiological discourse has normalized the perception that the domain of public health is the management of the virus, individual pathology, the construction of categories of risk, testing and treatment, contract tracing, partner notification, surveillance, education about risk reduction and coercion if necessary to encourage the compliance of individuals with the medical and behavioural guidelines for preventing the transmission of HIV prescribed by each public health unit. The policies and practices are similar across all jurisdictions. Case management starts with the reception of an HIV positive laboratory report and is designed to ensure risk reduction behaviour considered essential for containing the spread of the disease is followed by people who test positive. Case management is organized by "disease," and HIV case management nurses are trained to prioritize steps that promote the engagement of clients on a predetermined pathway that are similar to the steps in the "cascade of care" designed to promote 90-90-90 globally: ensure clients are properly informed of their infection, connected to appropriate clinical support services, and aware of actions required to minimize the spread of infection. In this virus-centric approach, case management is limited to "case finding" (Cassell & Surdo, 2007), and engaging "at risk" individuals in efforts to mediate the spread of the virus (e.g. testing, PEP, PrEP, HAART, risk reduction counseling) in order to achieve a reduced viral load at the level of the population (Hargreaves, Delany-Moretlwe, Hallett, Johnson, Kapiga, Bhattacharjee et al., 2016).

These findings support the theoretical argument proposed by Gagnon and Guta (2012), in “Mapping HIV Community Viral Load: Space, Power and the Government of Bodies,” that the singular focus on the virus in public health policies makes visible and manageable only individuals’ risks for transmitting the virus in public health care. What is essential and what is extra in case management nurses’ follow-up with clients is shaped by the singular target of achieving a reduced viral load based on a medical-epidemiological discourse accepted as the “true” priority in the public health response to HIV/AIDS. From a Foucauldian perspective of power/knowledge, the medical-epidemiological discourse circulating in and through the policies and practices of each public health unit appears to be determining ‘what may, or may not, be thought, said, or written’ by case management nurses and clients when engaged at the point-of-care (McHoul & Grace, 2002). In Gillet’s (2011) work, *A Grassroots History of the HIV/AIDS Epidemic in North America,* he similarly claims, “The medicalization of HIV/AIDS reconstituted the epidemic in relation to the discourses and practices of scientific medicine” (p. 21). Gillet (2011) defines the “process of medicalization” as the process of “pushing unquestioningly for a medical solution to a complicated social problem” (p. 143).

Alternatively, Farmer et al. (2013) have long argued that, “Microbes such as HIV…cannot be understood properly at the molecular, clinical, experiential, or population level without analysis spanning the molecular to the social” (p. 9). The description of public health nurses’ experiences in case management in Ontario offers examples of the effects of privileging a medical-epidemiological belief in biosecurity over relational care as a priority in the public health response. In this study it was confirmed that no social indicators have been developed to guide or evaluate the response to HIV in Ontario, and as critics of the new strategy published by CANFAR (2018) fear, attention to the social and structural drivers of the disease are frequently relegated to the margins of case management nurses’ practice priorities (Husbands, 2019; Nelson et al., 2019). In case management policies,

nurses are tasked with identifying clients who pose a biosecurity "problem" as opposed to developing strategies to address the emotional and social problems faced by clients related to living with HIV. It is mandatory for nurses to report the compliance and noncompliance of clients with the measures to promote biosecurity required by the A/MOH and the team of epidemiologists of each health unit on iPHIS, yet unnecessary to document and track clients' reasons for noncompliance (Kilty & Orsini, 2019; O'Byrne, 2019; Shaefer, Gregson, Fearon, Hensen, Hallett, Hargreaves, 2019). The overall effect is an unequal "voice," an underrepresentation of nurses' and clients' concerns with the emotional and social impacts of living with HIV, in the documentation and policies developed to manage the infection. While the steps for managing the virus are clear in case management policies, an equivalent set of policies and practice guidelines have not been developed to support the practice of relational care, account for the impact of social determinants of health, or address health inequities in the distribution of HIV/AIDS in the population.

Subsequently, with this study it becomes possible to further imagine a link between the shortcomings of case management policies in accounting for emotional and social issues experienced by people with HIV and the persistence of the highest burden of HIV in population subgroups affected by many of those issues (Chulach, Gagnon & Holmes, 2018; Gahagan, 2013; Kilty, 2018; Prentice, Peltier, Benson, Johnson, Larkin, Shore & Masching, 2018). In alignment with the goals and measures prioritized in case management policies, nurses across the province felt obligated to place biosecurity concerns with risk management in practice ahead of efforts to support clients in their management of emotional and social issues such as heteronormativity, homophobia, employment, immigration, mental health, homelessness, ability to afford medications, access to quality services in prison and on indigenous lands, and concerns about having healthy children. The "priority populations" currently identified as having the highest risk

appear to be the same groups most affected by the issues neglected in a biosecurity framework: gbMSM; newcomers to Canada; African, Caribbean and Black communities; people who use drugs; people in prisons, the Indigenous population; and “at-risk” women (CATIE, 2018; OHTN, 2019). As foreseen by Farmer et al. (2013) when raising concerns about the neglect of social, political, and economic forces that impact infectious diseases like HIV, “Such social forces become embodied as health and disease among individuals” (p. 9). The findings from this study therefore raise two important questions: Is the colonization of the public health response with a biosecurity approach subjugating the very knowledge and skills needed to better support the people at risk and living with the virus and help end HIV? If so, what would a more effective approach to managing the epidemic look like?

6.2 The Battle for Truth in the “War on HIV/AIDS”

The casting of HIV/AIDS as a matter of biosecurity was consolidated at the global level when the U.N. Security Council designated the pandemic a security threat in January 2000 (O’Manique, 2018). A global interest in a biosecurity framework occurred shortly after antiretroviral therapy capable of helping reduce the viral load and the risk of transmission became available in 1996 (Gillet, 2011). A shift was also noted at the time medication became available in the focus of case management from an emphasis on compassion to a focus on identifying risk and engaging high risk groups in testing and treatment (Chernesky & Grube, 1999; Gagnon & Holmes, 2008). According to Elbe (2009), the “securitization of HIV/AIDS” at the level of the U.N. marked a critical shift in thinking about the management of HIV from a matter of health and development to a matter of greater “governance” to scale up access to testing and treatment. Framing HIV as an urgent matter of international security offered an effective means of mobilizing the political will and increase in resources necessary to “fight” the threat of the virus on a global scale (Whiteside, 2016). Fears about HIV spreading across borders and creating social and

economic instability galvanized a collective “war-like” effort that included a greater sharing of surveillance data, targeted emergency responses, and worldwide coordination of governmental and non-governmental institutions, policies, funding, research and the regimes of practices aimed at containing the virus that dominate the infectious disease management landscape today (Barker, 2012; Elbe, 2009). In O’Manique’s (2018) words, policies and practices aimed at achieving “health for all” that recognized the linkages between the spread of disease, social determinants of health, community development and well-being, became subjugated to the more “pragmatic orthodoxy of the narrow, state-centric definition of national and global security” and the idea “that the individual (although embedded in a community) is the only reducible focus of security” as the locus of risk (p. 216). According to Elbe (2009) and others, the acceptance of biosecurity as a goal in the management of HIV was produced by fear and perpetuates a perception of the virus as the ‘enemy’ of the state and by extension, infected individuals and their bodies, as ‘threats’ to the public (Farmer, et al., 2013; Gagnon & Holmes, 2008; O’Manique, 2018; Sontag, 1991).

Arguably, it is this fear-driven response, organized around a singular goal of disease containment and measures to identify and “neutralize” the risks of harm to a population posed by an infectious disease, that underlies the modern conceptualization of the management of epidemics as “war” (Elbe, 2009; Foth, O’Byrne & Holmes, 2016; Gagnon & Holmes, 2008). As Sontag (1991) speculated in her critique of metaphors surrounding HIV/AIDS, “disease itself is conceived as the enemy on which society wages war” (p. 67). Based on this premise, this study provides evidence that the public heath response to HIV in Ontario has been conceptualized as a war (Juergensen, 2017). The public health policies and practices in Ontario are aimed at protecting the public from the threat of the virus. Health units engage in surveillance to identify high risk groups and the “priority populations” to target with interventions (OHTN, 2019). Case management nurses

are positioned on the “frontlines” of public health units across the province to engage all individuals who pose a risk in risk reduction measures. The main tactics used in the “fight” against HIV/AIDS are discipline (education about risk reduction measures) and if necessary force (e.g. Sections and threats of criminal prosecution), contact tracing to identify “victims” as well as new threats (Hays, 2009), and referral of people who test positive to specialists for treatment to contain the spread of the virus through individuals’ bodies to the public. Engagement with a public health official is mandatory and resistance is reported along the chain of command in a health unit. The application of force with graduated intensity is carried out by nurses on the orders of the Medical Officer of Health of each public health unit. Success is measured by the degree to which the threat of the virus, or viral load, in the “bigger” public has been eliminated. The language of war is embedded in the terminology and actions associated with the medical-epidemiological discourse dominating the public health response: risk, threats, priority populations, frontline, fights, orders, force, targets, officers, units, resistance, containment, elimination, security, and surveillance.

In *Society Must Be Defended,* Foucault once famously said, “politics is war pursued by other means” (2003b, p.123). The political decision to choose, in the battle for truth over the domain of public health in the HIV epidemic, to impose a biosecurity approach over a range of other possible goals and approaches, is an example of the link between “political rule” and war (Elbe, 2009). The findings of this study demonstrate that the case management of HIV is political despite claims that the avoidance of emotional and social concerns and a focus strictly on HIV tests, treatments, viral load, and monitoring of risk factors such as types of sex, numbers of partners, condoms, needle use, and disclosure are “objective” measures (Holmes & Gastaldo, 2002; Gagnon & Holmes, 2008). Inevitably, the war on HIV is a war on people, or rather the management of people through the “scaling-up” of one discourse and set of tactics under the threat of force to ensure

conformity with public health expectations about how to live with the virus "rightly and wrongly." In Foucauldian terms, the act of war in the management of HIV means "to govern, in this sense, to structure the possible field of action of others" (Foucault, 1982, p. 790), and "victory is measured by the normalization, or perhaps better put, the rectification of being-human with an extremely narrow a priori definition of what, who, and how to count as human" (Zigon, 2019, p. 9). In the management of HIV/AIDS, it has been decided that "what counts" is biosecurity and each individual "becoming undetectable" in order for 90-90-90 to be achieved (UNAIDS, 2014). In this regard, the U=U movement, and growing concern among people with HIV with having to "brand" themselves as "undetectable and untransmittable," can also be seen as a victory in the process of normalization in a war concerned with biosecurity. Becoming "U=U" and being able to "confidently declare to sexual partners, 'I'm not infectious!'" are increasingly the characteristics that shape the identity of people with HIV (Edmiston, 2017 in CATIE, 2018). It is another indicator that in the battle for truth in the war on HIV, agreeing to conceptualize the public health response to the epidemic as a matter of biosecurity has redefined the meaning of health, case management nursing, and living with HIV as predominantly a matter of "being safe" and "avoiding trouble." Gillet (2011) similarly claimed that when the public health response began to focus on testing and treatment, "[v]iral load measures, especially if the result was undetectable, became for many people with HIV/AIDS a new way of understanding themselves in relation to the virus and a sign of their success or failure" (p. 121).

The main concern with a biosecurity approach described by Elbe (2009) in his work, *Virus Alert: Security, Governance, and the AIDS Pandemic*, is the "fervor" with which "medical, public health and other progressive political actors" continue to build the HIV response uncritically around a singular biomedical indicator of success and perception of the virus and "at risk" individuals as potential threats to society (p. 10). Elbe (2009) and others cite a lack of evidence to substantiate biosecurity as the most pressing issue in the

pandemic and question the cost-effectiveness of diverting the majority of available funding away from social and structural issues, towards the types of technical and pharmaceutical prevention and treatment strategies that have failed after more than 25 years to produce 'an HIV/AIDS-free generation' (Foth, O'Byrne & Holmes, 2016; Gagnon & Guta, 2012; Gillet, 2011; Husbands, 2019; Krishnaratne et al., 2016, Nelson et al., 2019). Whiteside (2016), for example, conducted an extensive analysis of available data and global reports of the socio-economic impact of HIV/AIDS and concluded that, "The most we can say is countries (and people) would be better off not experiencing AIDS, but the extent is not clear in macro-economic terms" (p. 71).

Instead, Whiteside's (2016) analysis supports a different argument advanced by economists that "given the cost of maintaining lives is so low . . . there is a moral duty to rescue those infected" (p. 71). In this alternative economic analysis, the premise of the 90-90-90 strategy, that "[i]t will be impossible to end the epidemic without bringing HIV treatment to all who need it" (UNAIDS, 2014, p.1), is not generally disputed in the battle for truth over the direction of the HIV response. Increasing the availability of testing and treatment technologies has had a substantive impact on stabilizing the number of new infections worldwide. UNAIDS (2014) estimates that achieving 90-90-90 globally by 2020 would lead to an end in the vertical transmission of the virus and avert twenty-eight million infections and prevent twenty-one million deaths by 2030. Theoretically, a large-scale reduction in the number of new infections could also help free up funding (~US$24 billion) spent on treatment for alternative goals and measures in the future (Whiteside, 2016). The hesitancy in supporting a biosecurity approach largely centres around "the unspoken assumption that interventions will work as well as projected" (Whiteside, 2016, p. 117). Critics fear that the declaration of war on the virus simply "creates the potential for state institutions to invoke the imperatives of 'security' to justify the use of heavy-handed or draconian measures in order to confront the threatening condition or to silence opposition,"

if necessary, to actualize their biomedical goal (Elbe, 2009, p. 15). Three examples of "heavy handed" measures of concern to nurses in this study are the "Sectioning" of clients who are uncomfortable providing the names of partners, the ordering of some clients who test positive for subsequent STIs to report to a public health unit for counseling "for life," and the "overbroad" use of criminal law to prosecute people who are unwilling or unable to disclose their HIV status (Canadian HIV/AIDS Legal Network, 2019; Housefather, 2019; Loufty et al., 2014), for which some nurses who expressed opposition have been effectively silenced.

As the Former Administrator of the United Nations Development Programme (UNDP), Helen Clark (2015) warned in her address on World AIDS Day at the beginning of the campaign to end HIV/AIDS, engaging people in a predetermined path to treatment alone will likely not be enough to end HIV:

> If we maintain the status quo, HIV will continue to outpace the response, and the goal of ending AIDS as a public health threat by 2030 will not be reached. Alternatively, if defeating HIV remains a top priority, and if HIV responses and policies are approached in a holistic, non-discriminatory manner, where marginalized groups are placed at the forefront of our efforts, we can reach our goal. (para. 8)

To be cost-effective and morally sound, critics claim that an integrated model of care will be necessary to accomplish medical and epidemiological targets in the HIV response, one that includes "a more relational approach" recognizing that "HIV prevention is a socially embedded phenomenon" (Mykhalovskiy, 2011, p. 7). At the core of infectious diseases management a debate is emerging not about whether there is a need to invest in medical and epidemiological measures in the management of infectious diseases (see for e.g. Gallagher, J., 2019; Hamilton et al., 2019), but about the value of centering a public health response around a medical-epidemiological discourse with a singular goal of biosecurity *at the expense of* better understanding and addressing the goals and concerns of clients and other community stakeholders.

According to Human Rights Watch (2014), measures carried out in the name of public health to manage an epidemic should comply with accepted standards of international human rights law; this means measures strictly necessary for meeting medical-epidemiological objectives should be combined with social support, respectful of human dignity, be neither arbitrary nor discriminatory, based on evidence and subject to review. Decisions about "best" practice should be "achieved through community engagement and attention to the special needs of disadvantaged groups" (Human Rights Watch, 2014, p. 1). From a human rights perspective, public health's management of infectious diseases is required to account for the experiences of people with HIV/AIDS, and from the perspective of people with HIV the management of the infection is complex:

> The truth, of course, is a blend of confusing public benefits, insecurity about returning to work, relationship adrift, a dangerous and unsure sexual landscape, the departure of committed advocates, and an uninformed public convinced the crisis has eased. The only certainty that remains is how creative AIDS can be in its cruelty. (King, 1999 in Gillet, 2011, p. 117.)

According to nurses in this study, the issues of importance to clients in Ontario are similar: "to let them know they are not alone [and] also, letting them know the progression they can make;" that people with HIV have obtained an undetectable viral load, "got jobs, and went on to have relationships and families…that it is not a life-threatening disease anymore" (P8). The "truth" of what it means to live with HIV extends beyond a capillary measure of viral load and bodily control over the risk of transmission, as will the indicators and measures required to end the epidemic from the perspective of many people affected by the virus (Fink, 2015; Husbands, 2019; Ibanez-Carrasco, 2018). Given the plurality of perspectives circulating as "truth" about what is important in the management of the epidemic, the "war on HIV" is in reality a political choice to adopt a singular perspective aimed at promoting compliance with transmission reduction behaviours, and *not* to meaningfully engage in dialogue and initiatives aimed at understanding and supporting alternative goals and issues related to living with the virus (see for e.g. Burchardt, 2010;

Hammond, Holmes & Mercier, 2016). Using Foucault's (1983) words, it is not the "truth or falsity" of a biosecurity approach that is questionable in the war on HIV, but the claim in the battle for truth that "war on the virus" is "really" the only way to manage the epidemic.

It is the lack of critical reflection on the potential consequences of a hegemonic approach calling for the scaling-up of technologies for testing and treatment as the main method for managing infectious diseases in public health that is becoming a growing concern both locally and globally (Farmer, 2003; Gillet, 2011; Mason & Degeling, 2016; Mykhalovskiy, 2012). As Elbe (2009) points out, "few have reflected on the prior question of whether there are also political dangers associated with construing HIV/AIDS as a security threat" (p. 7). The main concerns raised by case management nurses in this study align with current critiques of public health priorities. Several nurses challenged assertions in their health unit about the necessity and effectiveness of having to privilege medical, epidemiological and legal directives related to biosecurity over attending to the diversity of emotional and social concerns expressed by their clients in practice. Public health nurses provided numerous examples to support their belief that the singular focus on disease containment at the point-of-care may be one of the main reasons people affected by HIV/AIDS are "being driven underground" and avoiding engagement in testing, treatment and support services. The fear of repercussions for noncompliance connected to the use of threatening letters, Section 22s, being reported to the A/MOH, and having to appear before a court of law for the non-disclosure of their HIV status, is one reason shared by nurses across all health units that many clients appear to be avoiding follow-up care in case management. Nurses fear the emphasis on a goal of biosecurity in public health policies is contributing to the conditions that make some people 'hard-to-reach' and inevitably to the persistence of new infections. From a case management nursing perspective, the main problem in the struggle to end HIV *is* the public health response to HIV, specifically a lack of support for individuals who have the most difficulty coping with

the current medical-legal climate due largely to its singular focus on the virus. O'Manique (2018) arrived at a similar conclusion in her review of the global impact of building a public health response to infectious diseases around security goals and measures: "The dominant narratives, however, pay scant attention to the conditions incubating those novel viruses [HIV, TB, Ebola and Zika], nor do they address in any meaningful way the social suffering of those who fall ill or experience more intensely the multiple impacts of epidemics" (p. 215).

The public health nurses participating in this study did not view themselves as participating in a "war" on the virus but were generally complicit in encouraging clients to conform with the medical goal and behavioural expectations of their public health units with threats of forced measures. The rationality for carrying out the prescribed measures of a medical-epidemiological approach was that "somebody has to do it," an acknowledgement that attention to biosecurity in itself is not considered problematic by most nurses. How to reconcile the two different approaches in the public health response in a manner that fosters trust, mutual respect and a feeling of "being supported" rather than driven away by fear is the most pressing issue in the HIV response according to case management nurses in this study. The "true" challenge in public health care according to a nursing discourse is: (a) "fulfilling what we need to get for our mandate in public health, but just in a way that best serves that person" at the individual level; and (b) ensuring "everyone leaves the process respected, and everyone feels their needs have been met--on both sides too, not just the client, but as far as the team and the services, they worked together" at the level of the population.

This is one of the few studies that has examined the public health response from the perspective of public health nurses involved in case management on the "frontlines" (Wilson et al., 2013). However, the role of public health policies and practices in producing a culture of fear in the HIV epidemic through its focus on categories of risk (Mill, Edwards,

Jackson, MacLean & Chaw-Kant, 2010; Petersen & Lupton, 2000), individual lifestyle choices and compliance with ‘rules for good health and good conduct’ (Foth, O’Byrne & Holmes, 2016; Hammond et al., 2016; Wagner, A. C., McShane, K. E., Hart, T. A. & Margolese, S., 2016), partner notification (Klitzman et al., 2004), disclosure counseling (Kilty & Orsini, 2019; Mykhalovskiy, 2012; O’Byrne, Bryan & Roy, 2013; Sanders, 2015), viral load (Gagnon & Guta, 2012), and educational messages (Gagnon, Jacob & Holmes, 2010) have been reported elsewhere. This critical ethnography of the experiences of case management nurses in Ontario provides new insights about how these various policies and practices are interconnected in the HIV response in the case management process through a medical-epidemiological discourse, and in doing so, establishes a new focal point for efforts to improve the outcomes of the HIV response—an “analytics of government” in the management of the HIV epidemic (Dean, 2010). An analytics of government in case management in this study included efforts to understand how current power relations and techniques of power governing the HIV response in Ontario are resulting in one discourse and course of action being privileged above all others in nurses’ practice, and helped identify tensions and innovations that may be a useful starting point for better addressing structural drivers of the epidemic through public health care in the future.

6.3 Case Management Nursing as a means of Governmentality

Through an “analytics of government” in the public health response to people who test positive for HIV in Ontario, it becomes evident that case management nursing can be viewed as a means of “governmentality,” a process concerned with “authority over the bodies of knowledge, beliefs and opinions in which we are immersed” (Dean, 2010, p. 27). Public health policies govern the terms and guidelines used by nurses to define what is meant by “case” and “management,’ and nurses provide counseling and referrals based on the guidelines in the practice of case management to govern the decisions and actions

of clients as they respond to being diagnosed with HIV. Both nurses' and clients' behaviour are governed or shaped by the medical-epidemiological discourse circulating in and through the policies and practice guidelines for case management. In this regard, it is easy to conceive how case management is involved in "government" as defined in a Foucauldian sense as the "conduct of conduct," the management of individual behaviour "in its depth and its detail" in order to achieve compliance at the level of the population with the biological and behavioural goals and measures considered necessary for containing the spread of HIV in medical-epidemiological terms (Foucault, 2003a, p. 102).

Holmes and Gastaldo (2002) were among the first to suggest that nursing is a means of governmentality: "Throughout history, nurses have been involved in the governance of individual bodies by using an array of power techniques whose effects construct subjectivities, such as establishing standards for 'good patient' [and] 'healthy citizen'" (p. 561). The authors theorized that disciplinary power, understood as the education or training of at-risk individuals, is one of the main governmental tactics through which behavioural norms or "forms of rationality inscribe themselves in practices or systems of practices" in nursing (Foucault, 1991a, p. 79). Based on the interviews with public health nurses in this study, "education" is also the most important mechanism of power that accounts for how "thought becomes linked to and is embedded in technical means for the shaping and reshaping of conduct" in case management practice (Dean, 2010, p. 27). The compliance of public health nurses with the definitions and guidelines in case management policies is procured through a training process that involves a review of policies, shadowing experienced nurses, practice through mock interviews, following scripts, adherence to checklists, and being observed until able to demonstrate compliance with policies without supervision. Nurses then play an active role in translating the medical-epidemiological knowledge and guidelines in policies into a regime of practices to encourage the conformity of clients. In this study, it became clear that case management

nurses in Ontario are engaged in process of governmentality with their involvement in a series of steps to promote the compliance of each person who tests positive for HIV with the rules for good health and ethical conduct established by public health unit's policies: (1) mandatory engagement; (2) following a predetermined pathway; (3) explaining what is expected; (4) making it easy and making sure; (5) judging each individual's ability to conform; (6) intervening with graduated intensity and forced measures.

The main steps of case management nursing centre around assessing each client's risk factors and educating clients about "transmission reduction measures." This process of case management closely matches the steps through which 'discipline' proceeds as described by Foucault: (1) case management nurses first assess and *rank* individuals according to the risk they pose to the public (low, medium or high risk); (2) nurses then explain the *activities* to each client *that contribute to maximal productivity* when living with HIV/AIDS from a medical-epidemiological perspective, matching the "rules for good health and ethical conduct" to individual risk factors and needs; (3) algorithms with the timelines and progression of steps to be implemented with graduated intensity are used to *mark* each individual's *progress* in the case management process and scale up education efforts until conformity is achieved; and (4) *coordination of these elements to ensure individual achievement of required knowledge, attitudes, and skills* is accomplished through the joint writing of policies and procedures, mandatory reporting of cases to public health units, internal reporting of potential "problems" to an A/MOH, team meetings to arrive at a collective judgement about the actions to be taken in cases of noncompliance, authority over final decision-making granted through legislation to the A/MOH, and surveillance to identify lapses and reengage clients in the education process as necessary (McHoul & Grace, 2002, pp. 69-70). Through public health policies, training processes, surveillance and a hierarchical organization of public health units across Ontario, the "power [of the medical-epidemiological discourse] reaches in and through

[nursing care] into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives" (Foucault, 1980, p. 39).

Public health nurses are first taught and then teach each client to follow the "rules for good health and ethical conduct" not for the sake of improving each individual's health alone, but with an overall aim of ensuring each infected individual is able to engage in self-governance in accordance with the rules in order to protect the health of the "bigger" public. As Holmes and Gastaldo (2002) further elaborated: "Governing is as much about practices of government as it is about practices of the self because the concept of governmentality deals with those practices that try to shape, mould, mobilize and work through the choices, desires, aspirations and needs of individuals and populations" (p. 559). In the current model of government based predominantly on a medical-epidemiological discourse, the individual at risk or living with HIV is "responsibilized" with protecting the public through public health education and expectations that they will engage in self-governance (Foth, O'Byrne & Holmes, 2016). Subsequently, from a Foucauldian perspective, case management can be understood as one governmental tactic involved in a process of biopower: engagement in biopolitics (the management of the population) through anatamo-politics (the management of individuals). This finding aligns with the perception of Perron, Fluet and Holmes (2005) that nurses act as "agents of the state" through the "act of care-giving," the promoting of health of populations through strategies that promote self-care. Using Perron et al.'s (2005) words, case management can be conceptualized as a form of biopower, the management of "the individual and collective characteristics that pose a threat to the social order" (p. 537).

Perron et al. (2005) theorized that nurses work at the intersection of biopolitics and anatamo-politics to produce subjects that comply with the norms of social policies. Through the process of case management nursing care with individuals at risk and living

with HIV, “[s]ocial policies supervise populations to ensure their compliance with respect to the tasks and requirements faced by the state” (Perron et al., 2005, p. 541). Through the adherence to public health polices in practice, and participation in the education and surveillance of individuals at risk and living with HIV, case management nurses play an integral role in perpetuating the political decision to manage HIV as a war on the virus and achieving medical-epidemiological aspirations for a “HIV-risk free” social order. In the words of Perron et al. (2005):

> These interventions attempt to encourage citizens to take responsibility for their health in order to achieve an optimal level of health. When an entire population does this, it functions at maximum capacity with nothing but benefits for the state. (p. 542)

Through compliance with the current social policies, case management nurses help produce subjects compliant with the medical-epidemiological goal and measures determined by experts to be a requirement to maintain the status quo.

Currently, the overall goal of case management nursing practice arguably aligns with the goal of modern government as described by Foucault (2003b), not of achieving health equity in society, but of “regulatory mechanisms . . . to establish an equilibrium, maintain an average, establish a sort of homeostasis, and compensate for variations within the general population and its aleatory field” that present a threat to the social and economic order (p. 246). Through public health policies and practices, biopower helps ensure “security” against “random elements” in a population with a goal of optimizing individual and social life (Foth & Holmes, 2018; McClelland, Guta & Greenspan, 2018). In this study, public health policies and other regulatory measures used to discipline individuals in case management are geared towards achieving the normalization of “healthy sexuality” in the population as defined by biomedical terms and an epidemiological analysis of risk as “safe(r) sex” (e.g. protected oral, vaginal and anal sex, and increasingly PrEP), regular STI testing and treatment, disclosure of an HIV positive status, and follow-up with a public health practitioner, primary care provider, infectious

diseases specialist and/or ASO for specialty care (Ibanez-Carrasco, 2018). Success is conceptualized with population level indicators of compliance with risk reduction behaviour such as an undetectable viral load in “90% of 90% of people on HAART” (UNAIDS, 2014), or an estimated 73% of people with HIV (OACHA, 2016). The goal of discipline in public health care is not the “end” of HIV for all people, but the containment of disease in the majority of the population in order to protect the ability of society to function. The findings provide insight into the process by which Elbe (2009) asserted that infection control can be viewed in relation to biopolitics as “efficiently managing diseases in the population and keeping them within socially and economically acceptable limits” (p. 66).

Social and economic goals are not outlined in the policies used for case management in public health units in Ontario; however, they are evident in the rationales provided in global policies calling for a biosecurity approach with which case management policies are aligned. As Whiteside (2016) explained, the arguments for scaling up testing and treatment globally are often based on economic speculation, namely rationalities such as: “AIDS is assumed to affect growth through reduced savings and investment, by cutting the size of the labour force, and by causing efficiency and productivity losses” (p. 69); “World Bank economists estimated a 1.2 per cent point reduction in annual growth for a 20 per cent prevalence rate” (p. 69); “High mortality may destroy human capital” (p. 69). Based on the rationalities given for investing in the current global public health response, the bodies of people with HIV are valuable mainly to the extent they can serve as instruments for the larger economic good. Subsequently, the focus on discipline and coercion in the current model of case management appears to be grounded in a belief that encouraging individual self-governance in accordance with predetermined behavioural norms for sexual health is the most likely and efficient approach for promoting productivity and economic stability in a population.

It is the combination of the neglect of strategies to improve social conditions for people with HIV/AIDS and arguments about economic efficiency that led co-author of the CANFAR (2018) report, Winston Husbands, to question the latest proposal to end HIV in Canada. Specifically, Husbands (2019) asks of public health authorities and practitioners who are calling for the scaling-up of the current measures to engage individuals in testing and treatment, "Why are decision-makers generally reticent to address structural issues in any substantive way?" Husbands (2019) speculated:

> Issues such as racism and poverty are perceived as too difficult or expensive to address in the short or medium term. Instead of attending to the systemic oppression and structural conditions that reproduce inequality, decision-makers promote "behaviour change" strategies based on discourses that pathologize disadvantaged communities. And of course, it is also politically and professionally expedient to ignore these communities and the issues that affect their well-being. (para. 7)

The current focus on identifying categories of risk, rules for healthy conduct, behaviour change and the "responsibilization" of individuals in the public health response to HIV is thought to be driven by a neoliberal agenda that views the role of government not as welfare or the promotion of individual well-being, but of promoting the knowledge, skills and space for individuals to become socially and economically productive for the benefit of the state (Foth & Holmes, 2018; Foth, O'Byrne & Holmes, 2016; Gagnon & Holmes, 2008; Husbands, 2019; Kilty, 2018; McClelland, Guta & Greenspan, 2018). Kilty (2018) posits that the trajectories of the current public health framework and a neoliberal approach "are not simply parallel but fused" in their efforts to manage populations through the management of individual self-government (p. 83).

Harvey (2005) defines *neoliberalism* as "a theory of political economic practices that proposes that human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by…[d]eregulation, privatization, and withdrawal of the state from many areas of social provision" (p. 2-3). In similar terms, in "Governing the Masses: Routine HIV Testing as a

Counteroffensive in the War on AIDS," Gagnon and Holmes (2008) assert that the public health interest in regulating individuals is "centred on the idea that every individual has a given capacity to make the right choice regarding their health and the health of others, thus generally failing to consider the material disadvantages of people's lives including the political environment, the social environment, and the physical environment" (p. 269). Foth, O'Byrne and Holmes (2016) further elaborate:

> Once people test positive for HIV, it is believed, they will inform themselves about the disease, regularly monitor their viral load, inform potential partners, engage in safe sex practices and follow through with the life-long treatment. From the neoliberal perspective, all this will be achieved voluntarily without force—only if individuals refuse to act in a responsible, rationale way will they be targeted by the judicial system. (p.102)

Gagnon and Holmes (2008) and Foth et al. (2016) argue that the hegemony of a medical-epidemiological discourse in public health policies and practice is produced by and reproduces the rationality of a neoliberal approach to government that conceptualizes a healthy lifestyle as a choice to be managed by individuals under the guidance of expert knowledge and threat of punishment, and the conditions that impact individual choices as outside of the regulatory domain of the state.

Notably, a rationale for adopting a singular focus on disease containment, a biosecurity framework and the steps aimed at helping each individual "avoid trouble" is not evident in the public health policies guiding case management nurses' practice. The documents referenced in the policies are primarily medical guidelines created to support the diagnosis and treatment of infectious diseases (e.g. PHAC, 2016). There is little discussion or evidence in either the policies or the supporting documents for the decision to structure case management nursing practice around each sexually transmitted infection, a definition of public health as the "absence of disease" in the population, and risk management in accordance with a medical-epidemiological discourse *as opposed to* a nursing discourse that views health as holistic, case management as involving relational

care, and the emotional and social concerns of people suffering from infectious diseases as the domain of public health (Merson et al., 2008; O'Byrne et al., 2015). The adoption of a medical-epidemiological discourse as the "essence" of case management nursing practice in public health appears to be accepted unquestioned. As Petersen and Lupton (2000) noted, "[l]ittle attention has been paid to analyzing the fundamental principles, discourses and practices of public health from an epistemological position, or to exploring public health as a sociocultural practice and a set of contingent knowledges" (p. x).

In reality, however, the current direction of case management appears to be influenced by a number of existing policy and position statements. For example, in the new national strategy to end HIV published by CANFAR (2018), the UNAIDS (2014) 90-90-90 strategy is cited as the basis for the decision to focus on biomedical goals and measures to end HIV. CANFAR was invited to develop the new strategy for HIV to supplement the Government of Canada's (2018) latest plan to address the rise in rates of STBBIs across the country. New in the Government of Canada's (PHAC, 2018c) plan titled, *Reducing the Health Impact of Sexually Transmitted and Blood-Borne Infections in Canada by 2030: A Pan-Canadian STBBI Framework for Action*, is the call for an "all of government" approach in the response to HIV and other STBBIs. In this approach, infectious disease management is contextualized within Canada's commitment to UNAIDS' (2014) 90-90-90 strategy, the World Health Organization's (WHO, 2016) Global Health Sector Strategies to address HIV, viral hepatitis, and sexually transmitted infections, and the United Nation's (2015) Sustainable Development Goals (SDGs) to which the Federal Government is also committed. In the 2030 Agenda for Sustainable Development (United Nations, 2015), health is understood as one of 17 goals (SDG #3) that are "indivisible," meaning the management of HIV and other health issues should always be considered in the context of other social determinants of health. Therefore, an "integrated approach" is called for in Canada's (2018) plan--a comprehensive approach

that views health as holistic, and combines prevention, treatment, care, and support to address the context of HIV and other STBBIs, and "requires collaboration to succeed" (pp. 4). It is not clear why CANFAR (2018) embraced only the UNAIDS (2014) targets for HIV and not the SDGs in their proposal to end HIV. It is also unclear why neither case management nurses, nor the public health policies for case management involved in this study mention the 90-90-90 strategy or SDGs as a rationale for the current approach. However, it is evident from the description of nurses' care that the steps of case management support the UNAIDS (2014) 90-90-90 targets, and the data entered into iPHIS by nurses are used to track and report Ontario's (OHESI, 2017) and Canada's (PHAC, 2018) progress to the United Nations (Bourgeois, Edmunds, Awan, Jonah, Varsaneux & Siu, 2017). These findings confirm that case management nursing is clearly situated within a complex social matrix and constructed from an assemblage of local, provincial, national and global institutional policies, practices and agendas. While there are few guidelines and policies published specific to the role of case management nursing in public health care, there are a number of policies in circulation that shape current thinking about the management of people with HIV, as well as additional policies such as the SDGs with the potential to also inform case management nursing policy and practice development (UNAIDS, 2019).

Nurses' current lack of awareness of their role in efforts to help address the 90-90-90 targets may be a product of gatekeeping reported in previous studies by nurses involved in HIV care (Richter et al., 2012). Case management nurses often depended on managers for relaying information to and from the A/MOH about how to proceed with clients. It is also possible that a lack of understanding of the links between case management and the broader array of policies and political agendas informing--or with the potential to inform--their practice, is one of the reasons public health nurses in this study as well as in others (Drainoni et al., 2009; Freedman et al., 2006; O'Byrne & Gagnon,

2012) feel powerless to challenge policy decisions when there is a disagreement or tension in practice. Within the “discursive field” in which case management is situated, public health nurses were in many instances not able to identify the origins of decisions affecting their practice. For example, the rationale was unclear for differences in policies between health units about the need to collect names and ‘double check” if contacts were notified of their exposure to HIV, when to apply forced measures, and the role of nurses in counseling and verifying disclosure of HIV status. Nurses were also unclear of the rationale for institutional changes made in the positioning of case management within the organization of their public health unit over time. It was speculated by some nurses that authority for decision-making in case management might stem from the HPPA (1990), an A/MOH, the *Canadian Guidelines on Sexually Transmitted Infections* published by the Public Health Agency of Canada (PHAC, 2016), the *Public Health Nursing Discipline Specific Competencies* (CHNC, 2009), a manager, public health and criminal laws, “the province” or more vaguely, “the powers that be.” Although situated within a hierarchical system of knowledge sharing, from the perspective of nurses, “power is everywhere” (Foucault, 1979, p. 93).

Similar to Foucault’s (1980) description of government under contemporary forms of liberalism and capitalism, there appears to be no single authoritative body responsible for the HIV response, but rather a state apparatus or *dispositif,* a “heterogeneous ensemble consisting of discourses, institutions, architectural forms, regulatory decisions, laws, administrative measures, scientific statements, philosophical, moral and philanthropic propositions” (p. 194), through which responsibility for governance over the HIV response emanates. This finding corresponds to the description by Holmes and Gastaldo (2002) of how the experience of powerlessness among nurses may be an effect of practicing within a complex sociopolitical environment, or “discursive field” traversed by multiple discourses. Within a complex social matrix, a variety of discourses shape reality. From a

Foucauldian perspective of power/knowledge, discourses compete to produce the reality under which nurses are expected to conform:

> In this complex context, nurses may see their practices strongly shaped by economic and health care reforms. Their powerlessness would be even more evident when they chose to provide quality services (spending time on patient education, keeping a certain number of working hours for revising practices according to new scientific evidence or engaging in long-term healthy community development), but they are compelled to be loyal to urgent patient needs and employer's strategic plans, and keep the system running under almost any circumstances. (Holmes & Gastaldo, 2002, p. 558)

From the perspective of governmentality, nurses' experiences of feeling powerless can be traced to the subjugation of a nursing discourse valuing a focus on quality of life in the management of the HIV epidemic by a medical-epidemiological discourse that "drilled into their heads" the need to prioritize a focus on individual risk and biosecurity in the public health response to HIV. From the perspective of governmentality, it becomes evident that it is not simply the HPPA (1990), an A/MOH, a manager, a court of law, or the court of public opinion that exerts power, but the dominance of a medical-epidemiological discourse in case management practice that is rendering nurses powerless to shape nursing care in a manner that aligns "best" with their professional values and perspective of what is important when engaging in HIV case management. In Foucault's (1990) words, "power is not an institution, and not a structure, neither is it a certain strength we are endowed with; it is the name that one attributes to a complex strategical situation in a particular society" (pp. 92-93).

This evidence suggests that not a singular "sovereign" or authority is responsible for the agenda of the HIV response, but a system of governance in which legislation, public health units, infectious diseases management and case management nurses play an integral part. There is continuity among the values and beliefs in the discourses privileged in global, national, provincial and local policies, and the direction of HIV response in each public health unit in this study. The value placed on biosecurity at the global level

influences the care possible in nurse-client relations at the "frontlines." Case management nursing care is shaped by and contributes to an assemblage of global and local policies, government agendas, legislation, organizational hierarchies and regimes of practices linked by an unquestioned acceptance of a medical-epidemiological definition of epidemic management as war with a goal of protecting the public from the spread of HIV. Within this "discursive field," public health units and case management nurses play an integral role in producing and reproducing the dominance of a medical-epidemiological discourse through the policies and procedures used to "conduct the conduct" of people at risk and living with HIV.

In the current organizational arrangement, the hierarchical order of a public health unit both reflects the privileging of medical-epidemiological knowledge and technologies of government locally and globally, and perpetuates the authority of a medical-epidemiological discourse to shape what is considered the "true" priority in case management among the variety of discourses circulating as "truth" in the public health response. The granting of "the final word" to an A/MOH through the HPPA (1990) and the preference given by A/MOH's to epidemiological knowledge and skills over nursing knowledge and skills in the current institutional arrangements of a public health unit, both reflect and reproduce the primacy of a medical-epidemiological perspective in case management and subjugation of a nursing perspective. Therefore, through this analytics of government in the public health response to HIV circulating in and through case management nurses' practice in Ontario, it is possible to comprehend that in a web of social relations, nurses "are always in the position of simultaneously undergoing and exercising power" (Foucault, 1980, p. 98). Nurses are both powerless to fully develop relational goals and expand the scope of case management practice, and powerful in perpetuating a biosecurity approach that sets the limits of case management in the HIV response in accordance with a medical and epidemiological goal and measures. The

findings demonstrate how nurses' participation in ensuring people exposed to the virus engage in testing and "[t]reatment is aimed at restoring the right balance—in political terms, the right hierarchy" of power/knowledge according to Sontag (1991, p. 77).

A medical-epidemiological discourse currently exercises the most power in the HIV response to decide the "right' way to live with HIV (i.e. safely) and to practice case management (i.e. as risk management) through an assemblage of legislation, institutions, policies, scientific and governmental technologies that value a biomedical definition of healthy sexuality and public health, and together regulate the values and beliefs circulating as reality in a neoliberal, capitalist society. Through this hierarchy of knowledge, decisions are made in public health units about the strategies that fit or do not fit in the public health response, including nurses' goals and measures for addressing HIV and practicing case management. It is not a single sovereign entity, but the political power of a singular paradigm of thought, the privileging of a medical-epidemiological discourse in definitions of what it means to be infected with HIV, that determines the parameters of the HIV cascade of care, and establishes the vision of a "healthy public" that this study reveals is driving Ontario's current approach to case management and alternative ideas and people "underground" in the management of the epidemic.

Acknowledging that case management is political--a matter of governance in a battle for truth--opens up the possibility of re-orienting the response to HIV and possibly other infectious diseases towards innovations in governance as a potential solution for improving their management and outcomes. Greater dialogue and research about the direction of HIV case management and its links to governance also has the potential to contribute new evidence and ideas that support thinking in a broader debate about the direction of public health care in Canada. In the words of Dr. Trevor Hancock (2018), in "Public Health in the 21rst Century: Governance for a Healthy, Just and Sustainable Future:"

> Governance is the process by which we make decisions and involves far more than government. It should be a collaborative community and societal process involving the public, private, nonprofit and community sectors and individuals working together for a common purpose. But what is the purpose? What business are we in—or, more to the point, should we be in? (p. E634)

According to Hancock (2018), the purpose of governance in public health care "should be to maximize the health and well-being of the entire population, and to improve the quality of life and the level of human development and happiness," and "Instead, [the] focus is on economic development and growth of gross domestic product (GDP), which is equated—confused, really—with social progress" (p. E634). Through an analytics of government of the case management of people with HIV, the findings from this study lay the foundations for future research, policy and practice questions in the area of governmentality in public health care, such as: What are appropriate goals for public health in the management of HIV and other infectious diseases, and how should they be arrived at? What institutional arrangements support/do not support this process? What governmental measures have been examined for their (in)effectiveness? What additional indicators could be used to evaluate case management and the public health response to people with infectious diseases? What initiatives already exist that can be built on if a more robust response is desirable and to be achieved? Why have such governmental structures, rationalities, indicators and measures not been adopted in public health units to date?

6.4 Gender and the Subjugation of Nursing Knowledge and Skills

The two different approaches operating within case management in Ontario—a medical-epidemiological approach linked to risk reduction education and surveillance, and a relational approach centred around the establishment of trusting relationships and principles of harm reduction--are also the most common approaches described in the literature in the field of HIV care (Drainoni et al., 2009; Freedman et al., 2006; Robillard et al., 2013). In this study it becomes clear that one approach is not necessarily adopted in place of the other, but both are integrated in the practice of case management by public

health nurses. In case management, the different strategies and goals were not necessarily seen as divergent, but in most situations as complementary. Education about risk reduction was one contribution case management nurses could bring "to the table" in a nurse-client relationship. Information about risks, prevention and treatment was tailored to each client's physical, emotional, and social needs. The knowledge and skills used by nurses to create time and space for open-ended discussions is what nurses believe enabled them to participate in a mutually respectful exchange of information with clients about a variety of topics, to learn the goals and concerns of clients, and connect them to health and social services specific to their unique strengths and needs. According to nurses, the knowledge and skills that enabled them to accommodate the variety of goals and needs of different stakeholders developed with training and experience and were often considered to be the strengths of their practice. Accommodating clients and accounting for the needs of the variety of stakeholders involved in the process of case management, including the testing clinician, administrative assistants, epidemiologists, needle exchanges, homeless shelters, ASOs, social workers, Infectious Diseases Specialists, managers and A/MOHs, were viewed as consistent with a nursing definition of health as holistic and healthcare as relational and comprehensive (CNO, 2018).

A blending of different sets of knowledge, skills and approaches in case management was also identified as a positive attribute in other HIV clinical settings (Drainoni et al., 2008; Freedman et al., 2006; Wagner et al., 2016). For example, in focus groups where healthcare providers and service users from a variety of settings were asked to discuss their experiences with HIV stigma in the Canadian healthcare system, it was noted that "[b]eing compassionate, honest, making time for the patient, being non-judgmental, and feeling comfortable" as well as possessing "increased knowledge" of risks and resources was linked to better outcomes and experiences for people with HIV (Wagner et al., 2016, p. 65). The authors conclude that when combined with knowledge

of risks and experience providing HIV care, positive provider attributes "such as being non-judgmental and open" help to mitigate the culture of fear and negative client perceptions of interactions. It was recommended that these positive provider attributes be "bolstered" in healthcare policies and practices in the future (Wagner et al., 2016, p. 68). These findings suggest that it may be in the best interest of public health units to better support case management nurses in their efforts to develop a relational approach, and encourage further research to determine the impact of the steps used to promote inclusion and collaboration in goal-setting at the point-of-care such as learning a client's story, starting where the client is at, sharing mutual concerns, matching information to needs, and facilitating connections.

The integration of two different approaches at the point-of-care challenge conceptualizations of the HIV care cascade as predetermined and linear, and speculation that public health care is a formulaic process grounded in a unified agreement on tactics stemming from a single medical-epidemiological discourse about risk management common in critiques of the public health response in the literature (see for e.g. McNaughtnon, 2011; Petersen & Lupton, 2000). The discursive complexity of case management nurses' response to HIV may also explain the failure to arrive at a singular definition or description of HIV case management practice across studies (e.g. Wilson et al., 2013). The finding that case management nursing practice in Ontario is inscribed with multiple discourses and goals provides evidence to support recent writings in the field of public health from a poststructuralist perspective (Holmes & Gagnon, 2018; O'Byrne, 2019) and posthumanist lens that issue a cautionary warning to "avoid overly monolithic views of public health or indeed the state or governmental regime—views that imagine the state as a stable and given entity rather than a dynamic set of contingent practices" (Will, 2017, p. 300). While case management nurses engage clients on a "predetermined pathway" towards the adoption of a medical-epidemiological goal and measures aimed at

"good" conduct, the attention in this study to norms and differences highlight the existence and potential role of "minority knowledge" within public health practice, namely the steps for a relational approach to care operating around a plurality of concurrent goals to contribute to a process where "everyone leaves the process respected." Holmes and Gagnon (2018) describe "minority knowledge" from a poststructuralist perspective as "repressed" knowledge, and its potential role as the starting point in nursing for activism or "political becoming" given its ability to help "break free" from the policies and practices "codified" as norms (p. 5). In this regard, the ability of case management nurses to integrate approaches born of different disciplinary perspectives and goals raises important questions about the continued organization of public health in Ontario around only one goal (disease containment) and indicator of success (an undetectable viral load), and the hegemony of one "paradigm-theory-method" in the management of HIV derived from the values and beliefs of a medical-epidemiological lens (Fassin, 2013; Holmes & Gagnon, 2018). For example, what might be the impact of more fully developing an integrated approach to case management with greater sensitivity to multiple goals and indicators of success in the HIV cascade of care? Could case management nurses lead the development of a more epidemiologically sound *and* people-centred public health response to HIV? Why are the relational knowledge and skills of nurses' currently invisible in case management policies? What assumptions are preventing the adoption of more than one goal and indicator of success in the public health response to infectious diseases?

When only one type of knowledge and evidence is considered in the process of decision-making, and policy is developed based on a singular goal, totalizing vision and an overriding authority, as is occurring in case management in Ontario and proposed in the new strategy by CANFAR (2018), critics have suggested that the management of epidemics appear to be 'more about politics than evidence' (Bova, 2000; Husbands, 2019;

McKirdy, 2014). Decision-making to address problems emerging at the point-of-care in public health units participating in this study were based on consensus, were typically not made with clients and other stakeholders present and varied according to the values of the A/MOH who exercised authority at a distance. The result is an "authoritarian, top-down" approach governing the actions of nurses and clients. The subjugation of nurses' knowledge and skills in relational work by a single biosecurity discourse appears also to be resulting in a perception of case management nurses' work as 'punitive,' a form of policing or "snooping" into the personal and social preferences of clients (O'Byrne & Gagnon, 2012). The coopting of nurses' abilities to establish trust, collaborate, accommodate and negotiate with clients and other stakeholders to meet the medical-epidemiological (90-90-90) priorities of risk reduction education, disclosure counseling, and surveillance leaves nurses relatively little time and space in case management to actualize the relational approach borne of their own professional values and goals.

In "Counselling about HIV Serological Disclosure: Nursing Practice or Law Enforcement? A Foucauldian Reflection," O'Byrne et al. (2014) explored the potential consequences for nurses of the medical directive issued by Ontario's Chief Medical Officer of Health ordering all public health practitioners to inform people living with HIV of the need to disclose their HIV positive status (p. 41). The authors were among the first to question "why nurses would engage in [disclosure] counselling" (p. 41), and argue that disclosure "is an imposed aspect of the criminal law" that "does not, overwhelmingly, belong within the domain of healthcare" (O'Byrne et al., 2012, p. 42). It was recommended that public health nurses critically reflect on the fit of disclosure counselling within the context of the professional values, ethics and priorities of nursing when developing strategies to support clients rather than accept public health unit guidelines unquestioningly. According to O'Byrne et al. (2012), the professional knowledge and ability of case management nurses involved in this study to establish trust, build relationships, encourage a mutual exchange

of information and match information to needs could be equated with discipline rather than support--another form of biopolitics or social regulation described by Foucault as “pastoral care.” Through mandatory engagement, nurses as public health authorities can be viewed as “pastoral agents,” able to provide a “compassionate ear” to extract information about the physical, emotional and social concerns of clients and use it to tailor educational messages about risk and risk management to persuade clients to adopt the values and behaviours considered “best practices” by a public health unit (Foucault, 1991; Holmes & Gastaldo, 2002; Holmes & O’Byrne, 2006; O’Byrne et al, 2012). Based on these findings, public health nurses are urged to consider how, organized around a singular medical-epidemiological goal, a relational approach may no longer be about helping clients identify and meet their own goals, but be serving as a subtle form of coercion to ensure clients are aware of and conform to the predetermined goal (90-90-90) and priorities of their public health unit. Alterations to case management practice such as changing documentation practices to prepare charts for subpoena, discussing clients’ needs before discussing disclosure counselling to avoid “scaring clients away,” and focusing on the mitigation of clients’ and health unit’s fears as opposed to developing efforts to mitigate the sources of fear surrounding case management are evidence of the colonization of a nursing practice by a medical-epidemiological and ethical-legal discourse that positions biosecurity as the primary goal of public health and views diversity as a potential threat (Mykhalovskiy, 2012; O’Byrne & Gagnon, 2012; Sanders & Bisaillon, 2019).

The assumptions that enable the colonization of public health nursing practice with medical-epidemiological and ethical-legal goals and measures have not been well studied. In a paper by Sharma et al. (2018), the introduction of a medical intervention into the practice of public health nurses working in STI clinics was viewed as “task-shifting.” The intervention was part of a study protocol examining the differences between family physician- and public health nurse-delivered PrEP in Toronto. The aim of the intervention

was to decentralize the administration of PrEP by “harness[ing] the skills of sexual health clinic nurses” who may have a greater “comfort level and skill to discuss sexual activity” than physicians and “already offer a slate of biomedical and behavioural HIV prevention interventions like counseling and STI management” (Sharma et al., 2018, p. 3). The authors argue that helping administer PrEP fits within the “expertise” of public health nurses because it can be “highly protocolized” and “[by providing extensive training to the nurses, basing the medical directive on evidence-based Canadian guidelines, and ensuring the availability of specialist consultation, this model [of PrEP delivery] is also a form of inter-professional mentorship and collaboration that optimizes the scope of practice of each health professional” (p. 8). Missing from the study protocol is an understanding of public health nurses’ views of the impact of the intervention on their scope of practice. Although the initiative is referred to as a “nurse-led” intervention, there is no description of the participation of nurses in the development or evaluation of the proposed model of care; as it is written, only provider fidelity with the prescribed protocol will be evaluated (i.e. through quizzes and chart review) with the input of public health nurses. The study protocol is contextualized within a “dissemination” as opposed to an “integrated” knowledge translation framework and the concept of task-shifting defined by the WHO (2008) as “the rational redistribution of tasks among health workforce teams [whereby] specific tasks are moved, where appropriate, from highly qualified health workers to health workers with shorter training and fewer qualifications in order to make more efficient use of available human resources for health” (p. 2). Similar to the experiences of case management nurses in public health care, “interprofessional mentorship and collaboration” appears to be conceived by the authors as a one-way, top-down process that conscripts nurses and colonizes their practice with tasks that are considered a priority from a medical-epidemiological perspective through a neoliberal rationality of scarcity and efficiency.

It is not the introduction of disclosure counselling or nurse-delivered PrEP that are considered problematic *per se*, but the unquestioned practice of designing interventions *for* rather than *with* public health nurses that appears to be common in the domain of public health and controversial for case management nurses (O'Byrne, 2019). Scarcity and efficiency do not adequately account for a lack of inclusion of point-of-care nurses in public health unit or study protocol decisions that impact their practice. It may be that the assumptions driving the colonization of nurses' work--and "uneven relations" between a medical-epidemiological perception of case management and a nursing approach—are also artifacts of hierarchical beliefs about ethnicity and gender that have historically shaped the division of labour in the Canadian healthcare system (see for e.g. Armstrong & Armstrong, 2010; McPherson, 2009; Rodney & Varcoe, 2012). The lack of authority of nurses over practice decisions and the coopting and relegation of their knowledge and skills related to relational work to the intimate spaces of the nurse-client relationship may be a legacy of past "relations at the bedside" that were "constructed by a labour process, which divided tasks among doctors and nurses, but also by the social relations of ethnicity and gender" (McPherson, 2009, p. 18). In this study, a number of nurses believed their identity as predominantly "straight white women" limited their ability to offer greater support to clients and function at the full scope of their practice. Nurses who raised these concerns were not able to clearly articulate the influence of ethnicity and gender on their practice or the outcomes of case management, but agreed that greater gender and ethnic diversity was "what some of our clients would like to see" and a lack of diversity among "applicants" is a public health problem.

In an analysis of five generations of nursing in Canada, McPherson (2009), similarly established that nursing has long been "an occupation comprised predominantly of women who were White, Canadian-born, English or French-speaking, and of northern European descent," but the "meaning of 'whiteness' for the occupation" is poorly

understood. According to McPherson (2009), limitations in the current understanding of the role of ethnicity and gender is “due to the paucity of nursing-generated primary documentation relating to those minority women who were successful or unsuccessful in earning a place in the occupation” (p. 23). In general, a race and gender-based analysis of the experiences of community health nurses remains uncommon in scientific studies, as is research about the role of nurses in the management of HIV and other infectious diseases (Arthur, Beausoleil, Guay & Gahagan, 2013; Gahagan et al., 2013; O’Manique, 2018; Premji & Etowa, 2014). Further research from the perspective of a diversity of nurses is needed to better understand how conceptualizations of race and gender shape nurses’ perceptions of their “belonging” in the public health arena, influence the roles and status of nurses in public health units, determine health unit policies and practices, and impact the experiences of people at risk and living with HIV.

A potential connection in nursing between gender, lack of autonomy, and inability to adequately support clients was noted by Underwood et al. (2009; 2010) in an extensive study of the work-life experiences of community health nurses in Canada. The descriptions of nurses’ experiences were based on a review of the Canadian Institute for Health Information nursing data bases (1996-2007), a survey of over 13,000 community health nurses working in various roles and settings, and 23 focus groups across the country. Underwood et al. (2009) estimated that roughly 95% of the community health nursing workforce were women, and the main finding was that across Canada, nurses were primarily concerned with limitations on their professional autonomy and narrowing of their scope of practice. Public health nurses were more likely than other nurses practicing in community settings to report an issue with control over the direction of practice at the point-of-care. Underwood (2010) further elaborated:

> All the focus groups told us public health nurses need autonomy to work effectively and they need to be seen as leaders who can determine the right thing to do in their assigned activities. Rural groups said autonomy is the ability to be creative and

> responsive to meeting community needs, while urban groups described autonomy as freedom of action in everyday practice and physical separation from managers and doctors. Front-line nurses said managers must let them be flexible in how they approach their work. Some nurses said autonomous practice needs a broad job description so that they're not pigeon-holed into a small area of practice. (p. 15)

According to the authors, "Management practices at the front line were by far the most important organizational attributes for optimal public health nursing…profoundly affect[ing] whether public health nurses are using all their competencies" (Underwood, 2010, p. 14). Along with the claims of case management nurses in this study, the results of the study by Underwood et al. (2009; 2010) suggest that a potential consequence of being predominantly women in public health nursing is a collective experience of feeling that "everyday practice" and "freedom of creative action" is constrained by "job descriptions" advocated by managers and doctors.

The study by Underwood et al. (2009; 2010) is one of the few studies published with an interest in the perceptions of nurses involved in public health care. While the evidence presented could be viewed as dated, the subjugation of a nursing approach experienced by frontline nurses in the study resonates with contemporary descriptions of nurses in case management of their challenges implementing nursing ideas about "the right thing to do." Underwood (2010) reported that, while three-quarters of registered nurses said they had flexibility to vary the amount of time spent with clients, only half of participants felt supported in their work with clients by provincial policies, 40% noted a lack of opportunities to discuss program issues or to adapt nursing care plans, and public health nurses were more likely to report strained relationships with physicians than all other nurses working in community health care. The areas of care most impacted by a lack of autonomy and tensions with physicians were nurses' ability to respond to the emotional and social needs of clients, develop policies to support their priorities, and form relationships with community stakeholders. The majority of nurses surveyed believed their organization did not use community-based approaches to address social determinants of health (47%),

and few (38%) felt they had timely access to good quality resources to support their clients (Underwood, 2010).

Across studies examining the perspectives of public health nurses (Cohen, 2006; Falk- Raphael & Betker, 2012) and nurses involved in HIV care in local and global settings (Mill et al, 2013, O'Byrne et al, 2014; Rossi et al., 2011; Sanders, 2015; Sanders & Bisaillon, 2019; Van der Elst et al., 2013), there is agreement among nurses that time constraints, differences in priorities, lack of policies and limited access to new knowledge impact their ability to develop their practice in directions that align with their values. These studies do not specifically articulate a link between gender, constraints in practice, the privileging of a medical-epidemiological discourse in policies, and/or governance in public health care. However, many of the recommendations involved developing the role of nurses with the aim of "enabling" them to practice at their "full capacity and potential" (Underwood, 2010, p. 4). For example, Underwood (2010) encourage employers and managers to "demonstrate trust in nurses, recognize contributions, and involve them in program planning; support nurses to work independently, give them flexibility to meet client needs; support nurses to build relationships and partnerships with other professionals and with communities; provide training opportunities on successful teamwork; plan nursing services based on evidence of their impact and results; work with academic researchers to gather information and develop staffing models that allow for changing needs—including emergencies, epidemics and the growing prevalence of chronic disease… [and] invest in professional development to provide public health nurses with learning opportunities, set clear benchmarks, and support nurses' participation" (pp. 4-5). The focus on expanding the role of public health nurses in the areas of relationship-building, responsiveness to clients, and participation in planning in order to move beyond a medical model correspond with the areas of relational care public health nurses feel are being repressed in case management practice under the current medical-epidemiological model

of HIV care in public health units. Together, these studies suggest there is a need in public health units to better "understand the role of the public health nurses who work for them and make it possible for nurses to work to the full scope of their competencies" in order to build on nursing strengths and explore the potential of nursing approaches to help improve client outcomes (Underwood, 2010, p. 5).

It is not clear to what extent a nursing approach is "misunderstood;" however, nursing knowledge and skills appear to be invisible to the medical-epidemiological paradigm informing public health related documents outlining how the HIV response should be constructed. With the exception of one health unit in Ontario, only the roles and responsibilities for case management nurses are "laid out for them" in the Policy and Procedure manuals despite the involvement of a variety of internal and external stakeholders in the public health response to people newly diagnosed with HIV. When the roles and responsibilities of the A/MOH and managers are articulated, these roles include advising, decision-making, issuing orders and ensuring policies and procedures are followed, whereas the expectations for nurses are to follow policies and procedures and "document the recommended courses of actions" when provided advice by a manager or A/MOH about how to proceed in a case. The care advocated by case management nurses relative to a goal of "everyone in the process feeling supported" receives minimal or no attention in the documents used to inform case management nursing practice. Yet, nurses' concerns with identifying and addressing the emotional and social conditions affecting client outcomes is central to the values and responsibilities articulated in the policies and positions statements published by nurses, including attention to social justice (CHNC, 2019; Edwards & MacLean Davison, 2008, Gagnon, 2012), the U.N. Sustainable Development Goals (ICN, 2017), primary health care (CNA, 2015), and social determinants of health (RNAO, 2013). In the Canadian Public Health Association's publication, *This is Public Health, A Canadian History (Rutty & Sullivan*, 2010), nurses'

role in carrying out medical or technical tasks such as vaccination programs are celebrated, but little discussion is dedicated to the core concern of community health nursing of “social justice” and public health nursing contributions through relational work to street health and other forms of outreach that aim to foster inclusion in communities with a history of marginalization (Edwards & MacLean Davison, 2008). Process and outcome indicators of support and mutually respectful engagement advocated by public health nurses in the HIV response in Ontario as stipulated, for example, in the principles of Greater Involvement of People with HIV/AIDS/Meaningful Engagement of People with HIV/AIDS (GIPA/MEPA) (UNAIDS, 2007; 2014), Nothing About Us, Without Us (Canadian HIV/AIDS Legal Network, 2005), and recommendations for *“Good Medicine:” Decolonizing HIV policy for Indigenous women in Canada* (Prentice et al., 2018), are also missing in the HIV cascade of care, policies, and assessment forms developed for case management practice.

In addition, the knowledge and skills identified as valuable to public health nursing in case management such as relational inquiry, mutual respect, meaningful engagement, accommodating multiple goals and perspectives, harm reduction, social support, and community development are not explicitly listed as core competencies in the Public Health Agency of Canada’s, *Public Health Competencies: Information and Tools* (PHAC, 2015). Despite the fact that nurses constitute a substantial portion of the public health workforce, the Public Health Agency of Canada (2015) defines “public health sciences” largely in medical-epidemiological terms as:

> A collective name for the scholarly activities that form the scientific base for public health practice, services and systems. Until the early 19th century, scholarly activities were limited to natural and biological sciences sometimes enlightened by empirical logic. The scientific base has broadened to include vital statistics, epidemiology, environmental sciences, demography, genetics, nutrition, molecular biology, and more. (para. 1)

Public health nurses’ commitment and capacity to develop initiatives to engage *with* clients

in efforts to identify and address their emotional and social concerns appear to be inherent to community health nursing frameworks but not well recognized in the public health science arena. More interdisciplinary dialogue and research is needed to determine the rationale for the limited references to nursing knowledge and skills in relational care and as advocates for social justice in the public health literature. Historical and case study research with a gender-based analysis, and policy deconstruction informed by a poststructuralist or posthumanist theoretical lens sensitive to minority knowledge, could be useful for helping identify whether or not nurses' capacity to provide relational care and promote meaningful engagement is considered public health "knowledge" by other health disciplines, believed to be incommensurate with the paradigmatic lens informing public health science, or simply viewed as inherent to nursing "because nurses are mostly women."

Nurses have long argued for a shift from the emphasis on "lifestyle and health behaviour of individuals" towards greater "consideration of social systems, organizational priorities, professional behaviours, and other environmental factors" in community health care (Stewart & Langille, 1995, p. 77; see also CNA, 2003; McGibbon, Etowa & McPherson, 2008). In *The Legacy of Domesticity: Nursing in Early Nineteenth-Century America*, nurse historian Patricia D'Antonio (2007) suggests that the current tension between the two different foci in healthcare—the social and the individual--can be traced to past "disciplinary tensions between nurses and physicians" about the "kinds of work" considered "proper" for nurses "as women" and necessary for "good" health that resonate today. In D'Antonio's (2007) words, "the patterns of relationships that have arisen between nurses and physicians…reflect an ongoing, torturous groping toward new ways to care for the sick when older ways lose their validity and power" (p. 45). While physicians have tended to envision the role of nurses in biomedical terms as "the help," D'Antonio (2007) suggests that "nursing women experimented with different ways to reassert the centrality

of the therapeutic relationship" in their roles in response to the medical discipline's efforts to limit it to assistance with "making the doses [of drugs and other medical treatments] as palatable as possible" to clients (p. 42). In this study, nurses' efforts to incorporate relational care into the limited time and space available at the point-of-care and resist the complete colonization of case management practice with a biosecurity goal and measures may reflect a contemporary struggle to reassert the centrality of community health nursing values and strategies for social justice into the public health response to HIV in order to address the issues of mistrust and the stalled progress in reducing rates of new HIV infections related to the current approach. This examination of case management nurses' experiences in public health care suggests that areas of "disciplinary tension" may not necessarily be a sign of direct conflict between physicians and nurses as articulated in historical writings about gender roles and relations in nursing, but in Foucauldian terms, more likely representative of a "fracture" at the intersection of the medical-epidemiological and nursing discourses competing for space in the provision of care—a tension in the current system of care where the boundaries of the dominant discourse in public health policies and minority knowledge meet but do not overlap.

Subsequently, it is the "uneven balance" in case management between a nursing discourse that values a relational approach with a medical-epidemiological discourse that focusses on biosecurity that may be gendered. For example, in *Gender, class, and ethnicity: Reconceptualizing the history of nursing,* McPherson (2009) described the hierarchy between nurses' and physicians' approaches in relation to paradigms based on traditional conceptualizations of gender and gender roles:

> Nursing has been defined by particular feminine paradigms, and nursing educators labour to ensure that new recruits conformed to these codes of gender-specific behaviour. The dominant feminine paradigm has been a familial one, in which…nurses assumed a subordinate wifely position relative to the male doctor and a maternal position relative to the dependent patient…If doctors assumed authority, it was an authority based on control of ownership over production-–as head of the health-care team—and masculine control over domestic life—as head

> of the household. At the same time, the personal service tasks demanded in patient care were deemed natural for women to execute. (p. 15)

In line with McPherson's (2009) historical analysis, the adherence of case management nurses to a relational approach that includes establishing trust, listening to clients' stories, accommodating different stakeholders' needs, "making it easy and making" sure rules for good health are followed, and "doing for" people what is needed for "everyone to feel supported" is consistent with historical roles of nurses viewed from a feminine paradigm. The control of physicians in public health units over the goal and measures preferred in practice, their concern with protection and the "bigger" public as opposed to individual emotional and social concerns operating in the intimate spaces of the nurse-client relationship, and interest primarily in "objective" physical signs of success in the management of people with HIV can be viewed as consistent with a traditionally masculine paradigm. The deferral of case management nurses to the priorities of a medical-epidemiological model of care and engagement in a form of pastoral rather than democratic care as a safeguard against conflict and in response to a fear of discipline and punishment can be viewed as a form of maternalism in a patriarchal system from a feminist lens (Weedon, 1999).

The contextualization of case management nurses' experiences of power and powerlessness in discourses about gender and gender roles in this study creates an additional site for examining why and how testing and treatment technologies are privileged and concerns with emotional and social conditions are marginalized in the HIV response. According to Weedon (1999), power relations between different "narratives" at the basis of the division of labour are largely grounded in assumptions about gender and gender relations that view differences in the knowledge and roles traditionally occupied by women and men as natural, rooted in biology, and in binary opposition to the other, limiting the possibilities for how roles and healthy sexuality can be expressed. In Weedon's (1999)

words, "[d]ifference as lack and inferiority has remained a key aspect of many influential twentieth-century theories of sexual difference" (p. 9), resulting in women and knowledge from a feminine paradigm being "defined as different [from a masculine paradigm] and implicitly or explicitly inferior" (p. 5). From a feminist poststructuralist lens, nursing knowledge of a relational approach and concerns with emotional and social concerns in public health care are likely subjugated within a medical-epidemiological discourse due to its alliance with the traditional values and forms of knowledge development considered inferior from a public health science perspective. Critiques of the hierarchy of evidence that ranks the descriptions of subjective positions and results of qualitative studies below objective measures and quantitative approaches in the development of knowledge support these assertions (see for e.g. Holmes, Murray, Perron & Rail, 2006; Mykhalovskiy & Rosengarten, 2009).

Viewed from the poststructuralist feminist lens and writings of Chris Weedon (1999; 2008), an additional starting point for improving the outcomes of the public health response to HIV could be with challenging the grounding of case management nurses' knowledge and goals in discourses that "fix" relational care and healthy sexuality within the parameters of a singular paradigm concerned with mitigation of risk and safety. In *Feminist Practice and Poststructural Theory*, Weedon (2008) first challenges the unquestioned acceptance of the hegemony of patriarchal discourses in the development of knowledge, suggesting that it is important to "challenge the boundaries of existing knowledge, the questions which it asks and answers and its patriarchal implications" in order to "contribute to the development of practical strategies for change" (p. 14). Second, in *Feminism, Theory and the Politics of Difference*, Weedon (1999) challenges the subjugation of different perspectives in the development of knowledge that shapes one conceptualization of sexual identify as normal and others as deviant. Weedon (1999) suggests that:

> One productive approach would be to move away from monolithic views of

> heterosexuality as merely a tool of patriarchy and to begin from the different ways in which it is materially produced through a variety of discursive practices. All those discourses—medical, psychological, religious, demographic, familial and cultural, to name but a few—which from a Foucauldian perspective can be seen as constituting the domain of sexuality, privilege heterosexuality as the natural way to be. (p. 45)

The approach advocated by Weedon (1999) may be useful for examining the rationalities informing the privileging of a singular medical-epidemiological goal and "paradigm-theory-method" in public health policies and practices for nurses that limit the definition of healthy sexuality to "safe(r) sex" and creates pressure among people living with HIV to identify as "U=U."

The starting place for addressing shortcomings in the HIV response from a feminist poststructuralist perspective are the fractures or tensions in case management nursing care, "the politics of the personal, in which women's subjectivities and experiences of everyday life" have become the site of a struggle over meaning (Weedon, 2008, p. 5). These sites could include the sites of ambiguity and tension at the point-of-care identified in this study as sites of conflict between medical-epidemiological and nursing priorities. Efforts would include: (a) raising questions related to assumptions about the approaches preferred in public health units which biomedical, patriarchal and neoliberal discourses "posit as true, pointing to their irrelevance to [nurses'] experience;" and (b) "addressing the production and distribution of knowledge and developing new strategies which would better serve feminist interests" (Weedon, 2008, p. 5). From a feminist poststructuralist perspective, improving the HIV response would involve efforts to promote dialogue between nurses and across public health units about the limitations of the current model of public health care that promotes an authoritarian, top-down, medical-epidemiological approach to case management at the expense of a collaborative, nursing approach informed by relational inquiry, and further research to identify strategies that constrain and support the development of nurses' knowledge and ability to "live with a client for a while." A feminist poststructural analysis of governance would explore governmental processes

and tactics that value diversity and question those that view diversity as a threat. For example: What beliefs about women and men, nurses and people with HIV, allow for the subjugation of a democratic approach by an authoritarian approach to governance in the HIV response? What changes in governance would promote mutually respectful and meaningful engagement with clients and community partners at all levels of public health care, and a more collaborative approach to policy and practice development, as opposed to an approach that decides what is “best” practice for nurses and clients, expects conformity, and uses forced measures if necessary to achieve compliance?

6.5 Geographies of Exclusion in the Organization of HIV Case Management

By mapping the spatial organization of public health units in this study, it has become evident that the institutional arrangements linked to case management both reflect and reinforce the social divisions related to the “battle for truth” in the HIV response. Case management is organized around the diseases it aims to control, and public health units are organized to support the flow of “HIV positive cases” from the testing clinician, through a case management nurse to a specialist for treatment, and entry into iPHIS for ongoing surveillance. Correspondingly, case management nurses are situated at the intersection of the point-of-care where clients can receive testing and treatment and the offices of the management team (managers, epidemiologists, and the A/MOH) with authority to determine the direction of the public health response to HIV. From this position, nurses are “responsibilized” with education and enforcement of “the rules for good health and ethical conduct,” and describe their role as the balancing of clients’ individual needs with the needs and expectations of the public health unit. The overall arrangement is the compartmentalization of HIV care into separate units bounded by concerns with different aspects of the disease, and the effect is the scrutiny and discipline of individuals with HIV from the different perspectives of the sexual health clinic, case management, health promotion, epidemiology, and management team in order to achieve disease containment

and population health. The built environment of public health units in Ontario can subsequently be described as suggested by Sibley (2007) in, *Geographies of Exclusion: Society and Difference in the West*, as a form of “territorialization,” a social construction of space in accordance with a medical-epidemiological discourse that conceptualizes the case management of people with HIV as the management of the virus at the individual, institutional and societal levels.

Similar to the institutional arrangements of hospitals, prisons and asylums once described geographically in relation to the concept of power/knowledge by Foucault (1978), the results of this study suggest that the structure of the social space of public health units also mirrors the vision, values and beliefs of a dominant discourse held about the knowledge and steps required to promote compliance with norms for good conduct to protect the status quo. Protecting the public from infection is the primary goal around which public health units are organized, and the promotion of inclusive practices and health equity is secondary or invisible in the governance structures of public health units, including the architecture and organizational arrangements. In Sibley’s (2007) words, “Thus, the built environment assumes symbolic importance, reinforcing a desire for order and conformity” and “in this way, space is implicated in the construction of deviancy… A rejection of difference is embedded in the social system” (pp. 66-67). In the current model of care, a medical-epidemiological “frontline” (i.e. viral load, U=U, risk free behaviour) has been drawn between those considered safe and those considered a threat of infecting the public. A line or social division also exists between the boundaries of a singular paradigm-theory-method approach and an approach that attempts to accommodate a diversity of paradigmatic perspectives about what constitutes the “right” way to live with HIV. Positioned within a battle for truth on the frontline, case management nurses’ experiences of tension and ambiguity appear to be a result of having to function within this contested space.

In this study it became apparent that both containment of disease and containment of deviance in public health units is monitored, diagnosed, problematized, and reported to the manager and A/MOH, and if considered through a collective judgement to pose a threat, subject to discipline or punishment in accordance with public health law and/or criminal law. The policies and practices for governing clients' and nurses' adherence to norms enable the A/MOH to govern from a distance (i.e. by email, or from a different floor, building or city) in a manner described by Foucault (1977) as "panopticism." Similar to Bentham's Panopticon, the individuals entering the domain of public health become subject to a regime of practices supported by the flow of the laboratory report of a positive test result through testing clinicians into the assemblage of public health administrators and practitioners "responsibilized" with identifying, dividing, categorizing, examining, training, and evaluating an individual's compliance with the rationalities and routines preferred for a population (Foucault, 1980a). In public health units, the spatial organization of health unit teams from the administration at the front entrance, the case management team next to the clinic, and the managers, epidemiologists, and A/MOH farthest from the point-of-care supports this regime of governmental practices, meaning that the architectural and organizational arrangements of public health units can also be considered techniques for discipline and social control (Sibley, 2007).

Together, global and local policies, public health and criminal laws, architectural and institutional arrangements form an "assemblage of power," a governance structure aligned through a biosecurity goal and discourse to promote self-government among nurses and clients using "the least intrusive, most effective approaches:" education, training, surveillance and as a last resort, coercion (Allard, Kazatchkine & Symington, 2013). In contrast, case management nurses engage in government (the "conduct of conduct") by meeting people "where they were at" and implementing inclusive practices to make clients "comfortable" such as creating a "non-threatening environment," listening to

their story, and using non-judgmental language, in order to encourage clients to engage in dialogue about their well-being and share their concerns about living with HIV. The reports of nurses across public health units of a lack of adequate time and space to engage with clients in a relational approach is evidence that the regime of collaborative practices preferred by nurses is marginalized in the physical as well as scientific domain of public health units. The institutional arrangements support a case management approach driven by a "top-down" medical-epidemiological paradigm-theory-method and are ill-suited for dialogical engagement, and effectively subjugate a less hierarchical, more democratic approach to governance that nurses believe their "clients would like to see more of."

Therefore, this study provides important insight into some of the structural conditions that may be contributing to a social division in case management at the "frontline" of public health care and their links to a battle for truth about which discourses and approaches should be prioritized in the public health response in order to improve client outcomes and "end HIV." The study demonstrates how the social and physical structural organization of public health units around a predetermined goal and linear cascade of care is produced by and reproduces an expert-led, disease specific, compartmentalized experience in public health care for clients in Ontario and inhibits the implementation and development of a more people-centred, holistic approach to the case management of people affected by HIV. Concerns about the fragmentation of care and its effects on maintaining people in the cascade of care are well documented (Allard et al., 2013; Haruna, Assenga & Shayo, 2018; Kerkerian et al., 2018; Shacham, Lopez, Brown, Tippet & Ritz, 2018). For example, in "Health System Features that Enhance Access to Comprehensive Primary Care for Women Living with HIV in High-income Settings: A Systematic Review," O'Brien et al. (2018) reported that concerns with "navigating a fragmented system" were identified across studies and the authors concluded that "coordination of care within a single facility, or through case management, nurse

navigation, or peer support, [are] all highly valued in the literature" (pp. 144-145). Using Sibley's (2007) words, what is considered fluid in health and healthcare delivery by clients and nurses appears to be interrupted by the structures imposed on the landscape of HIV care by a medical-epidemiological approach (Sibley, 2007). Imposing a predetermined goal and framework can result in the imposition of artificial boundaries around individual experiences living with HIV that are not fixed but contingent on the context or setting and change over time (Ceci, Pols & Purkis; 2017). In this regard, it can be argued that the built environment of public health units are symbolic of "the act of drawing the line in the construction of discrete categories [that] interrupts what is naturally continuous and are by definition an arbitrary act and thus may be seen as unjust by those who suffer the consequences of the division" (Sibley, 2007, p. 35).

These results suggest that improving client outcomes may depend on revisiting the structure of public health units and governance of case management practice to assess their capacity to account for the context of HIV and respond to changes in the illness and wellness experiences of people at risk and living with the virus across settings and over time. Yousefi-Nooraie, Dobbins, Brouwers, and Wakefield (2012) completed a social network analysis in a large public health unit in Toronto in order to map the flow of information and its association with organizational structures in the institution. A sociogram was created from the responses of 257 (41%) staff members of various job titles including public health nurses, epidemiologists and the management team. The results revealed that "people mainly partitioned together within their divisions," turned primarily to peers for information, and there was little reciprocity between staff and the management team in consultations, similar to the communication patterns reported by case management nurses in this study. The flow of information in case management is mainly vertical, and information exchange primarily takes place in cubicles between nurses or with clients at the point-of-care. Public health units can be described as both

strongly framed spaces, with their panoptic structure where “[d]ecisions about what is permissible come from above and inter-subject communication is minimized” (Sibley, 2007, p. 80), and *strongly classified* spaces, with their internal homogeneity around a biosecurity discourse and division into separate teams with distinct roles aimed at achieving this goal. As Sibley (2007) suggests, in strongly classified and framed institutions, minority knowledge may be seen as threatening and difference as subversive since ambiguous boundaries are not well tolerated, and this seems to be the case in Ontario. While case management nurses are “given space” at the point-of-care for assessing the personal and social context of each individual’s ability to manage the virus, nurses’ communication with clients, the management team and community partners was mostly “one-way” and focused on education about HIV prevention, reporting outcomes, or requests for help with a case. Two-way exchange of information between nurses and the management team primarily occurred when “problems” with compliance were identified by nurses and direction was required by the A/MOH for how to proceed. With few exceptions, the A/MOH rarely met with the case management team. The current style of governance and structural arrangements of space appear to reinforce power relations and limit the boundaries of case management practice, nursing care, and the contours of the public health response.

The hierarchical arrangement, marginalization of a relational approach to the intimate spaces of the nurse-client relationship, one-way communication, and regime of practices that promote governance from a distance in public health units, all enable the colonization of nurses’ practice (and clients’ concerns) with a singular medical-epidemiological goal and create the conditions for the coopting of nurses’ knowledge and skills for “making it easy and making sure” compliance is attained and threats to the public mitigated. The structural arrangements are determined by and contribute to the classification of knowledge, practices and people in relation to whether or not they “belong”

with a medical-epidemiological discourse, and those that deviate are either excluded, or monitored until no longer considered a threat to the established order. Tensions in practice tend to occur when there is a "transgression" in this established order, or noncompliance with the policies, rules for "good health and ethical conduct," and use of time and space. Therefore, the organization of the public health response around risk management can be viewed in Sibley's (2007) terms, as the organization of social and physical space to prevent transgressions.

The focus of case management practice on promoting norms and identifying people who pose a threat to the public can also be understood through the concept of "abjection," a concern with the purity of spaces and a lack of tolerance, fear or disdain for diversity and difference (Sibley, 2007). Abjection explains the main findings of this study of a culture of fear, the preoccupation with "avoiding trouble," and the war-like effort to protect the public from the spread of the virus as central to the public health response to HIV. The fear of disrupting the status quo appears to be driving efforts to identify and separate the infected from the non-infected in society based on measures of viral load, disclosure, the practice of safe(r) sex and needle sharing, and branding of people as "U=U." A perception of "difference" as abject may also explain the prioritizing of the predetermined 90-90-90 strategy (UNAIDS, 2014) as opposed to nurses' efforts to accommodate diversity, the lack of integration of the variety of concerns (e.g. homophobia, racism, sexism, employment, etc.) of people affected by HIV into the new national plan proposed by CANFAR (2018), and resistance to developing a range of emotional and social indicators of success in the HIV response. Dealing with individual emotional concerns and tackling the social determinants of health are considered "more complicated" and "less efficient." The reticence with mixing paradigms, goals, and approaches in public health care can subsequently be traced to fears that deviance from norms complicates case management and could result in the contamination of individual

bodies and the disruption of the normal functioning of society. This is clear in the value of case management of a "clean case" versus "difficult" cases that can create a "mess."

In this study, it has become evident that efforts to promote conformity to norms and fear of transgressions underlies the war on HIV/AIDS. Problems with conformity created tensions, are "hated" and mitigated from the start in case management with efforts to "avoid trouble" in public health units across the province. It is not the client that is risky and problematic from a case management perspective, but the fixed and singular medical-epidemiological goal that determines what is "true" and "right or wrong" that is at risk when challenged by beliefs, goals and approaches that are different than the status quo. It is the disruption of the order of things based on a medical-epidemiological, neoliberal, patriarchal perspective that is feared and driving a top-down, authoritarian approach and suppression of a relational approach, greater collaboration, and the development of more inclusive practices in the HIV response.

6.6 Implications for Research, Policy and Practice

This research did not set out to identify and choose one approach to case management over another approach. However, the main finding is a "battle for truth" over the direction of case management nursing practice in Ontario that appears to be representative of a conflict at the core of the public health response to HIV at a provincial, national and global level. The "battle for truth" between a medical-epidemiological discourse and a nursing discourse reflect a tension noted in research, policies and practice between: (a) calls for greater investment in testing and treatment technologies to scale-up the current approach to "end HIV," and (b) arguments for the development of a more robust response to HIV with an integrated model of care that accounts for the impact of social drivers in the management of infectious diseases. These results provide evidence to suggest that the "War on HIV" is, in actuality, a battle for control over the knowledge, skills and priorities that guide the public health response that can be conceptualized in Foucauldian terms as

a process of governmentality, a process concerned with "authority over the bodies of knowledge, beliefs and opinions in which [nurses] are immersed" (Dean, 2010, p. 27). Viewed as a process of governmentality, the decision to engage in a "War on HIV" as opposed to building capacity in nursing to promote dialogical engagement with people living with HIV to better address their emotional and social needs, is political. These findings support the results of a growing number of studies and position statements in public health nursing and social science that are beginning to question assumptions circulating in and through the public health response that the "absence of disease" is the "true" indication of a healthy public, healthy sexuality is primarily a matter of safe(r) sex and risk management, and the privileging of biomedical and behavioral approaches over attention to social and structural issues in the management of people at risk and living with HIV is efficient, evidence-based, and "best" practice. Therefore, the implications of this study are that more research is needed to better understand the discourses and governmental practices fueling the tension between a focus on biomedical-epidemiological-legal goals and measures at the expense of more relational goals and practices in HIV care, and whether or not a "war on HIV" or a more democratized approach to the management of infectious diseases will result in improved outcomes for people at risk and living with the virus.

The identification of different discourses operating in case management nursing in this study, and examination of their meaning in policies and practices through the concepts of power/knowledge and government as the "conduct of conduct," contribute to a greater understanding of the complexity of the public health response to HIV than reported elsewhere. The study illuminated a number of tensions at the point-of-care where a medical-epidemiological lens focused on biosecurity is undermining nurses' ability to actualize relational goals in public health care. More research is needed specifically to understand and address these tensions. While a number of the sources of tension have

been studied independently such as risk reduction education, contact tracing, and disclosure counseling, the focus on how tensions are related to discourses through an analytics of government in this study suggests that efforts to address issues at the point-of-care will likely require a shift from a focus solely on the tasks and outcomes of case management towards the decision-making processes and power relations in public health care. Based on these findings, studies capable of examining the impact of different discourses on both the organization of care and how they impact the experiences and outcomes of different care providers and people at risk and living HIV will be an important next step. Methodologies that are more sensitive to both the calls for an “all of government” approach (Government of Canada, 2018), and the concept of “Nothing About Us, Without Us” in relation to *all* community stakeholders (Canadian HIV/AIDS Legal Network, 2005; Prentice et al., 2018), may be warranted to account for transdisciplinary, cross-sectoral concerns and competing priorities with research. Community-based participatory research (Irene, Louis, Hillary & Shine, 2017), practice-led approaches (Orser & O’Byrne, 2019) and methods such as “rapid, site-switching ethnography” (Armstrong & Lowndes, 2018) are all promising new research strategies in this regard. Through each of these methodologies, studies, themselves, become the starting point for breaking down silos, working through tensions, and arriving at solutions that account for multiple stakeholder strengths and needs.

As an ethnography based in one province in Canada, this study does not provide evidence to support decisions about which approaches to HIV care, governance styles in the HIV response, or additional indicators of success in case management would be most effective or desirable, but instead raises important considerations for developing an epidemiological sound *and* people-centred approach to case management more capable of responding to social issues and calls to action for greater involvement and meaningful engagement of people at risk and living with HIV at all levels of decision-making. To

understand how to design a more robust response to HIV, greater attention needs to be given to the following questions in future research, policy and practice debates: What are the social and economic costs of organizing the public health response around a singular biomedical indicator of success, and what indicators might better reflect the diversity of different stakeholder goals and needs in each province? Is the practice of colonizing case management nursing policies with medical-epidemiological priorities and measures an extension of historical values and beliefs about gender and gender roles in healthcare? What governmental rationalities and tactics about nurses and people at risk and living with HIV support a top-down, one-way, authoritarian approach to public health care and what institutional arrangements would promote more dialogical engagement as opposed to a culture of fear in case management practice?

This study illuminated the potential within the work of case management for public health nurses to play a substantive role in developing additional targets, relational policies, inclusive practices and social indicators for a more robust response to HIV/AIDS. Within nurses' approach to case management practice are the knowledge and skills capable of better accounting for the diversity of concerns of people at risk and living with the virus such as stigma, homophobia, racism, poverty and other social conditions that impact their willingness and ability to engage with public health and obtain specialized medical care. A key lesson is that better engaging people in testing, treatment and support services will likely require a greater emphasis on identifying strategies that promote community development and not simply a virus-centric approach, starting with a commitment by public health agencies to collaboration within and across health units, and the formation of issues-based coalitions to address ambiguities and tensions at the intersections of care. These findings lay the groundwork for future discussions about how to build capacity within public health to support the efforts of case management nurses to establish more meaningful and mutually respectful partnerships with clients and other stakeholders, foster

greater lateral communication, and participate more actively in policy debates about the direction of "frontline" practices. Including nurses in research as well as policy and practice discussions may help to address current gaps in knowledge about how to form more effective partnerships in the process of case management and address *as opposed to* "live with" the avoidance of public health care and the preference of many people, particularly those with a history of stigma and discrimination, of anonymous testing.

Given that a pressing issue in the HIV response is how to better engage people with a history of marginalization in testing, treatment and support services, critical reflection on the governance structures and their ability to account for competing discourses are a necessary starting place for improving the outcomes of the HIV response—especially for those who are currently "left farthest behind." Ten recommendations with particular implications for improving the ability of governance structures to support future research, policy and practice initiatives aimed at building on the strategies used by public health nurses in this study to balance a medical-epidemiological goal and measures with efforts to account for the complexity and diversity of goals and needs of different stakeholders in the HIV response when attempting to achieve public health are presented below.

6.6.1 Recommendations

Based on this study, the capacity of case management nurses to engage people at risk and living with HIV/AIDS in HIV care in Ontario might be better supported by:

1. Increasing efforts to actualize affirmative action policies when recruiting and hiring;
2. Committing to greater mutual engagement and collaborative practices within and across public health units;
3. Clearly outlining the roles and responsibilities of all members of a health unit team who, in addition to nurses, are involved in decisions about the management of cases;
4. Advocating for an end to the overbroad application of criminal law and prioritizing a

public health approach to better support people living with HIV with their challenges around disclosure;

5. Promoting a safe environment and forms capable of capturing through documentation the social and emotional experiences and priorities of clients at the point-of-care to integrate into program planning and evaluation;
6. Promoting strategic dialogue with community partners at the point-of-care about how to address tensions and ambiguities that exist across programs and services;
7. Jointly developing goals, indicators, policies, and plans to address stigma and other social conditions that appear to be impacting clients' ability to obtain quality care;
8. Integrating the 90-90-90 strategy into the community development framework and social indicators of the United Nations' Sustainable Development Goals to which Canada is also committed;
9. Forging partnerships to conduct community-based participatory research to increase evidence-informed decision-making in public health practice and policy development;
10. Expanding local networks to establish access to a central repository of evidence, existing policies, educational materials, templates of forms, and support for nurses engaged in HIV care.

CONCLUSION

The purpose of this doctoral study was to explore how conceptualizing the management of epidemics as “war” shapes public policy, public health practices, and the experiences of people with HIV in Canada. Despite the availability of effective testing and treatment, progress in the management of the HIV epidemic appears to be stalled. Canada, like other countries globally, has made important gains in reducing the rate of new infections since the introduction of HAART in 1996; however, more than 2000 new HIV infections continue to be reported across the country each year (UNAIDS, 2016). People from communities with a history of marginalization due to stigma and discrimination are disproportionately affected by HIV/AIDS (Bourgeois et al., 2017). Ontario is the province reporting the highest number of new infections annually. A critical reflection on the policies and practices used for case management in the public health response to HIV in Ontario was undertaken as a means of helping identify new knowledge and strategies to better engage people at risk and living with the virus in testing, treatment and support services.

The objectives of the study were to describe the experiences of case management nurses involved in the follow-up of people who test positive for HIV in public health units across Ontario and identify how public health policies shape the boundaries of nursing care and client outcomes in the response to HIV. A theoretical framework integrating the writings of Michel Foucault (1978-2008) on governmentality, Chris Weedon (1999; 2008) on gender, identity, and experience in patriarchal societies, and David Sibley (2007) on the geographies of exclusion was developed around the concept of power/knowledge to help explore and articulate how case management nursing practice may be socially constructed by the variety of different discourses competing over the direction of the HIV response. The research question guiding the study was: “How are public health nurses'

experiences in case management in Ontario aligned with policies governing the response to people affected by HIV/AIDS?"

A qualitative design was proposed given the paucity of available research on the topic of HIV case management from a public health nursing perspective. The study was based on a critical ethnographic design (Thomas, 1993) for its ability to help identify the discourses circulating in and through case management nurses' practice, the power relations and processes involved in the privileging of certain discourses over others in the HIV response, and the effects on people with HIV in their encounters with public health care. A purposive sample of 22 Registered Nurses engaged in case management in the public health response to HIV in Ontario participated in the study. Nurse participants provided a tour of the public health unit, and described the policies, practices and spaces used for case management in their jurisdiction. Four sources of data were collected at each participating public health unit: observations (e.g. organizational drawings); oral interviews; mute evidence (e.g. copies of policies, forms and educational materials); and field notes with reflexive journaling. A total of 14 public health units located in both urban and rural centres, and at least one in each public health jurisdiction in Ontario, were visited between April-October 2016. The public health units involved in this study accounted for more than 85% of the cases of HIV management in the province since the beginning of the epidemic in Canada in 1982 (see Appendix B). Approval for the study was first obtained from supervisors responsible for case management with the support of Ontario's Ministry of Health and Long-Term Care. Approval from the Research Ethics Boards at the University of Ottawa, Ottawa Public Health and Toronto Public Health was also obtained prior to the start of field work (see Appendix D for certificates).

Data analysis started in the field with reflexivity on norms and differences in policies and practices at and between each site to guide interview questions and observations and continued after field work was completed. Each type of data was first analyzed

independently using NVivo software and traditional techniques for content analysis including line-by-line coding of transcripts, policies and forms, and then a constant comparative approach to identify themes. The main finding is that the meaning of "engagement in HIV care" as understood by nurses is invisible in the official policies and forms around which case management practice is organized. Instead, case management practice appears to be structured around the goal of achieving the UNAIDS (2014) 90-90-90 strategy (90% of people diagnosed, 90% linked to specialized medical treatment, and 90% achieve viral suppression by 2020). In the current approach, success is narrowly defined using a single biomedical indicator (a reduction in viral load), and the focus is on surveillance and other epidemiological concerns with managing each client's risks. While engaging clients in risk reduction counseling, specialized medical care and surveillance are integral to successful case management, from a nursing perspective the goal of engagement is also for clients "to feel supported" regardless of whether they are willing or able to engage in testing and treatment. Nurses describe the steps of case management as "learning a client's story," "starting where the client is at," "sharing mutual concerns," "matching information to needs" and "facilitating connections." Despite a relational approach being integral to case management from the perspective of nurses, no social indicators have been developed to guide and evaluate the HIV response, and there is little evidence of attention to the emotional and social concerns of people affected by HIV in the policies and forms developed for case management practice.

The data demonstrate how the limited priority given to social and emotional goals and indicators in the current approach to the public health response to HIV is resulting in the marginalization of the relational concerns of nurses, and a lack of development of initiatives aimed at maintaining trusting relationships, improving quality of life and ensuring adequate support for people living with HIV, particularly those experiencing the most challenges. Instead, three themes (each with subthemes) characterize case management

nurses' current practice: "Avoiding trouble," "Living with a client for a while," and "The whole dance we do." Several concrete ideas could be drawn from nurse participants' experiences with balancing a dual obligation to provide both epidemiologically sound *and* people-centred care about how to improve the capacity of public health units to develop more effective partnerships with key stakeholders and better engage the people most affected by HIV/AIDS in testing, treatment and support.

The two separate discourses operating in and through case management nurses' practice are similar to those at the centre of public health policy debates about how to "end HIV:" a medical-epidemiological discourse tied to a biosecurity approach and goal of disease containment, and a nursing discourse linked to a relational approach aimed at promoting mutual respect and social support for people exposed to HIV in the management of the epidemic. This study demonstrates how each discourse is linked to a different set of priorities, knowledge, and skills in the public health response to HIV and often compete for time and space within the practice of case management. These findings support assertions in the media that decisions in the field of HIV prevention are political and not only medical in nature, and suggestions in previous studies that public health nursing is a process of governmentality, a process concerned with "authority over the bodies of knowledge, beliefs and opinions in which [nurses] are immersed" (Dean, 2010, p. 27). The results confirm that at the core of the public health response to HIV in Ontario is a "battle for truth" over the direction needed to improve the outcomes of the management of the epidemic. The key lesson is that the policies, governance structures and institutional arrangements of public health units in Ontario are neither organized around an intention to create a supportive environment, nor to address the social determinants of health driving the epidemic such as homophobia, racism and poverty, to name a few. From the description of the steps in public health policies and interviews with nurses, it has become evident that case management in Ontario has been conceptualized

as a war with its focus on scaling up efforts aimed at disease containment, protecting the public from the spread of infection, and the use of terminology and actions prioritizing the mitigation of risk such as threats, priority populations, frontline, fights, orders, force, targets, officers, units, resistance, containment, elimination, security and surveillance.

The thesis of this study is that the hegemony of a medical-epidemiological discourse and narrow focus on a biosecurity indicator of success in public health care is contributing to the marginalization of attention to social determinants of health and the concerns of people who are unable or unwilling to conform to risk reduction measures to manage the virus. Specifically, the findings of this study demonstrate how the organization of the public health response around a singular goal of disease containment is resulting in a decontextualized, virus-centric approach to the case management of people at risk and living with HIV in Ontario despite awareness that HIV is both a medical and a social issue. The result of a reliance on a medical-epidemiological discourse to define the meaning of public health as the absence of disease in the population, is a biomedical definition of the meaning of “case” and “management” in public health care. The practice of case management has been conceptualized as one segment along a linear pathway or cascade of care between testing and ongoing surveillance of people with HIV, focussed on risk reduction education and the encouragement of individual compliance with the behavioural goals and expectations of each A/MOH for reducing the community viral load and transmission of HIV in the population. The result is a compartmentalized approach to the management of people newly diagnosed with HIV that is disease specific, with an emphasis on identifying people who pose potential threats to the public, and the implementation of “forced measures with graduated intensity” to prevent non-compliance or transgressions from the prescribed cascade of care.

The effect of organizing case management nursing care around a singular medical-epidemiological paradigm-theory-method, in Foucauldian terms, is the

conceptualization of case management as a form of biopower: the management of HIV in the population (biopolitics) with “an endless effort to prevent illness one person at a time” (anatamo-politics) (Potvin, 2014, p. E403). The political decision to engage in a war on the virus as opposed to engaging with the people most affected by HIV to address the issues that promote quality of life and dignity renders nurses relatively powerless to promote health as holistic and ignores Canada’s commitment to the SDGs that conceptualize healthcare as indivisible from the material and social conditions that drive disease. The results provide evidence of how the colonization of case management nursing policies and practices with medical-epidemiological goal and measures leads to the coopting of nurses’ knowledge and skills in relational work to meet the expectations of the public health units as opposed to the diversity of concerns of their clients. Nurses’ engagement in relational care practiced within an authoritarian system of governance and a culture of fear created by the threat of public health law and criminal law, can be viewed as pastoral care, a form a maternalism, and punitive as opposed to “meaningful engagement” as set out in the principles of GIPA/MEPA (UNAIDS, 2007; 2014), Nothing about Us, Without Us (Canadian HIV/AIDS Legal Network, 2005), and reconciliation (Prentice et al., 2018).

The choice in how to better manage HIV from the perspective of case management nurses, is not between the two different discourses, but how to arrive at a better balance in public health care in implementing measures to protect people from the spread of the disease with efforts to support people living with HIV meet their unique health goals. The results of this study appear to have implications for how to improve the outcomes of the management of other infectious diseases such as Ebola, TB, Syphilis and Measles where effective treatment is available but lack of trust and collaboration in public health care also appear to be resulting in increasing rates of new infections. The challenge for public health care from the standpoint of nurses involved in the case management of people with HIV

at the point-of-care in Ontario is: (a) “fulfilling what we need to get for our mandate in public health, but just in a way that best serves that person” at the individual level; and (b) ensuring “everyone leaves the process respected, and everyone feels their needs have been met--on both sides too, not just the client, but as far as the team and the services, they worked together” at the level of the population.

The findings from this study about the shortcomings of a medical-epidemiological paradigm-theory-method for managing infectious diseases provide evidence of minority knowledge and approaches in the public health response practiced by nurses with the potential of helping arrive at a more robust response to the case management of diseases like HIV. The ability of public health nurses to accommodate multiple goals and measures of different stakeholders in this study point to the possibility of the development of a more integrated approach to public health care. These findings shift the focus in research and policy development in the field of infectious disease management from the tasks (contact tracing, partner notification, disclosure counselling) and practices that “responsibilize” individual nurses and clients with behaviour change, to the discourses and structures governing the public health response as a potential starting point for improving the outcomes of public health care. The colonization of case management nursing practice is problematized as a result of this analytics of government of the HIV response. A series of questions and ten recommendations for exploring the potential benefits of a community development approach to public health governance are provided to guide future research, policy and practice development needed to address tensions between the two different approaches to case management noted at the point-of-care.

The findings and recommendations of this study are consistent with calls to action arising from within the domain of infectious diseases management for more critical reflection on the “business” of public health (Farmer et al., 2013; Hancock, 2018), the limitations of conceptualizing the domain of public health care with a biosecurity framework

(Elbe, 2009; O'Manique, 2018), and the "dangerousness" of governance based on neoliberal rationalities of scarcity and efficiency (Foth et al, 2016; Gagnon & Holmes, 2011; Husbands, 2019). In a global public health gathering attended by 900 participants from 72 countries, Dr. Mandeep Dhaliwal (2017), Director of HIV, Health and Development Group at UNDP, called for more inclusive practices and greater intersectoral collaboration at all levels of the public health response to improve the outcomes for people with HIV/AIDS: "To make advances on the health of vulnerable groups, there is a need for a greater effort to reach those who are left furthest behind, for deeper cooperation across all sectors and levels, and for a renewed focus on addressing the root causes of the economic, social and environmental determinants of health" (p. 2). The data collected in this study help establish the foundation for further dialogue and research with case management nurses and people affected by HIV/AIDS in Canada about how to form more effective partnerships and build issues-based coalitions to address the social conditions impacting the ability of people to live with HIV while scaling up testing and treatment to prevent the spread of the virus in the public.

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Appendix A

Map of Public Health Units in Ontario by Region

Source: Association of Local Public Health Agencies (2015)

Appendix B

HIV cases per Public Health Unit in Ontario

Table 1.15 Number of HIV diagnoses and rate per 100,000 by public health unit and sex, Ontario, 1985 to 2011

	Males		Females		Unknown	Total		
Public health unit	**No.**	**Rate**	**No.**	**Rate**	**No.**	**No.**	**Rate**	**Rank**
Algoma	38	63.0	20	32.2	4	62	50.6	17
North Bay-Parry Sound	61	98.9	13	20.6	3	77	61.7	14
Northwestern	24	56.7	10	24.1	5	39	46.5	18
Porcupine	22	47.8	5	11.1	4	31	34.0	26
Sudbury	218	222.9	76	75.8	20	314	158.5	6
Thunder Bay	100	123.5	55	67.7	1	156	96.2	8
Timiskaming	6	33.0	1	5.4	0	7	19.1	36
Northern	**469**	**115.1**	**180**	**43.7**	**37**	**686**	**83.7**	
Ottawa	**2,713**	**682.0**	**745**	**182.1**	**100**	**3,558**	**441.0**	2
Eastern Ontario	75	77.6	22	22.4	3	100	51.3	16
Hastings-Prince Edward	52	66.7	7	8.7	1	60	38.0	25
Kinston-Frontenac	310	337.5	46	49.3	52	408	220.4	4
Leeds-Grenville-Lanark	59	72.3	8	9.6	0	67	40.5	23
Renfrew	21	42.0	4	7.9	0	25	24.8	32
Eastern, other	**517**	**129.8**	**87**	**21.4**	**56**	**660**	**82.1**	
Toronto	**16,908**	**1,340.8**	**2,414**	**182.5**	**812**	**20,134**	**779.2**	1
Durham	168	64.2	43	16.2	10	221	41.9	22
Haliburton-Kawartha-Pine Ridge	34	40.7	8	9.5	1	43	25.6	31
Peel	699	135.5	244	47.2	26	969	93.9	9
Peterborough	62	97.4	20	29.8	2	84	64.2	13
Simcoe-Muskoka	155	69.4	27	12.0	12	194	43.3	21
York Region	227	59.8	73	19.1	8	308	40.4	24
Central East, other	**1,345**	**88.0**	**415**	**26.9**	**59**	**1,819**	**59.3**	
Brant	42	66.0	14	21.4	0	56	43.4	20
Haldimand-Norfolk	24	43.8	11	20.1	1	36	32.9	28
Halton	191	98.9	42	21.2	4	237	60.6	15
Hamilton-Wentworth	694	275.5	211	81.7	30	935	183.3	5
Niagara	269	128.4	98	45.1	12	379	88.8	10
Waterloo	241	106.1	78	34.0	7	326	71.4	11
Wellington-Dufferin-Guelph	135	108.9	37	29.8	3	175	70.5	12
Central West	**1,596**	**142.0**	**491**	**42.8**	**57**	**2,144**	**94.4**	
Chatham-Kent	33	60.0	5	8.8	0	38	34.0	27
Elgin-St. Thomas	18	42.7	8	18.8	0	26	30.7	29
Grey Bruce	36	45.6	2	2.5	0	38	23.9	34
Huron	10	32.4	3	9.6	1	14	22.6	35
Lambton	28	43.1	5	7.5	1	34	25.8	30
Middlesex-London	1,056	511.1	216	100.3	34	1,306	309.5	3
Oxford	19	37.0	6	11.6	0	25	24.2	33
Perth	29	76.4	4	10.4	1	34	44.4	19
Windsor-Essex	474	243.0	111	56.7	19	604	154.6	7
Southwest	**1,703**	**223.3**	**360**	**46.2**	**56**	**2,119**	**137.4**	
unknown	**1,127**		**249**		**51**	**1,427**		
Total	**26,378**	**448.7**	**4,941**	**82.1**	**1,228**	**32,547**	**273.6**	

Data sources: HIV Laboratory, Public Health Laboratory – Toronto, Public Health Ontario
2001 population estimates provided by Statistics Canada

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Source: Ontario HIV Epidemiological Monitoring Unit (2013)

Appendix C

Data Collection Guides

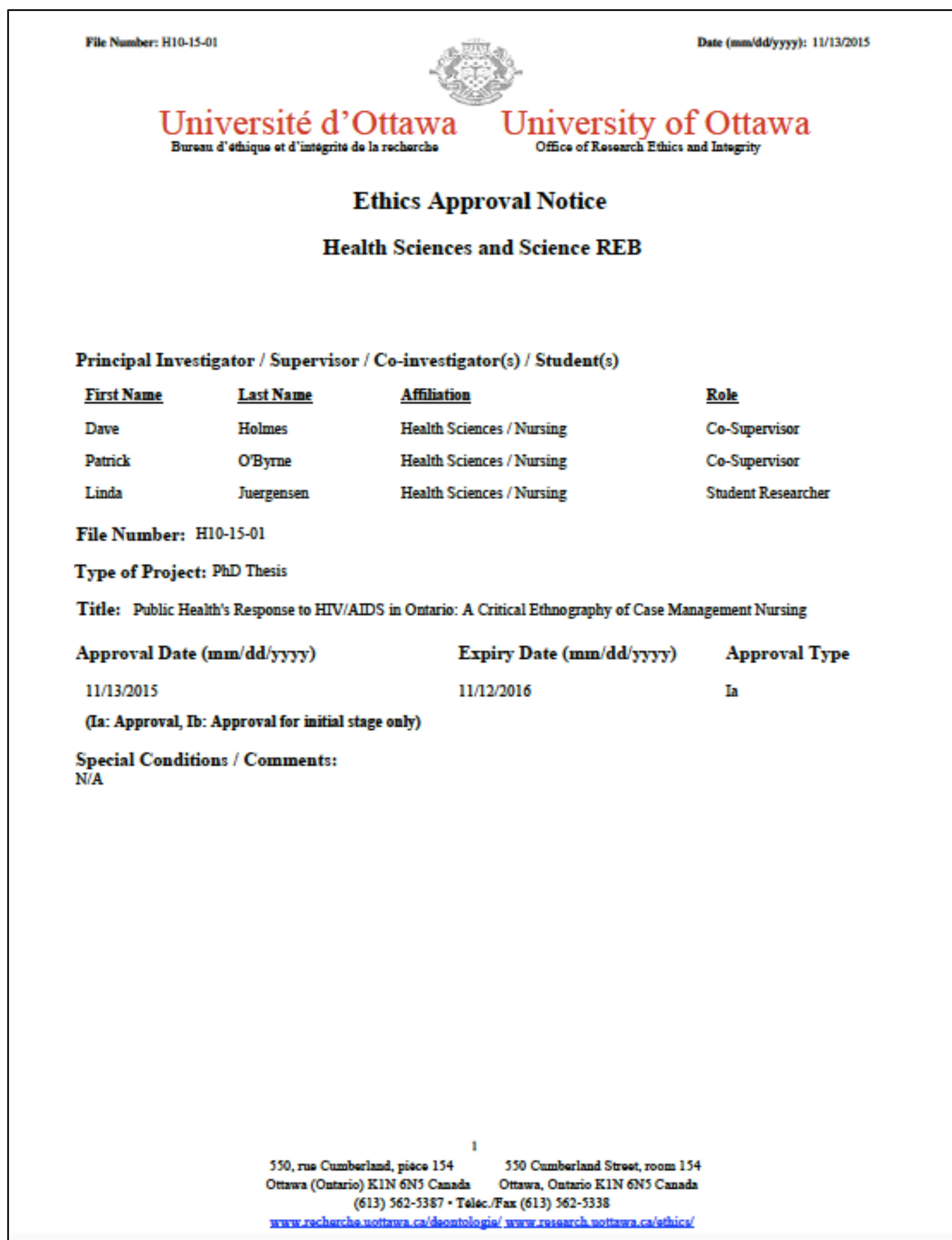
Interview Guide
How is your case management unit organized?
Can you show me the spaces used to carry out case management?
How do you define case management?
How would you describe the role of a case manager?
Tell me about your experiences as a case manager?
What are your goals in HIV case management?
Can you describe for me a typical workday?
What strategies are used to accomplish case management goals?
What is the rationale(s) behind these goals and strategies?
How are these rationalities arrived at? Are alternatives considered?
What ideas, information, and resources inform your practice?
What are your main concerns in HIV case management?
How are these issues addressed?
How are decisions in case management made?
How would you describe nursing's contribution to HIV care?

Observation Guide
What 'spaces' are utilized by a case manager? (Physical? Virtual? sketch)
How is the configuration of a case manager's space related to nursing practice?
What spaces are used for HIV care? Problem-solving? Administration? Communication?
How is a case manager positioned within public health?
How does space shape a case manager's role?
What behaviours are supported by the space and configurations available?
What are the limitations?
Combine with interviews to map relationships of space (virtual & physical) to lines of communication and practice

Document Guide
What documents exist to support HIV case management work?
How are documents written?
How are they read? How are they used?
Who writes them?
For what purposes? On what occasions? With what outcomes?
What is recorded, and how? What is omitted?
What does the writer seem to take for granted about the reader(s)?
What do readers need to know in order to make sense of them?

Appendix D

Ethics Approval Certificates



File Number: H10-15-01

Date (mm/dd/yyyy): 11/13/2015

Université d'Ottawa — University of Ottawa

Bureau d'éthique et d'intégrité de la recherche — Office of Research Ethics and Integrity

Ethics Approval Notice

Health Sciences and Science REB

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

First Name	Last Name	Affiliation	Role
Dave	Holmes	Health Sciences / Nursing	Co-Supervisor
Patrick	O'Byrne	Health Sciences / Nursing	Co-Supervisor
Linda	Juergensen	Health Sciences / Nursing	Student Researcher

File Number: H10-15-01

Type of Project: PhD Thesis

Title: Public Health's Response to HIV/AIDS in Ontario: A Critical Ethnography of Case Management Nursing

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
11/13/2015	11/12/2016	Ia

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:
N/A

1

550, rue Cumberland, pièce 154 — 550 Cumberland Street, room 154
Ottawa (Ontario) K1N 6N5 Canada — Ottawa, Ontario K1N 6N5 Canada
(613) 562-5387 • Téléc./Fax (613) 562-5338
www.recherche.uottawa.ca/deontologie/ www.research.uottawa.ca/ethics/

File Number: H10-15-01 **Date (mm/dd/yyyy):** 11/13/2015

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

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement (2010) and other applicable laws and regulations in Ontario, has examined and approved the ethics application for the above named research project. Ethics approval is valid for the period indicated above and subject to the conditions listed in the section entitled "Special Conditions / Comments".

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

Please submit an annual report to the Ethics Office four weeks before the above-referenced expiry date to request a renewal of this ethics approval. To close the file, a final report must be submitted. These documents can be found at: http://research.uottawa.ca/ethics/submissions-and-reviews.

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

Signature:

Hoda Shawki
Protocol Officer for Ethics in Research
For Daniel Lagarec, Chair of the Health Sciences and Sciences REB

550, rue Cumberland, pièce 154 550 Cumberland Street, room 154
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada
(613) 562-5387 • Téléc./Fax (613) 562-5338
www.recherche.uottawa.ca/deontologie/ www.research.uottawa.ca/ethics/

April 8, 2016

Research Ethics Board
Ottawa Public Health
100 Constellation Crescent
7th Floor West
Ottawa, ON K2G 6J8

Linda Juergensen
School of Nursing
Faculty of Graduate and Postdoctoral Studies
University of Ottawa

Dear Ms. Juergensen,

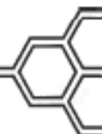
Re: Research Project #218-16 Category 1 Approval
Public health's response to HIV/AIDS in Ontario: A critical ethnography of case management nursing

I am pleased to inform you that the Ottawa Public Health Research Ethics Board has reviewed and accepted your research proposal entitled, *Public health's response to HIV/AIDS in Ontario: A critical ethnography of case management nursing*. You may begin data collection per the schedule you have established.

For your consideration the delegated reviewers provided one recommendation to clarify clinic observations. They suggested you note in the Information Session (Appendix A4) that no patient interactions will be observed in the HIV clinics. This would alleviate potential concerns that nurse might have, particularly as one example question in the Information Session concerns nurses' experiences with clients.

You are reminded to inform the Board if you have any major changes in your proposal by completing Appendix F (attached). At the end of your study, you are to submit an end of project report using Appendix H (attached). Please submit the completed forms as indicated to the Ottawa Public Health Research Ethics Board Secretariat via email.

The term of approval ends on April 11, 2017. Should you require additional time, please contact the REB secretariat to obtain a renewal document which much be submitted in order to extend the time frame of the project.



On behalf of the Board, we wish you well in your research. Please do not hesitate to contact Eva Stewart-Bindernagel, Secretariat to the Research Ethics Board at oph.ethics@ottawa.ca or 613-580-6744, ext. 23595 if you require further information.

Marguerite Soulière
Chair, Research Ethics Board
Ottawa Public Health

Attachments: 2

Public Health
277 Victoria Street
5th Floor
Toronto, Ontario
M5B 1W2
toronto.ca/health

September 23, 2016

Ms. Linda Juergensen
PhD Candidate
University of Ottawa
School of Nursing

Dear Ms. Juergensen,

Re: New Study Submission - The Public Health Response to HIV/AIDS in Ontario: A Critical Ethnography of Case Management Nursing (File Number 2016-07)

Principal Investigator: Ms. Linda Juergensen

I am writing to advise you that the Toronto Public Health Research Ethics Board (TPH REB) has reviewed and approved the research proposal referenced above for a period of one year, until **September 23, 2017**. If the study is expected to continue beyond this date you will need to complete a Continuing Research Renewal Form by **August 23, 2017** and forward it to the REB or your ethics approval will expire.

If changes are made to the approved research proposal, implementation protocols, and/or consent materials an amendment form will need to be submitted to the REB for review and approval prior to implementation. Any adverse or unanticipated issues or events that occur during the course of the study that may increase the level of participants' risk or have other ethical implications that may affect participants' welfare (e.g., unexpected reactions by participants, unavoidable single incidents, inappropriate/unauthorized use of information, privacy breaches) must be reported to the REB immediately.

Upon completion of the project an End of Research Project Reporting Form and a final report must be submitted to the REB. All relevant forms are available on the Toronto Public Health Research Ethics Review website.

Best wishes for the successful completion of your project.

Yours sincerely,

Heather Sampson
Chair, Toronto Public Health Research Ethics Board

Enclosure: Approved Consent Form (September 12, 2016 version)

cc Dr. Dave Holmes
Dr. Patrick O'Byrne
Dr. Herveen Sachdeva
Dr. Rita Shahin
Megan Easto
File #2016-07

Appendix E

Consent Form

Université d'Ottawa
Faculté des sciences de la santé
École des sciences infirmières
University of Ottawa
Faculty of Health Sciences
School of Nursing

Research Project Title:
Public Health's response to HIV/AIDS in Ontario:
A Critical Ethnography of Case Management Nursing

Principal Investigator:
Linda Juergensen, Doctoral Candidate
School of Nursing
Faculty of Graduate Studies, University of Ottawa
451 Smyth Road, Ottawa, ON, K1H 8M5
Tel: (613) 562-5800
Fax: (613) 562-5443

Thesis Supervisors:
Dr. Dave Holmes, Full Professor, School of Nursing
Faculty of Health Sciences, University of Ottawa
451 Smyth Road, Ottawa, ON, K1H 8M5
Tel: (613) 562-5800 x 8341
Fax: (613) 562-5443
Email: dholmes@uottawa.ca

Dr. Patrick O'Byrne, Associate Professor
School of Nursing
Faculty of Health Sciences, University of Ottawa
451 Smyth Road, Ottawa, ON, K1H 8M5
Tel: (613) 562-5800 x 8917
Fax: (613) 562-5443
Email: pjobyrne@uottawa.ca

This consent form is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. Please take the time to read it carefully. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. A copy of this form will be left with you for your records and reference.

Invitation to participate:
I am invited to participate in the abovementioned research study conducted by Linda Juergensen. I understand that Linda is a graduate student and will be supervised by her thesis supervisors. I am also aware that this project is part of the requirements for her program at the University of Ottawa and this invitation to participate is in no way related to my responsibilities at the Public Health Unit where I am employed.

613 562-5473
613 562-5443
451 Smyth
Ottawa ON K1H 8M5 Canada
www.uOttawa.ca

Overview of the study:
The purpose of this study is to understand how the framework used for managing infectious diseases in Canada has shaped nurses' roles and experiences in the HIV/AIDS response. Public health nurses involved in the case management of HIV are well positioned to help better link people at risk or living with HIV/AIDS to testing, treatment, and support services in Ontario. However, little is known about their roles and experiences with clients. Therefore, the aims of this study are to identify and document the variety of policies, strategies, rationalities and work settings currently used by nurses for HIV case management across the province. This research will be used to construct a provincial profile of case management practice from a nursing perspective and arrive at ideas for how nurses may be able to help public health more effectively engage people in Ontario in HIV care.

I understand that the findings from this research may be used to inform public health policies and guidelines. I am also aware findings may be published and/or presented in peer-reviewed journals, conferences, and/or webinars as a means to share this knowledge with other stakeholders from similar settings.

Participation details:
Participation will entail accommodating the researcher during a typical 8-hour shift, or two 4-hour shifts, on a site visit that will resemble a 'job shadowing' experience common in public health.

Each field visit will involve a mix of observation and interviewing, starting with introductions and a tour of the workspace used for case management. During this time, which may take 60-90 minutes, the researcher will ask for a description of the steps used for HIV case management. When convenient, I will then be asked to join the researcher for a more formal interview about my practice experiences and the strategies used to engage clients in HIV care. The interview might last for 30-60 minutes, and be audio-recorded if I consent, as indicated in the check box below. It will take place in a confidential location of my choosing.

The second half of the 'shadowing experience,' or second 4-hour shift, will involve minimum participation. This time will be used by the researcher for reviewing documents such as guidelines and brochures used for practice and making notes. At the end of the site visit, 30 minutes will be set aside for a 'member-checking' session, where the researcher may ask for feedback or for additional insights to help clarify information collected, as well as answer any questions I may have about the study.

Benefits:
One benefit of this study is the potential to contribute to a new knowledge base about HIV case management nursing practice. The information I share might promote a new pattern of engagement with clients at risk or living with HIV/AIDS needed to help address current shortcomings in the HIV response. Also, being given the opportunity to voice and pool experiences with other nurses in the same position across the province might lead to a feeling of being part of a community and feeling supported in my practice and professional development.

Risks:
While I may be concerned with how I will be represented in the findings, I understand that every effort will be made to minimize these risks. The information shared with the

researcher will be kept confidential, no information will be shared directly with supervisors or administrators, and individual perspectives and quotes will be presented in the context of pooled data in order to preserve the anonymity of participants.

Confidentiality and anonymity:
I have been informed that my name and any other identifying information will be removed from transcripts and quotes, and a unique code will be used instead. No information will be released or printed that would disclose my personal identity. These measures are consistent with the overall aim of the study of constructing a provincial profile of case management practice.

Conservation of data:
Audio-recordings will be transcribed by the Principal Investigator onto a password protected laptop computer and stored in a password protected folder. During field work, the computer will be kept in a locked briefcase along with field notes and documents collected on site. Only the Principal Investigator will have access. After site visits, electronic data will be copied onto a password protected flash drive and securely stored in a locked file cabinet in the office of the Principal Investigator. On completion of the study, the password protected flash drive, field notes and audiotapes will be transferred to a locked cabinet in the office of the main supervisor, Dr. Dave Holmes, where they will be securely conserved for 5 years. After 5 years, all written material will be shredded, audio tapes destroyed, and electronically stored information erased using secure deletion software (e.g. Freeraser).

Compensation:
A $10 Tim Horton's gift card will be offered at the end of the site visit regardless of the length of my participation.

Voluntary participation:
I understand my participation in this study is voluntary. I am aware that I am under no obligation to participate. If I choose to participate, I may also refuse to answer any questions, and/or withdraw from the study at any time, without suffering any negative consequences. If I choose to withdraw, the data gathered up until that time will not be used in the study and destroyed.

Acceptance:

I, ____ (please print your name), agree to participate in the above research study conducted by Linda Juergensen, a doctoral candidate in the School of Nursing, Faculty of Graduate and Postdoctoral Studies at the University of Ottawa. Any questions I have asked about the study have been answered to my satisfaction. If I have any further questions, I may contact the Principal Investigator or Thesis Supervisors.

If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5
Tel.: (613) 562-5387
Email: ethics@uottawa.ca

There are two copies of the consent form, one of which is mine to keep.

I hereby consent to be audio-recorded during the formal interview in this study:

Yes ☐ No ☐

Participant's signature: ______________________ Date: ________________

Researcher's signature: ______________________ Date: ________________

Appendix F

Demographic Questionnaire (Verbal Script)

Demographic Information (Researcher to fill in)	
What is your year of birth?	
What is your gender?	
What ethnicity do you most identify with?	
What nursing degree(s)	Diploma
have you completed?	BSN
(Circle all that apply)	MSN
	Doctoral
How many years in total have you been practicing as an HIV case manager?	
How many years in total have you been practicing as a Registered Nurse?	
How many hours per week do you work on average?	