Health services utilization among persons living with human immunodeficiency virus infection in Ontario

by

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Abstract

The goals of this dissertation were to investigate aspects of the health services utilization of marginalized persons living with HIV (PLWH), including women, recent immigrants, heterosexual men and individuals living in low income neighborhoods. In the first study, an algorithm of three physician claims for HIV-infection within a three-year period was validated for case-ascertainment of PLWH in administrative databases. The sensitivity and specificity of the algorithm were 96.2% [95% confidence intervals (CI) 95.2% to 97.9%] and 99.6% (95% CI 99.1% to 99.8%), respectively. The algorithm was used to conduct a population-based study examining rates of hospitalization among all PLWH receiving care in Ontario. The introduction of combination antiretroviral therapy was associated with more pronounced reductions in rates of total (-89.9 vs. -60.5 per 1000 PLWH; p = 0.003) and HIV-related hospitalizations (- 56.9 vs. -36.3 per 1000 PLWH; p < 0.001) among men relative to women. Between 2002 and 2008, higher rates of total hospitalization were associated with female sex [adjusted relative rate (aRR) 1.15; 95% CI: 1.05 to 1.27] and low socioeconomic status (aRR 1.21; 95% CI: 1.14 to 1.29). Higher rates of HIV-related hospitalizations were associated with low socioeconomic status (aRR 1.30; 95% CI: 1.17 to 1.45). Recent immigrants had lower rates of both total (aRR 0.70;
95% CI 0.61 to 0.80) and HIV-related hospitalizations (aRR 0.77; 95% CI 0.61 to 0.96). Finally, a theoretically-informed qualitative study was conducted to characterize the help-seeking experiences of heterosexual men living with HIV. The results indicate that without the symbolic appeal of women and the social connections of gay men, heterosexual men lack the composition of capital required to benefit fully from or improve their positions within the existing HIV health and social service fields. The findings of this dissertation illustrate important disparities in health services utilization among PLWH in Ontario.
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Chapter 1

Introduction

The purposes of this chapter are to:

1. Provide an introduction to the dissertation and study questions to be examined.
2. Review trends in the epidemiology of human immunodeficiency virus (HIV) infection in Canada and Ontario.
3. Introduce the three projects comprising the dissertation.

1.1 Background

1.1.1 Introduction

The introduction of combination antiretroviral therapy (cART) has indisputably altered the prognosis of individuals living with the human immunodeficiency virus (HIV), such that sustained reductions in morbidity and mortality attributable to advanced immunosuppression have been well documented.\(^1\)\(^,\)\(^2\) However, despite expansion of the antiretroviral armamentarium and an improved overall outlook for persons living with HIV (PLWH), several studies have suggested that the benefits afforded by advances in HIV medicine have not been shared equally by all sub-groups of these patients. Specifically, women, injection drug users and ethnic minorities have historically constituted the disenfranchised segments of the population of PLWH, in that the intersecting effects of gender and low socioeconomic status converge with cultural and societal stigmas associated with HIV to construct a myriad of social and structural obstacles to accessing care.\(^3\)\(^-\)\(^11\) The manifestations of these overlapping and colluding
impediments to care are evident in the accumulating body of literature indicating that marginalized PLWH such as women and ethnic minorities are less likely than others to access and stay in care, thereby remaining at heightened risk of hospitalization, illness and death, even in the modern era of cART.\textsuperscript{12-18} Interestingly, while heterosexual women living with HIV have long been considered among the PLWH at risk of poor outcomes because of challenges connecting with community-based care, heterosexual men living with the virus have traditionally not been included under this same rubric, and have remained largely invisible in the HIV-related literature.\textsuperscript{19} Nonetheless, it is possible that vestigial perceptions of HIV as a disease of gay men and the cultural displacement of HIV from heteronormative sexual practices act to undermine help-seeking behaviour by heterosexual men living with the virus and drive them to the fringes of HIV-related health service use.\textsuperscript{20} Because of the potential challenges faced by marginalized PLWH such as women, ethnic minorities and heterosexual men, it is important to understand patterns and experiences of health service utilization among these patients in order to ascertain if disparities exist in access to care and/or treatment outcomes.

The overarching goal of this dissertation is to contribute to the field of HIV-related health services research by examining utilization outcomes and help-seeking experiences of Ontario’s marginalized PLWH, including women, individuals from countries with a high prevalence of HIV and heterosexual men. The specific sections comprising the dissertation are a study validating various case-finding algorithms derived from Ontario’s administrative databases for conducting population-based HIV-research, a study examining temporal trends in rates of hospitalizations among PLWH in Ontario, and a study examining the help-seeking experiences
of heterosexual men living with HIV. The specific study questions that were addressed within each of these sections were:

1. What is the best algorithm for identifying PLWH within Ontario’s health-care administrative databases?
2. Did the impact of cART on hospitalization rates among PLWH vary according to sex and/or socioeconomic status?
3. Are marginalized PLWH (i.e. women, recent immigrants and individuals living in low income neighborhoods) hospitalized to a greater extent than their reference populations of PLWH in the modern cART era?
4. How do heterosexual men living with HIV characterize their help-seeking experiences?

The unifying theme of this dissertation is the use of multiple methods to examine the varying dimensions of health service utilization among disenfranchised PLWH living in Ontario. These data are intended for the audience of policy-makers, AIDS service organizations and clinicians who are involved in the provision and evaluation of HIV-related care to these groups of PLWH, and are relevant to both the provincial and national contexts given the changes in HIV demography which have occurred over the preceding decade in Ontario and Canada.

1.1.2 Epidemiology of HIV Infection

As of 2008, the Public Health Agency of Canada estimates that approximately 65,000 Canadians were living with HIV infection. Although men who have sex with men (MSM) continue to constitute the largest group of affected individuals, trends in the demographic profile of PLWH
suggest that the epidemic appears to be evolving in nature at the national level. For instance, women accounted for 22% of the national total of PLWH, up from 17% in 2005. Furthermore, relative to 2005, the number of prevalent infections acquired via heterosexual transmission among individuals from countries with a high prevalence of HIV infection and individuals originally from Canada increased by 18%. As a result, these groups comprised 14% and 17% of the national population of PLWH in 2008. In the case of both women and individuals from endemic countries, the increases in HIV prevalence may be at least in part attributable to a change in immigration policies implemented in January 2002 mandating the routine screening of all potential applicants to Canada for HIV infection.

Changes in the national make-up of PLWH have been mirrored by trends in the demographic composition of this population of patients in Ontario. Specifically, women represented approximately 25% of Ontario’s population of PLWH in 2008, while the prevalence of HIV-infection among persons from an endemic country has increased 62% during the years 2003 to 2008. Furthermore, there has been a marked increase in the prevalence of HIV among persons infected heterosexually who are not from endemic countries. The prevalence of HIV in this population has increased 41% in the five years spanning 2003-2008, such that 3,920 persons infected with HIV heterosexually were living in Ontario as of December 2008. In line with this trend, the numbers of men who have acquired HIV through heterosexual transmission has increased, such that heterosexually infected men represented 13.8% of HIV diagnoses among men in 2008.

In summary, the field of HIV has undergone an important evolution in Ontario over the preceding decade that has been marked by continued advances in the treatment of PLWH and
changes in the demographic composition of this population. Importantly, women, individuals from endemic countries and heterosexually infected men are increasingly represented among the provincial population of PLWH. In this climate of significant change in both the epidemiology and life-expectancy of PLWH, studies describing the various dimensions of health services utilization and outcomes among PLWH living in Ontario are required. However, such research in Ontario has been historically hampered by the lack of a population-based database of PLWH that can be used for facilitating longitudinal surveillance of HIV-associated health service use and outcomes. Because Ontario has a single-payer health-care system which is administered by the provincial government, utilization of health services can be potentially tracked using the provincial health care administrative databases, thereby affording a means by which a population-based cohort of PLWH who are in care can be assembled. In the context of health care services, administrative data are electronic records which are generated following the provision of a specific service (e.g. a physician visit), the dispensing of medication to individuals insured under provincial drug plans, use of emergency department services or hospital discharge. The appeal of using administrative databases rests with their representative nature and ability to examine and integrate the various aspects of HIV-related care. Nonetheless, while such databases provide a powerful means for conducting chronic disease surveillance and identifying where disparities may exist in health service utilization or outcomes, they lack the illuminative capacity to shed light on the structural and social bases of any inequities identified by population-level approaches. In contrast, methods of qualitative research and analysis are well suited to unpacking the root causes of disparity and thereby complementing findings generated from population-based studies. An approach to health services research that capitalizes on the representative strength of administrative databases and
the explanatory power of qualitative research would therefore constitute a formidable multi-
method approach to understanding the various dimensions of HIV-related care among Ontario’s
marginalized PLWH. For this reason, this dissertation aims to validate an algorithm derived
from administrative databases for identifying PLWH, apply this algorithm towards ascertaining
whether there are disparities in rates of hospitalization according to sex, socioeconomic status or
immigrant status, and understanding the help-seeking experiences of heterosexual men living
with HIV using qualitative methods. Each of these projects will be introduced in greater detail
in the ensuing sections.

1.2 Validation of case-finding algorithms derived from administrative data
for identifying adults living with HIV in Ontario

As mentioned earlier, administrative data are one means by which a population-based research
program tracking the health service use and outcomes of PLWH who are eligible for provincial
health insurance and accessing care can be undertaken.25 In Ontario, these data are maintained
by the Institute for Clinical Evaluative Sciences (ICES) through an agreement with the Ontario
Ministry of Health and Long-Term Care. In addition to ease of access, generalizability to the
entire population of PLWH receiving care in Ontario and comprehensive capture of health
service use, administrative data have several important advantages relative to alternative methods
for conducting health services research.24 Specifically, as administrative data are generated
without requiring individual patients to consciously participate in a research study, volunteer bias
and bias associated with faulty recall when ascertaining health service use are obviated.29
Similarly, the accrual of follow-up time without the need for direct patient contact facilitates the
collection of longitudinal information with relatively few missing data related to attrition when
compared with conventional methods of disease surveillance, such as longitudinal surveys or
disease based registries. Finally, the administrative health data at ICES can be linked with other information sources held on-site, such as the Canadian Community Health Survey, the national census and the Registered Persons Database, which includes demographic information on all residents of Ontario eligible for provincial health insurance. The ability to enrich the health services utilization data held at ICES with sociodemographic information such as place of residence and neighborhood income enhances the scope of analysis possible when conducting health services research with Ontario’s administrative health databases.

Nonetheless, despite the previously described strengths of administrative data for conducting health services research, several limitations of these data sources merit consideration when used for this purpose. As administrative data are occasioned in the process of billing for medical care that is covered by the provincial health insurance program, health services research which relies on Ontario’s health databases is necessarily restricted to only those services, products or procedures that are included in these data repositories. For example, the study of trends in prescription drug use in Ontario is limited to those medications that are listed in the Ontario Drug Benefit (ODB) formulary and further restricted to those individuals who are covered by the ODB program, notably adults aged 65 years and older and persons receiving social assistance.

Another limitation of administrative data relates to the nature of information collected for inclusion in the relevant databases. In general, information related to the processing of payment is prioritized when administrative data are generated, such that the accuracy of recorded information is likely highest when directly connected with reimbursement for a service, product or procedure. In contrast, fields which are not required for payment may be coded in a less stringent manner. Similarly, the emphasis on capturing data required for payment has
understandably resulted in databases that are generally lacking in clinical data relevant to many research questions but not necessarily important when billing for services.\textsuperscript{24,25} Furthermore, administrative data can only provide information on individuals who access care and/or are covered by the provincial health insurance program.\textsuperscript{24,25} As a result, groups that are particularly vulnerable or marginalized may not be represented in Ontario’s administrative health care databases. For example, refugee claimants in the province of Ontario are not covered under the Ontario Health Insurance Plan (OHIP), thereby discounting the use of administrative databases for studying utilization patterns and outcomes of this group of patients. Finally, and perhaps most importantly, administrative data are not generated for the specific intention of conducting research.\textsuperscript{24,25} As such, the accuracy of these data must be verified before they can be deployed for the purposes of chronic disease surveillance and health services research. As a result, validation of administrative data for the purpose of disease ascertainment has been identified as a priority by an international consortium of health services researchers.\textsuperscript{30} Using the administrative databases at ICES, algorithms for detecting individuals with hypertension, asthma, chronic obstructive pulmonary disease, myocardial infarction, mental health, pediatric inflammatory bowel disease and diabetes have been developed and validated, and have been subsequently applied towards studying trends in the prevalence, incidence, health services utilization and outcomes associated with these chronic diseases in Ontario.\textsuperscript{31-42} However, the accuracy of administrative data for ascertainment of HIV infection in Ontario had not been established, and was a necessary prerequisite for undertaking subsequent research examining hospitalization trends among marginalized PLWH.
1.2.1 Previous research validating case-finding algorithms for HIV disease ascertainment from administrative databases

Although administrative data have been used by many investigators for conducting HIV-related health services research, there are few preliminary studies evaluating the accuracy of these data for this purpose, particularly in the modern era of cART.

Keyes and colleagues conducted the first study evaluating the potential of using administrative data for identifying patients with the acquired immune deficiency syndrome (AIDS). Briefly, the investigators constructed several diagnostic categories based on the International Classification of Diseases, 9th Revision (ICD-9) diagnosis codes for both HIV infection and the various opportunistic infections and malignancies indicative of AIDS. Ultimately, a hierarchy of 17 diagnostic categories was selected as the basis for an algorithm which would be examined for its accuracy in identifying individuals with AIDS in the Medicaid claims files of California and New York. In California, the algorithm was tested for its sensitivity in identifying individuals with AIDS in the Medicaid database using a state registry of individuals living with the disease as the reference standard. Using this methodology, investigators identified 2,500 Medicaid recipients with AIDS in California between the years 1982 to 1986 and reported the test characteristics of the algorithm for 1985. Overall, the sensitivity of the algorithm was 93%, although this estimate varied among different patient sub-groups, ranging from 33% for women 50 years and older to 95% for disabled men aged 18 to 50 years. The diagnostic algorithm developed in California was then modified for evaluation in the Medicaid databases of New York by incorporating claims for the antiretroviral drug zidovudine and a fee code specific for the reimbursement of care provided to individuals with AIDS. However, because New York did
not have a state registry akin to that of California at the time the study was undertaken, the test characteristics of the diagnostic algorithm for identifying individuals with AIDS were determined using a small sample of Medicaid-eligible HIV-infected patients treated at two hospitals. Of the 125 patients, all but one were identified in the Medicaid data by the case-finding algorithm.\textsuperscript{44}

These early algorithms were subsequently updated by Thornton and colleagues and evaluated utilizing the administrative databases of the California Medicaid and national Medicare programs.\textsuperscript{45} Specifically, these investigators modified the algorithms by incorporating changes made to the AIDS case definition by the Centers for Disease Control and Prevention (CDC) in 1993 and supplementing the ICD-9 diagnosis codes with prescription claims for antiretrovirals which were available at the time, Medicare-specific diagnosis-related group codes, and fee codes which could serve as indicators of the receipt of extended services for patients with AIDS. Similar to the methodology described by Keyes, a hierarchy of diagnostic algorithms was proposed based on the investigators’ perception of the likelihood of accurately identifying individuals with HIV/AIDS in the administrative databases. For example, one inpatient or two outpatient claims with both an AIDS indicator condition and an HIV-related diagnosis code were rated as level 1 evidence for an AIDS case, as this particular definition was felt to most strongly conform to the CDC criteria for this condition. In contrast, level 4, less robust, evidence for AIDS from administrative data was defined as a single inpatient claim with an AIDS diagnosis code. The investigators compared the numbers of people with AIDS identified with each algorithm in the Medicaid (for calendar years 1991 and 1992) and Medicare (calendar years 1991 to 1993) databases with published estimates of the number of individuals with AIDS covered by
the two programs. However, because these investigators did not verify the accuracy of their proposed definitions against a reference source of data, they were unable to generate indices of validity for their algorithms.

Additional research examining the utility of case-finding algorithms was conducted by separate investigators using the Medicaid state databases of Ohio and New Jersey. In the case of the former, investigators used administrative data (i.e. claims with ICD-9 codes for HIV, prescription claims for antiretroviral drugs, and claims with service codes for HIV testing) to determine the number of PLWH in the Ohio Medicaid database, and compared these estimates with those of the Ohio Department of Health. Using all three sources of administrative data, the investigators identified 3,507 individuals with HIV/AIDS in the state Medicaid database, of whom 92% could be identified solely from claims with the ICD-9 code. The addition of prescription drug claims for antiretrovirals increased the yield by a further 8%, while claims with codes for HIV testing did not augment the performance of the algorithm. However, the accuracy of the estimates derived using the state Medicaid database do not appear to have been validated against the reference standard selected by the authors, thereby limiting inferences that can be drawn about the performance of algorithms used in this study. This limitation is addressed by the study of Medicaid claims in New Jersey, where investigators ascertained the validity of algorithms derived from administrative data for identifying PLWH by linking the state Medicaid files with the New Jersey AIDS/HIV registry. In this study, investigators determined the sensitivity of various algorithms that included assorted permutations of inpatient and outpatient claims with ICD-9 diagnostic codes for HIV and claims for prescription antiretrovirals available in 1996. Of 7,183 Medicaid beneficiaries identified through the linkage
between the administrative database and the state registry, 95% were correctly identified by case-finding algorithms that included prescription drug claims. The sensitivity of the algorithm decreased to 89% when claims for antiretroviral medications were omitted. Unfortunately, the authors did not provide details regarding the exact combination of inpatient, outpatient and/or prescription claims that were used when screening the Medicaid files. The study was further limited by its lack of HIV-negative controls, thereby rendering it impossible to determine the specificity of the algorithm.

The accuracy of hospital discharge data for HIV/AIDS disease ascertainment was evaluated by investigators using the Massachusetts Rate Setting Commission, a database of all hospital separations within the state. Using various combinations of ICD-9 codes for HIV or AIDS-defining conditions, the investigators evaluated the accuracy of nine algorithms derived from administrative data, using a statewide registry of all persons meeting the CDC definition for AIDS as the reference standard. Of the case-finding definitions which were evaluated, the algorithms that proved most accurate for the ascertainment of HIV/AIDS were either a single HIV-specific ICD-9 code or an HIV-specific ICD-9 code with a code for an AIDS-defining condition. The respective values for sensitivity, specificity and positive predictive value (PPV) for these two algorithms were 91%, 87% and 72%, and 93%, 86%, and 71%. Although the test characteristics of the algorithms were examined using data from 1988, an important contribution of this study was the finding that algorithms comprised exclusively of ICD-9 codes representing AIDS-defining conditions would not be useful for identifying patients with HIV/AIDS, with values of sensitivity, specificity and PPV of 7%, 14% and 3%, respectively. These results were similar to those obtained by investigators evaluating the accuracy of medical record coding.
among 7601 hospitalized patients living with HIV.\textsuperscript{49} Using a link between state AIDS surveillance registries and medical records, the positive predictive value and sensitivity of a single HIV-specific ICD-9 code for hospitalized patients was 97\% and 98\%, respectively. In contrast, the positive predictive values for ICD-9 codes representing selected AIDS-defining conditions ranged from 0 – 38\% among these patients.

The most recently published study describing the validity of administrative databases of HIV case ascertainment was conducted by Fultz and colleagues, who evaluated the test characteristics of claims-based algorithms for identifying HIV-infected individuals from the National Veterans Affairs Health Information System, using a clinical database as the reference standard.\textsuperscript{50} The sensitivity, specificity and positive predictive values for a single inpatient or outpatient claim with an HIV-related diagnostic code were 93.0\%, 99.8\% and 69.1\%, respectively. When the algorithm was modified to allow for greater than one inpatient or outpatient claim, specificity and PPV improved to 99.9\% and 87.9\%, respectively. Application of the algorithm to the administrative database for the period spanning the years 1997 to 2004 identified a cohort of 33,420 HIV-infected patients.

Although the previously summarized work was foundational in ascertaining the feasibility of using administrative data for HIV/AIDS surveillance, these studies had several limitations that render their findings non-transferable to the Ontario setting and, in some cases, the current era of HIV-related care. Because many of the studies were conducted prior to the availability of cART, a disproportionate weight was often assigned to hospital separation records relative to outpatient service claims when assembling case-finding algorithms, reflecting the high rates of
inpatient service utilization in the early years of the epidemic. Findings from these studies may therefore not be generalizable to the contemporary era of HIV-related care, in which the availability of viral load testing and cART have rendered HIV an illness that is managed predominantly in the outpatient setting.\textsuperscript{51-53} In addition, most studies utilized the state Medicaid files when evaluating algorithm performance. Because recipients of Medicaid receive prescription drug coverage, case-finding definitions incorporating antiretroviral prescription claims would be expected to augment the performance of algorithms for case-ascertainment from these databases, as noted in two of the studies identified in the literature review.\textsuperscript{46,47} However, all PLWH in Ontario do not receive drug coverage through the provincial ODB program, such that the use of prescription claims when conducting similar research in Ontario warrants further study. Furthermore, most studies restricted their algorithm generation to inpatient and/or outpatient service claims, but did not consider emergency department utilization, which may be an important site of health care access for the most marginalized of PLWH who may not be retained in primary care.\textsuperscript{54,55} Finally, and perhaps most importantly, the contextual generalizability of these studies to Ontario is limited by virtue of the single-payer health-care model in the province. Therefore, unlike the administrative databases examined in the reviewed studies, Ontario’s administrative databases contain the records of all PLWH receiving care in the province. By way of comparison, only 47\% of PLWH in the United States are enrolled in Medicaid.\textsuperscript{56} As these patients may have patterns of health service utilization that differ relative to their respective state cohorts of PLWH and patients who receive care in a setting of universal health coverage, the generalizability of these studies to the Ontario setting is limited. For these reasons, the validation of a case-finding algorithm designed to identify adult PLWH from Ontario’s administrative health databases was undertaken.
1.3 Temporal trends in hospitalization rates among PLWH in Ontario

The objective of the second component of the dissertation was to apply the algorithm validated in the initial stage of the thesis towards evaluating temporal trends in hospitalization rates among PLWH living in Ontario and to determine whether disparities exist in inpatient utilization according to immigration status, sex or socioeconomic status. These data are especially salient in the contemporary period of HIV management, as disparities in the rates of hospitalization among certain groups of PLWH relative to others may indicate inequity in accessing primary medical care, cART and/or the services of AIDS service organizations. We hypothesized that women, recent immigrants and PLWH living in low income neighborhoods would have higher rates of hospitalization than their respective reference populations of PLWH. The basis of this hypothesis included published literature indicating that HIV-infected women are at greater risk of hospitalization relative to men and that Canadians of low socioeconomic status have higher rates of inpatient utilization relative to Canadians living in high income neighborhoods.\(^{14,57-60}\)

With respect to recent immigrants, language barriers and a lack of familiarity in navigating the provincial health care system were conceptualized as potential barriers to accessing timely outpatient and/or community-based services.\(^{61-65}\)

1.3.1 Previous research examining trends in hospitalization rates among PLWH in the cART era

Studies evaluating inpatient utilization trends among PWLW in the years since cART has become available are summarized in Table 1.1.\(^{57,66-85}\) Although these studies were conducted in different regions and therefore among different groups of PLWH, several common findings are evident when interpreting the studies conducted immediately following the availability of cART.
Specifically, rates of hospital admission, inpatient costs and length of hospital stay decreased markedly during the years 1995 to 1997, the period corresponding to the approval of protease inhibitors and the widespread adoption of triple-drug therapy for treating HIV infection. Subsequent studies evaluating hospitalization trends during the later years of cART availability have noted findings that have been inconsistent with respect to hospitalization trends and risk factors for hospitalization. For example, while some investigators have noted continued declines in overall rates of hospitalization over the preceding decade, other studies have noted either stabilizing or increasing trends in these rates during this period. Furthermore, while women, racial minorities and individuals with public health insurance have been noted to be at increased risk of hospitalization in some studies, associations between inpatient utilization and sociodemographic variables have either not been observed or not evaluated by other investigative teams. However, despite the important contributions made by these studies to the field of HIV-related health services research, the current body of literature is not contextually transferable to the Ontario setting for various reasons. Most notably, because a diagnosis of HIV-infection has until recently precluded successful immigration to the United States, studies originating from this country could not evaluate the association between inpatient utilization and immigration status. Because of the increasing representation of recent immigrants among the population of PLWH in Ontario and the potential difficulties faced by this group in accessing care, examining the relationship between hospitalization and immigration status could provide important insight into the adequacy of community-based care for this group of PLWH. Furthermore, existing studies assessing the question of hospitalization among PLWH have been varied in terms of the comprehensiveness of their data sources and have not been population-based in nature, such that generalization to both the larger population of PLWH from which the various cohorts were
drawn and to other populations of PLWH is questionable. For these reasons, we conducted a population-based study of hospitalization rates among PLWH living in Ontario that examined whether the immediate impact of cART on inpatient utilization varied according to sex and/or socioeconomic status, and whether disparities in rates of hospitalization exist in the modern era of cART, defined as the period encompassing the years 2002 to 2008, after accounting for variables such as geographic residence within the province, extent of outpatient utilization and level of patient co-morbidity.

1.3.2 Analytical Considerations

Because of the temporally sequenced nature of the hospitalization data and the possibility that a given patient can be hospitalized in more than one year, standard approaches of multiple regression are not suitable for answering the study questions related to rates of inpatient service utilization. For example, although ordinary least squares regression could be theoretically used to examine pre- and post-cART trends in hospitalization rates by creating a dummy variable to denote the 1996/97 period when cART was introduced and an interaction variable to reflect the change in trend following this period, this approach assumes that the random disturbance for one observation is uncorrelated with that of any other observation (i.e. errors are independent of one another) and that the variance of errors is the same for all observations.\textsuperscript{86} That is:

\[
\text{cov}(\epsilon_i, \epsilon_j) = 0 \text{ and } \text{var}(\epsilon_i) = \sigma^2
\]

However, in temporally sequenced data, this assumption is prone to violation due to the autocorrelation of the error terms.\textsuperscript{87,88} Furthermore, because individual patients may appear in
multiple years of data if they are hospitalized on more than occasion, observations from different years are not fully independent. \(^{89}\) Failure to account for the autocorrelation of the error terms and correlation among observations originating from the same patients may result in standard errors that are biased and test statistics that are overstated in magnitude and significance. \(^{87-89}\) For these reasons, two statistical methods were used to accommodate the temporal nature and within-subject correlation of the data. Specifically, interrupted time-series analysis was used to account for autocorrelation when examining the impact of cART on hospitalization rates according to sex and socioeconomic status, and generalized estimating equations were used to deal with the correlation in observations for individual patients when analyzing trends in rates of inpatient utilization during the modern era of cART. \(^{87-89}\)

*Interrupted time-series analysis*

Interrupted, or intervention, time-series analyses compare observations before and following an identifiable event. \(^{88,90}\) Although segmented regression is an increasingly used and intuitively appealing form of interrupted time-series analysis, it could not be used in this study because of the requirement for linearity in the outcome variable within the periods preceding and following the intervention. \(^{91}\) Because the hospitalization data used in the current study do not conform to these requirements, autoregressive integrated-moving average (ARIMA) models were used to isolate and quantify the impact of cART on rates of hospitalization. \(^{88,90}\)

A given ARIMA model is characterized by three parameters \((p, d, q)\) that represent the autoregressive, stationary and moving average patterns in the time series. Identification and
estimation of a baseline ARIMA model is the process of deriving integer values for these parameters, and must be done prior to evaluating the impact of an intervention. When there is a direct relationship between adjacent observations in a time series, the value of $p$, or the autoregressive component of the model, exceeds zero. For example, a model with one autoregressive term (i.e. $p = 1$) is one in which a specific observation depends on, or is predicted by, the immediately preceding observation. In models with two such terms (i.e. $p = 2$), an observation depends on the two previous observations, and so forth, although it is uncommon to have a model with more than three autoregressive terms. As mentioned earlier, autocorrelation of the error terms poses a substantial problem when utilizing traditional methods of regression for analyzing temporally sequenced data. The advantage of ARIMA-based time series analysis relative to these methods of regression is that the autocorrelation in the data can be identified and reincorporated into the overall model, thereby producing unbiased estimates of the impact of the intervention.

Once the baseline model is identified, the impact of a specific intervention on the time-series can be determined. Such an analysis requires that an indicator variable be developed to flag the occurrence of the event of interest, which in this case, is the introduction of cART. In addition, a transfer function is specified which describes both how an intervention enters the model and the duration of the effect observed with the intervention. Therefore, transfer functions are characterized by parameters reflecting the magnitude of asymptotic change after the intervention is introduced (i.e. ‘$\omega$’) and the rate at which the post-intervention series approaches its asymptotic level (i.e. ‘$\delta$’). During interrupted time-series analysis, the null hypothesis that $\omega$ is zero is tested. If rejected, the impact of the intervention is statistically significant and the size of
the change is the value of $\omega$. The $\delta$ coefficient assumes values between 0 and 1, corresponding to abrupt and gradual onsets of change, respectively. That is, small, statistically significant values of $\delta$ indicate that the series reaches its asymptotic level quickly, while interventions that attain their peak effectiveness gradually are associated with values of $\delta$ which approach 1. In order to ensure that the autocorrelation has been accounted for in the final model and that estimates for the value of the intervention are therefore not biased, the Ljung-Box test is used to test the null hypothesis that the autocorrelation of the model residuals is zero. If the null hypothesis is not rejected, the autocorrelation has been accounted for and the ARIMA model is appropriate for characterizing the time series and evaluating the impact of the intervention.

*Generalized Estimating Equations*

Generalized estimating equations (GEE) were used in the analysis of hospitalization trends in the modern cART era as a means of managing the correlation among responses representing repeated hospitalizations of the same individual in different years. GEEs were introduced by Liang and Ziang in 1986 as an extension of generalized linear models (GLM), such that a known function of the marginal expectation of a dependent variable could be modeled as a linear function of a vector of explanatory covariates collected within subjects across time. In the case of repeated measures or observations, GEE extend GLM by allowing the correlation of outcomes within an individual to be estimated and taken into account when regression coefficients and their standard errors are estimated.
As with GLM, the use of GEE requires specification of a link function to relate the dependent variable to a vector of explanatory variables in the form of an additive model, and a variance function that relates the mean and variance of responses. Therefore, as an extension of a GLM, GEE do not require full specification of the form of the distribution, but only of the relationship between the outcome mean and the independent variables and between the mean and the variance (i.e., the first two moments). In the case of a continuous variable, the mean response over time is related to the explanatory covariates through the following general equation:

\[ \eta(\mu_{ij}) = X_{ij}\beta \]

where \( \mu_{i} = \text{E}(Y_{i}) \), \( Y_{i} \) is a vector of correlated responses (i.e., \( Y_{i1}, Y_{i2}, \ldots Y_{ij} \)) for the \( i^{th} \) subject \( i = 1, 2, \ldots n \), \( X \) is the matrix of explanatory variables for subject \( i \), \( \eta \) is the link function relating the responses to the explanatory variables, and \( \beta \) is a vector of parameters. In addition, the marginal variance of \( Y_{i} \) depends on the population-averaged mean according to:

\[ \text{var}(Y_{ij}) = v(\mu_{ij}) (\phi) \]

where \( v(\mu_{i}) \) is a known variance function and \( \phi \) is a scale parameter. The choice of link and variance functions is usually informed by the expected distribution of the outcome measures, such that, in the case of hospitalization rates which are assumed to follow a Poisson distribution, the link and variance functions are:

\[ \log(\mu_{i}) = X_{i}\beta \text{ and } \text{var}(Y_{i}) = \mu_{i}\phi \]
In addition to specification of a link and variance function, the GEE approach requires specification of a working correlation matrix which accounts for the within-subject association among repeated observations from the same individual. It is this third component which extends the GLM to longitudinal data analysis. The correlation between observations is accounted for by the a priori selection of one of several working correlation structures for the repeated measurements of $Y_i$. Possible working structures include the independence structure (i.e. the correlations between repeated measurements are assumed to be zero), exchangeable structure (i.e. the correlations between repeated measurements are assumed to be the same), autoregressive correlation structure (i.e. the correlations one measurement apart are assumed to be $p$; correlations two measurements apart are assumed to be $p^2$; correlations t measurements apart are assumed to be $p^t$), and unstructured structure (i.e. all the correlations are assumed to be different). However, while correct specification of the correlation structure augments the efficiency and precision with which $\beta$ is estimated, valid standard errors of the parameters are obtained using GEE even if the intracluster dependence structure is misspecified, assuming that the model for the mean response is correct and there is no correlation in the measured responses between individuals. That is, valid estimates of $\beta$ and its sampling variability can be obtained, even if the within-subject association has not been correctly modelled. This appealing property of the GEE approach is attributable to the so-called “sandwich” estimator algorithm, which is robust to incorrect assumptions about the covariance among repeated measures or variation in the strength of correlation between repeated observations from individual to individual. The resultant standard errors are referred to as robust standard errors, which are usually larger than the model-based standard errors that do not take the dependence among observations into account.
Once the link and variance functions have been specified, and a working correlation structure has been selected, the parameter estimates are obtained by iteratively solving the generalized estimating equations as follows:\textsuperscript{89}

\[ \Sigma D_i V_i^{-1} (Y_i - \mu_i) = 0 \]

where \( \mu_i \) is the vector of means and \( V_i \) is the working covariance matrix of \( Y_i \), so designated to distinguish it from the ‘true’ underlying covariance among the \( Y_i \). That is, the term ‘working’ acknowledges the uncertainty about the assumed model for the variances and within-subject correlations. The covariance matrix of \( Y \) is specified as:\textsuperscript{89}

\[ V_i = \phi A_i^{1/2} R(\alpha) A_i^{1/2} \]

where \( A_i^{1/2} \) is a diagonal covariance matrix with elements \( v(\mu_{ij}) \) (\( j \) is the time of measurement), \( R(\alpha) \) is the working correlation matrix and \( \phi \) is a scale parameter that corrects for over-dispersion.

Although the iterative algorithm for fitting models with GEE generates estimates of the regression coefficients and the parameters associated with the covariance and correlation among the repeated measures [i.e. \( A_i^{1/2} \) and \( R(\alpha) \)], the latter are generally regarded as nuisance parameters in most longitudinal studies as the substantive focus is typically on characterizing changes in the mean response over time.\textsuperscript{89}
In summary, interrupted time series analysis and generalized estimating equations were used to study temporal trends in hospitalizations among PLWH living in Ontario. This study has potentially important implications for policy makers and providers of community-based HIV-related care, as the presence of disparities in hospitalization rates among PLWH based on immigration status, sex or socioeconomic status may indicate that there are unmet needs at the community or outpatient level that are preventing these patients from deriving the benefits associated with contemporary advances in HIV medicine.

1.4 Administrative data sources used for validating case-finding algorithms and evaluating inpatient utilization among Ontario’s PLWH

The validation of case-finding algorithms for ascertainment of HIV-disease from administrative data and the study examining hospitalization trends among PLWH relied extensively on the use of the following five databases held at ICES: 1) physician billing information for inpatient and outpatient services from the Ontario Health Insurance Plan (OHIP); 2) acute care hospitalization records from the Canadian Institute for Health Information Discharge Abstract Database (CIHI DAD); 3) computerized pharmacy records of the Ontario Drug Benefit program (ODB); 4) emergency department utilization records from the Canadian Institute for Health Information National Ambulatory Care Reporting System (NACRS) and 5) basic demographic information from the Registered Persons Database (RPDB). More detailed descriptions of the databases are provided below.

*Ontario Health Insurance Plan database*
The Ontario Health Insurance Plan (OHIP) is a provincially funded program which reimburses physicians for the provision of medically necessary procedural, diagnostic and laboratory services to insured residents of the province of Ontario. Consequently, the OHIP database contains administrative data generated from all inpatient and outpatient physician billings. In order to receive payment for services rendered, physicians must submit the name, date of birth and Ontario Health Card Number of the individual patient seen, the service provided (i.e. a service code), and a single diagnosis code on each claim. For OHIP claims, the diagnosis code is a truncated three-digit version of the ICD-9 code for the relevant diagnosis. Service codes are four-digit, alphanumeric codes that describe the specific service that has been provided. Since service codes are more directly connected to physician reimbursement and are subject to audit by OHIP, these codes may be more accurately coded than the diagnostic code. Approximately ninety-four percent of Ontario physicians are reimbursed on a fee-for-service basis by submitting claims to OHIP.

The validity of the OHIP database with respect to demographic, procedural and diagnostic data has been evaluated in several hospital-based studies. Although patient demographic information such as name, age and place of residence has been documented to be complete on 93-100% of physician claims, the accuracy of clinical information has been more variable. Specifically, in a validation study using chart data drawn from 43 hospitals as the reference standard, the accuracy of diagnostic and procedural codes recorded in the OHIP database ranged from 37 to 81% and 88 to 95%, respectively. In contrast, respective figures from a similar study reviewing 300 records from a single hospital were 95 to 96% and 96%. However, despite the latter finding, there are several important caveats to consider when using OHIP data for disease
ascertainment. In contrast to abstraction from hospital charts, which is undertaken by trained health information professionals, outpatient claims may not necessarily be coded by individuals who are trained in reviewing medical records. Therefore, there may be a higher margin for error when capturing diagnostic and procedural information on outpatient claims relative to inpatient records. In addition, claims for outpatient physician services contain less diagnostic information than do administrative data generated from a hospital admission. That is, while hospital separation reports can include up to 25 diagnoses per discharge, physician outpatient claims are restricted to a single diagnostic code per encounter. In this scenario, important patient co-morbidities or secondary diagnoses are unlikely to be reported. Similarly, by being restricted to the use of a single truncated ICD-9 code when submitting a claim, additional diagnostic information may be omitted via the use of codes which encompass a broad diagnostic category rather than the specific presenting complaint of the patient. This concern has been corroborated by a study validating Canadian physician claims, in that only a 60% agreement was documented between billed diagnostic codes and the chief complaint recorded in 1215 medical charts.

The previously articulated concerns with outpatient claims have important implications when considering the feasibility of these data for the construction of an HIV case finding algorithm. For instance, the coding of a only a single diagnosis on outpatient claims may render it difficult to identify patients with HIV infection if the primary reason for the patient encounter was unrelated to HIV infection. For example, a physician treating an HIV-infected individual on an outpatient basis for the common cold may submit a claim with upper respiratory viral infection as the diagnosis. Because only a single diagnostic code can be submitted per outpatient encounter, HIV-infection would not be captured by this visit. Therefore, a risk of misclassifying
HIV-infected individuals exists with the use of outpatient claims in the OHIP database. In an opposing vein, physicians may submit a claim with a diagnostic code for HIV for a visit in which an individual with a high-risk exposure to the virus undergoes laboratory testing and counselling for HIV infection. In this scenario, the OHIP database would falsely identify this individual as being HIV-positive based on this visit, even if the test result is subsequently confirmed to rule out this diagnosis. However, despite these limitations, there are several reasons for utilizing information held within the OHIP database for the development of an algorithm for HIV disease ascertainment. Most notably, as HIV has been transformed into a chronic illness for which care is most likely to be received in the primary care setting, omission of these data may compromise the sensitivity of candidate algorithms. In addition, the inclusion of the HIV-related service code ‘K022’ in candidate algorithms may increase the specificity of our findings, as a direct financial incentive exists for physicians to use this code. Finally, by testing claims-based algorithms that vary according to the number of physician encounters and time period, it may be possible to mitigate the potential for misclassification bias when using the OHIP database.

*Canadian Institute of Health Information - Discharge Abstract Database (CIHI-DAD)*

The Discharge Abstract Database (DAD) contains information abstracted from all acute care hospital separations (i.e. discharge, sign-out, transfer to different facility, death) in the province of Ontario. Specifically, after each hospital separation, trained health information professionals in participating Ontario hospitals extract and code data from individual patient charts following standardized instructions outlined in the DAD Abstracting Manual. These data are subsequently forwarded to CIHI on a monthly basis for entry into the DAD. Abstracts deemed
incomplete by CIHI are returned to the hospital in question for revision, thereby maintaining the integrity of the database. Variables abstracted from patient charts and thereby included in the database are the patient OHIP number, demographic data, dates of admission and discharge from the hospital, the physician most responsible for the admission, the diagnosis representing the condition that is accountable for the greatest portion of the length of stay or greatest use of resources (i.e. the most responsible diagnosis) and up to twenty-five secondary diagnoses and/or complications. In addition, a maximum of ten procedures can be coded per hospital separation utilizing the taxonomy developed by the Canadian Classification of Diagnostic, Therapeutic, & Surgical Procedures.

The validity and accuracy of the DAD is evaluated regularly by CIHI as part of a data quality enhancement program. Specifically, CIHI undertakes ongoing re-abstraction studies wherein trained health information management professionals repeat the extraction of data from the inpatient charts of a nationally derived probability sample of 50 hospitals for ascertainment of coding completeness and accuracy. For the 2007/2008 fiscal year, the sensitivity and positive predictive value of the DAD for diagnostic data were 80% (95% CI: 78 to 82%) and 88% (95% CI: 87 to 89%), respectively. Corresponding values for the coding quality of interventions were 92% (95% CI: 90 to 94%) and 94% (95% CI (91 to 98%). Overall, agreement on the ICD-10 code for the most responsible diagnosis was observed for 74.9% (95% CI 72.3% to 77.6%) of all acute care hospitalizations reported to DAD during this time frame. Similarly, the coding of the most responsible diagnosis was found to be reasonably accurate in a separate re-abstraction study utilizing the charts of eighteen Ontario hospitals as the reference standard. Specifically, the median kappa, sensitivity and positive predictive values for the 50 most
responsible diagnoses were 0.81 [interquartile range (IQR) 0.70 to 0.87], 0.82 (IQR 0.71 to 0.89) and 0.82 (IQR 0.74 to 0.89), respectively.\textsuperscript{102} However, although overall agreement for many diagnoses ranged from good to excellent, considerable variability was observed in the sensitivity and positive predictive value of the original DAD record, depending on the diagnosis of interest. In addition, the coding accuracy of co-morbid conditions present either prior to the admission or developing during the course of hospitalization appears to be substantially poorer relative to the most responsible diagnosis, with a median kappa, sensitivity and positive predictive value of 0.56 (IQR 0.47 to 0.67), 0.75 (IQR 0.71 to 0.79) and 0.48 (IQR 0.38 to 0.65), respectively.\textsuperscript{102} In both the national and provincial chart validation studies, the DAD was noted to have excellent accuracy for non-medical data, such that the percent agreement ranged from 95 to 100\% for demographic variables and information pertaining to interfacility transfers.\textsuperscript{101,102}

In summary, while the most responsible diagnosis appears to be coded with a reasonable degree of accuracy in the DAD, the coding of secondary diagnoses appears to be less veracious. For the purpose of HIV-related research, the latter finding may carry significant repercussions. As hospitalizations for HIV-infected individuals are instigated less often by HIV-related causes in the cART era, it is likely that HIV infection will not be coded as the most responsible diagnosis for a considerable portion of admissions over the preceding decade. Therefore, it is possible that coding deficiencies of HIV as a secondary diagnosis may compromise the sensitivity of algorithms relying exclusively on the DAD. Nonetheless, because some patients may have poor adherence with primary care visits and therefore encounter the health care system only when becoming ill enough to warrant hospitalization, we evaluated the validity of algorithms that included either outpatient physician claims or hospital separations relative to those comprised of outpatient claims only.
Information regarding hospital emergency department visits and facility-based ambulatory care services are collected by the CIHI through the National Ambulatory Care Reporting System (NACRS). An individual NACRS abstract is completed for each client visit utilizing a variety of sources, including admission/discharge/transfer (ADT) systems, emergency department information systems (EDIS), patient records and laboratory and diagnostic imaging results. Although NACRS is a national database, the scope of data collection varies across the differing provinces, such that the majority of data are presently collected from hospitals in Ontario, where emergency data submission to NACRS is mandated by the Ontario Ministry of Health and Long Term Care (MOHLTC). In addition to emergency department reporting, Ontario hospitals also submit information from renal dialysis, cardiac catheterization and oncology clinics.

As with the DAD, extraction of data from patient charts is undertaken by trained health information personnel staffed at each hospital with the guidance of a standardized NACRS abstracting manual. Recorded data elements include patient demographic variables, service dates, up to 10 diagnostic codes (ICD-10-CA) and procedure codes. One of the problems listed in a given patient’s NACRS abstract must be designated as the main problem, defined as the most clinically significant reason for the client’s visit to the facility. In Ontario, the reason for visit must also be recorded, which is defined as the patient’s chief complaint or reason for seeking emergency medical care. Facilities submit their NACRS abstracts to CIHI where they are subject to an electronic editing system which ensures that mandatory fields are captured and data adhere to validation rules. If the data do not pass the editing system, they are returned to the facility for correction.
The validity of NACRS has been evaluated in a single reabstraction study of 7,500 unplanned emergency department visits at fifteen Ontario hospitals from April 1, 2004 to March 31, 2005. While a high agreement rate was observed for the selection of the patient’s main problem (85.5 ± 1.9%), agreement regarding the ICD-10 code selected to describe the main problem was only 68.8%. An additional finding of potential relevance when considering the use of these data for HIV case ascertainment was the under-reporting of problems for patients seen in emergency departments. In these cases, re-abstractors frequently encountered abstracts with only one diagnosis coded when multiple conditions were listed on the health record. Furthermore, a practice of ‘dummy coding’ was adopted by facilities in cases where the patient chart could not be found, wherein default or predetermined diagnosis codes were utilized in mandatory data fields to meet the MOHLTC and CIHI requirements for complete abstract submission within certain time frames.

NACRS data have not been traditionally utilized in the validation of case-finding algorithms in the province of Ontario. This study therefore represents the first attempt to employ these particular administrative data for this specific purpose. The potential advantage of engaging with data housed within the NACRS lies in the theoretical potential of identifying marginalized individuals who lack access to a primary care provider and consequently attain a significant proportion of their medical care in provincial emergency departments. However, the aforementioned findings of the data reabstraction study suggest that realization of this potential may be difficult. Notably, it is unlikely that HIV will be coded as the main problem for most patients receiving care at an emergency department, thereby resulting in a sacrifice in algorithm sensitivity. Compounding this problem further is the finding that a single diagnosis is often
coded despite the presence of multiple medical conditions. As a result, underlying HIV infection risks being completely omitted from the abstracts of HIV-infected patients submitted to NACRS. We therefore anticipated that sole reliance on the NACRS data would likely result in algorithms of low sensitivity and specificity.

Ontario Drug Benefit (ODB) Database

The provincially funded Ontario Drug Benefit (ODB) program covers the cost of prescription drugs for several specific groups of Ontario residents, the largest of which is comprised of the provincial population of adults aged 65 years and older. Additional groups eligible for drug coverage through the ODB include residents of long term care facilities, recipients of home care services and social assistance, and individuals who register with the Ontario Trillium Drug Program. The Trillium Drug Program was established as a means of providing an alternative prescription drug-funding vehicle for residents of Ontario who do not meet the aforementioned eligibility criteria for securing ODB coverage and/or do not receive complete remuneration for their drug costs through private insurance. Drugs which are covered by either the ODB or Trillium programs are listed in a provincial drug formulary by their unique drug identification numbers (DINs), which delineate the exact strength and dosage form of a given medication dispensed. With the exception of maraviroc and enfuvirtide, all licensed antiretroviral medications are listed in the provincial drug formulary and therefore covered by the ODB and Trillium drug programs. In order to receive compensation for prescriptions filled for Ontario residents covered through either the ODB or Trillium drug programs, community pharmacies submit electronic claims via a computer linked network to the MOHLTC. A complete ODB or
Trillium drug claim includes several drug, physician, patient and pharmacy specific variables, including the DIN number and patient OHIP number.

The validity of the ODB database with respect to coding of the DIN and date, quantity and duration of drug dispensed was evaluated in a review of 5155 prescriptions filled between July 1, 1998 and December 31, 1999. Overall, a total of 37 errors were found among the 5155 prescriptions dispensed, yielding an error rate of 0.7%. (95% CI: 0.5% to 0.9%). However, despite the reliability of the ODB, there are several considerations which merit emphasis when utilizing prescription claims as a component of case-finding algorithms in Ontario. As the only database that does not encompass the entire population of individuals living in the province, reliance solely on the ODB would likely limit the sensitivity of algorithms to only those individuals who qualify for coverage under this program. In addition, eligibility for ODB coverage may change for individuals less than 65 years old in accordance with their circumstances. For example, an individual receiving drug coverage through social assistance or Trillium will no longer be a candidate for these benefits should they secure employment which includes a drug plan providing full reimbursement for medication related expenses. Antiretroviral prescriptions for this individual would consequently no longer appear in the ODB database following the transition to drug coverage through a private insurer. Therefore, exclusive reliance on the ODB database for identification of HIV-infected individuals can introduce a bias associated with missing data arising from changes in individual eligibility criteria over time. An additional issue associated with the use of the ODB database in the construction of case-finding algorithms surrounds the prescription of cART to HIV-negative individuals following a high-risk exposure to the virus. In this setting of post-exposure
prophylaxis (PEP), an HIV-negative individual who is covered by the ODB or Trillium may be inappropriately flagged as HIV-positive even if subsequent HIV serology is negative. Similarly, patients with chronic hepatitis B who are covered by the ODB may be inaccurately identified as HIV-positive in the database as a result of receiving prescriptions for an antiretroviral agent (i.e. lamivudine, emtricitabine, tenofovir) which carries a dual indication for the treatment of chronic hepatitis B infection. In either case, a risk of falsely identifying HIV-negative individuals as PLWH is introduced with the use of the ODB database.

Although there are potential pitfalls associated with using the ODB database for the identification of HIV-positive patients, the potential gain in specificity associated with using antiretroviral prescription claims in the case-finding process merits that candidate algorithms including these data are examined. With the exception of the three agents utilized for the management of chronic hepatitis B, antiretroviral drugs are used solely for the ongoing treatment of HIV infection. Therefore, a prescription for any antiretroviral agent should, by definition, constitute evidence for HIV-infection. However, because of the aforementioned limitations of the ODB, algorithms comprised solely of prescription claims were not examined.

The Registered Persons Database (RPDB)

The Ontario RPDB is an electronic registry of all individuals who are eligible for provincial health insurance for a given year, and contains basic demographic information for each patient included in the two studies, such as postal code, sex and date of birth. Although date of death is
also listed in the RPDB, this field may be less reliably coded than others. We used the RPDB to identify demographic information such as age, sex and postal code.

In summary, the studies examining the validity of administrative data for HIV ascertainment and disparities in rates of hospitalization among PLWH living in Ontario rely extensively on the data holdings at ICES. This research is facilitated by cross-database linkage at the patient level using an encrypted version of the individual OHIP number. However, despite the appropriateness of administrative data for the aforementioned studies, these databases are not suitable for research questions examining the experiences of individual PLWH engaging with existing health services. For this reason, the third study in the dissertation utilizes qualitative methods of data generation, analysis and interpretation to explore the perceptions of heterosexual men living with HIV as they pertain to the existing array of health-care and community-based services available for PLWH in Ontario.

1.5 A qualitative study of the help-seeking experiences of heterosexual men living with HIV

Despite their increased representation among the provincial population of PLWH, heterosexual men living with HIV are virtually absent in the HIV-related health services research literature, such that only two studies have been published which address whether existing medical and community-based HIV support services are adequate in caring for this increasingly important demographic of PLWH.\textsuperscript{19,108} In one study, Doyal and colleagues examined the experiences of forty-six HIV-infected heterosexual men who had emigrated from various countries in Africa to London, England.\textsuperscript{19} Although the participants were asked how health services for African heterosexual men living with HIV could be improved, the use of health and support services
was not the focal point of the study, and as a result, very few data are provided by the authors which relate to this question. Instead, the study sought to provide an overview of the impact of HIV infection on the various aspects of the lives of the participants. The second study was also conducted among a sample of African men living in London, England, and included both HIV-positive (n = 17) and negative (n = 5) participants.\textsuperscript{108} The author of the study interpreted the data generated through interviews and focus groups through a lens of gender and masculinity. Participants in this study identified a number of unmet needs among the network of services available to them which were related to practical support (e.g. housing, immigration, employment) and social support. In addition, participants expressed a sense of frustration stemming from a lack of transparency in the management of community-based HIV services and the opportunity to provide input and feedback on available services. Based on these data, the author of the study provides several recommendations for action, including a greater focus on the provision of practical help by community-based HIV agencies, changing the structure of HIV-related services to increase the number of men undergoing HIV testing, and the need to provide more opportunity and space for men to talk about their health.\textsuperscript{108}

Because of the paucity of data examining the interaction between heterosexual men living with HIV and the various social contexts in which HIV-related care is provided, the objective of the third component of the dissertation was to characterize the help-seeking experiences of heterosexual men living with HIV, and account for these experiences in relation to the broader social relations and discourses in which they are embedded. In order to successfully meet these goals, it was essential to design a study that was internally consistent with respect to matters of
ontology and epistemology, theoretical framework, methodology and methods of data generation.

1.5.1 Epistemological and ontological considerations

In its classic sense, a paradigm refers to an individual’s over-arching world view on the nature of reality and knowledge. In the context of science, subscription to a paradigm guides the theoretical and methodological choices made by an investigator when undertaking a research study. In this manner, paradigms can be seen as conceptual bins, within which are stored a set of interrelated ontological and epistemological assumptions about the nature of the physical and social world that implicitly or explicitly frame a line of inquiry. Ontology refers to what is real and knowable. That is, questions of ontology surround the nature of reality and what can be known of it. Epistemology refers to how we come to know what is real, and in the context of research, encompasses the relationship between the participant or phenomenon of interest and the researcher. The major paradigms which guide research are positivism/post-positivism, constructivism and critical theory, and their ontological and epistemological orientations are briefly summarized below.

The origins of positivism can be traced back to the Enlightenment period of the 17th and 18th centuries, where scholars of the time challenged the hegemony of mysticism and royal doctrine as the vessels of knowledge and truth. In its modern incarnation, positivism is manifested through the familiar tenets of the scientific method, based on the use of tightly controlled experimental conditions and inferential statistics to verify hypotheses that are derived prior to the planning and execution of a particular research project. As such, adherents to a positivist
paradigm assume that the goals of research are to unearth natural laws about a true, measurable
reality that exists ‘out there’ and is independent of the observer, and to subsequently apply these
laws for predictive and explanatory uses. From a positivist perspective, this external reality is
fully apprehendable by scientists.\textsuperscript{109} In response to the perceived stringency of positivist
assumptions about the relationship between observers and an objective reality, post-positivism
emerged in the 1950s and 1960s as a similar, but perhaps ‘softer’ iteration of the formers’
assumption about the ability of scientists to fully comprehend the nature of reality.\textsuperscript{112} That is,
rather than adhering to a perspective that a true reality can be studied, measured and quantified,
post-positivist thinking places limits on the extent of human capacity to fully grasp what is still
acknowledged as a true reality. Adherents of post-positivism therefore maintain that human
scientific methods can only approximate the ‘truth’, rather than fully capture and apprehend it.\textsuperscript{109}
Nonetheless, despite this difference, the two philosophies maintain near identical perspectives on
the purpose of scientific endeavors (i.e. explanation and prediction, cause-effect linkages) and
the necessity of an objective, detached scientist whose personal biases do not contaminate the
research method. As expected, quantitative methods are typically used to conduct research from
either a positivist or post-positivist perspective, although this is not always the case. Indeed, it
can be argued that much qualitative research conducted within the health sciences is done under
the auspices of a positivist or post-positivist paradigm.

The paradigm of constructivism emerged in reaction to the assumptions couched within the
positivist and post-positivist perspectives.\textsuperscript{109,110} The origins of constructivism can probably be
traced back to the works of David Hume, and perhaps more importantly, Immanuel Kant.\textsuperscript{113,114}
Although Hume raised the specter of skepticism in the prevailing cause and effect approach to
science of his time, it was Kant who proposed abandoning the task of trying to know a reality ‘out there’ that is independent of the knower. Instead, Kant posited that “human claims about nature cannot be independent of inside-the-head processes of the knowing subject.” This statement underlies a central tenet of constructivist philosophy. That is, rather than belief in a singular reality, constructivist thought puts forth the notion that there are multiple realities that are constructed socially and in the minds of individuals, and that these realities can be elicited best through interpretation and analysis of the interaction between a researcher and participant. Therefore, unlike the positivist/post-positivist positioning of the researcher as a detached observer or investigator of an external reality, the constructivist researcher is construed as being active in the co-creation of knowledge. Not surprisingly, qualitative methods are the dominant modes of inquiry by proponents of constructivist thought, utilizing theoretical models such as symbolic interactionism or social constructionism to interpret and theorize the accounts provided by participants.

The third major paradigm comprises a series of varied perspectives known as critical theory. Although there are many schools of thought (e.g. feminism, critical race theory, queer theory) and theorists (e.g. Michel Foucault, Paulo Freire, Pierre Bourdieu) that are traditionally grouped under the rubric of the criticalist tradition, there are several commonalities underlying the varying perspectives. Like constructivists, critical theorists perceive of reality as being constructed through social interaction and contingent on social and historical contexts. However, the different lenses of critical theory are applied towards illuminating power relations that lead to oppression and disparity or revealing the way taken for granted social relations and
prevailing discourses shape individual experience. Ideally, these findings would be directed towards challenging social structures and constructs that create or perpetuate inequity. In preparing for this study, I viewed the participants as active co-creators of knowledge and conceptualized the data as being produced through the interaction between myself and the participants. In addition, I was interested in understanding both the experiences of the men and the social relations or discourses which produced these experiences. My own epistemological and ontological positions therefore resonate most strongly with the assumptions situated within the respective nets of the constructivist and critical paradigms.

1.5.2 Theoretical Framework

Just as regression models reveal associations between quantitative variables that are not readily apparent, theory functions as the lens in qualitative research through which generated data are interpreted and analyzed, revealing connections and abstractions which are not immediately self-evident. However, to maintain methodological congruence and study rigour, it is important that the theoretical perspective taken be consistent with the researcher’s epistemological and ontological positions. Therefore, selection of a theoretical framework for this study required the incorporation of several commensurable perspectives that are consistent with a constructionist epistemology and critical ontology. Specifically, I used a composite theoretical framework which borrowed broadly from the ideas of social constructionism, and more specifically from the conceptual arsenals of Pierre Bourdieu’s structural constructivism and Erving Goffman’s analysis of impression management and information control outlined in his book, *Stigma: Notes on the management of a spoiled identity.*
Social Constructionism

Although the term ‘social construction’ has a long history within the disciplines of anthropology and sociology, it was the 1966 book *The Social Construction of Reality*, authored by Thomas Berger and Peter Luckmann that advanced social constructionism as a theoretical framework which may be used to inform sociological, and in this case, health services research.\(^{116}\)

Influenced by the social phenomenology of Alfred Schutz, Berger and Luckmann focused on the means by which the social interactions of humans become onto-formative in constructing and shaping a taken for granted social world. Therefore, the thesis advanced by Berger and Luckmann stands in contrast to positivist views of an objective social reality of which language is a mirror. Instead, language and social interaction become productive, constituting and constructing social institutions and persons, rather than merely serving as their reflection. However, the constitutive relationship between social processes and larger social institutions is not merely unidirectional; rather, a reciprocative relationship exists wherein these social constructions also influence and constrain individual actions. In this manner, it becomes possible to speak of micro and macro social constructionism.\(^{121}\) That is, micro constructionism concerns the constructive role of discourse in the ontogenesis of social reality, whereas macro constructionism relates to the larger social structures, relations and discourses which constrain and coerce individual activity.

A critical aspect of Berger and Luckmann’s theorizing surrounds that notion that macro and micro constructionism exist in a dialectical relationship, such that analyses which focus only on the construction of experience through interaction or on the larger social institutions or relations
into which individuals are socialized provide an incomplete picture of the social world. Instead, these authors contend that the subjective elements of human experience are connected with larger objective structures and discourses through the inter-related and simultaneously occurring processes of externalization, objectivation and internalization. Briefly, externalization refers to the human production of social institutions, culture and society through the collective use of language, signs and symbols. These institutions, although socially produced, become objectivated, assuming the status of an objective reality akin to that of the physical world. A paradox is therefore created, in that socially constructed societies and institutions become apprehended as ‘second nature’ and independent of the human interaction which produced them. In other words, “man is capable of producing a world that he then experiences as something other than a human product”. The third moment in this dialectical process is internalization, or the process through which individuals actively re-absorb the objectified ‘facts’ of their society into their own internal consciousness. In this manner, socially constructed roles, identities and institutions become inscribed in the individual as he/she actively participates in the co-creation of their social world through externalization and objectivation. Berger and Luckmann summarize these three moments concisely as:

“Society is a human product. Society is an objective reality. Man is a social product.”

These pillars of social constructionism are consistent and congruent with my previously stated epistemological and ontological positions, rendering it an appropriate theoretical framework for addressing the research question. Specifically, social constructionism illustrates the dialectical relationship between individual subjectivity and objective social structures, relations and
discourses, thereby providing a useful starting point for analyzing the help-seeking experiences of participants in the study and the social relations in which these experiences are embedded.\textsuperscript{116} However, it was not immediately clear how to operationalize the theoretical principles of social constructionism into a conceptual arsenal that could be applied towards analyzing and integrating the subjective and objective aspects of the help-seeking experiences of heterosexual men living with HIV. For this reason, I turned to Pierre Bourdieu and his self-described approach of “structural constructivism”\textsuperscript{119}

\textit{Pierre Bourdieu’s ‘Structural-Constructivism’}

Pierre Bourdieu’s theoretical framework of ‘structural-constructivism’ integrates and overcomes what he considered an artificial and ruinous opposition between the ‘objectivist’ and subjectivist’ approaches to understanding the social world.\textsuperscript{119,122} For Bourdieu, objectivist approaches to science are characterized by analyses that seek to explain social reality as the sum of objective structures and relations that exist independently of human interaction and interpretation. In contrast, the subjectivist mode of inquiry asserts that social reality is constructed through interactions between individuals, and understood through interpretation. According to Bourdieu, objectivist and subjectivist positions exist in a dialectical relationship and both moments are necessary to understand human experience and action.

By structuralism or structuralist, I mean that there exist, in the social world itself, and not merely in symbolic systems, language, myth, etc., objective structures which are independent of the consciousness and desires of agents and are capable of
guiding or constraining their practices or their representations. By constructivism, I mean that there is a social genesis on the one hand of the patterns of perception, thought and action which are constitutive of what I call the habitus, and on the other hand of social structures, and in particular of what I call fields and groups, especially of what are usually called social classes.\textsuperscript{119, p14}

That is, while the social reality and lived experience that shapes individual perception and disposition is produced by interaction, it is done so within the constraints of objective social structures, relations and discourses which are themselves socially produced.

So the search for invariant forms of perception or of construction of social reality masks different things: firstly, that this construction is not carried out in a social vacuum but subjected to structural constraints; secondly, that structuring structures, cognitive structures, are themselves socially structured because they have a social genesis; thirdly, that the construction of social reality is not only an individual enterprise but may also become a collective enterprise.\textsuperscript{119, p18}

In effect, Bourdieu rejects a sharp distinction between individuals and the social world in which they operate. Thus, from a Bourdieusian perspective, research examining human experience must consider the social constitution of individuals and the social environments they must navigate as well as the conditions in which they interact with one another. To do this, Bourdieu has developed a theoretical arsenal composed of three inter-connected concepts: habitus, field and capital.\textsuperscript{122-124}
Bourdieu developed the concept of habitus as a means by which to integrate subjective personal experience with larger objective social structures, thereby transcending the structure-agency dichotomy he considered problematic for social science. The habitus is a set of unconscious, durable and transposable dispositions, or ‘common sense understandings, which reflects the social position of the individual and the regular conditions to which an individual is accustomed and at ease.\textsuperscript{122-124} These dispositions are acquired through lasting exposure to particular social conditions and conditionings and through the internalization of dominant social structures that operate at an unconscious level to mold individual behaviours, attitudes, tastes and body comportment.\textsuperscript{122-124} Although the habitus can be modified through the acquisition of new dispositions, early childhood socialization experiences are particularly important. Therefore, the habitus is structured, in that the incorporated dispositions reflect the objective social conditions within which they were acquired, and structuring, in that it orients individual subjective actions, beliefs, expectations, tendencies and inclinations without strictly determining them. Individuals who are subjected to similar conditions may share a common set of dispositions, or a ‘group habitus’, explaining, for instance, why individuals of the same nationality or gender may feel ‘at home’ with one another.\textsuperscript{123} In summary, habitus provides a way to conceptualize how individuals carry within them their history and how this history is imported into and across varied social contexts. Accordingly, the habitus can be studied by observing the enactment of dispositions in a particular context or setting. For this reason, habitus cannot be examined in isolation, but must be done so in relation to an analysis of the social settings or contexts in which individuals operate. In other words, habitus must be examined in relation to Bourdieu’s notions of field and capital.\textsuperscript{122-124}
Fields are semi-autonomous, structured social spaces of dominant and subordinate positions with their own sets of rules and hierarchies of relationships in which individuals engage in a struggle for legitimization. Bourdieu defined a field as “a structure of juxtaposition of social positions”, illustrating the properties of hierarchy, status and relational thinking which characterize this concept. Examples of fields include the health care system, families and academia. Because each field is replete with its own rules, regularities and sense of logic, Bourdieu frequently invokes the analogy of a game when describing how fields operate. That is, Bourdieu posits that some individuals will have developed a practical mastery (i.e. a “feel for the game”) of the competitive social space constituting a given field as a result of habitus, and will therefore likely gravitate towards social fields that fit best with their inculcated dispositions. Positions within the hierarchy of a particular field are determined largely by the composition and volume of capital possessed by an individual entering that field. For Bourdieu, capital is any resource that is effective in a given social field that enables an individual to improve their position or benefit from their participation within the field. Bourdieu distinguishes between four principal forms of capital, including economic, social, symbolic and cultural. Social capital is accumulated through membership in or access to a particular group or network. Symbolic capital manifests in the form of prestige and reputation. However, symbolic capital can also be deployed in a reverse manner wherein groups of individuals are negatively labeled, judged or ostracized (e.g. racism).

On their own, Bourdieu’s concepts of habitus, field and capital lack analytical and explanatory purchase. Instead, it is the relationship among the three interconnected concepts that can be used
in the analysis of social life, practice and experience. In his book *Distinction*, Bourdieu conceptualized the relationship between habitus, field and capital as an equation:

\[(\text{habitus})(\text{capital})] + \text{field} = \text{practice}^{124, p101}

In other words, social practice or experience arises out of the relationship between an individual’s dispositions which have been inculcated over years of exposure to particular social conditions (i.e. habitus), the resources possessed by the individual entering a field (i.e. capital) and the social circumstances in which one finds themselves (i.e. field). In this manner, Bourdieu connects individual subjectivity with objective social structures in a manner that is analogous to that of Berger and Luckmann’s inter-related notions of externalization, objectivation and internalization, but does so with a set of conceptual tools that facilitates the analysis and interpretation of generated data.

*Erving Goffman’s Stigma*

Although the bulk of the analysis of qualitative data in this study was informed by social constructionism generally and Bourdieu’s concepts specifically, I was also theoretically sensitized to the work of Erving Goffman and his now classic book, “*Stigma: notes on the management of spoiled identity*”.\(^{120}\) In this book, Goffman defines stigma in this manner:

“The term stigma, then, will be used to refer to an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes,
For Goffman, therefore, stigma is a social process, wherein language and imagery are deployed to generate categories of people who become either discredited or discreditable because they possess a trait that is socially constructed as being undesirable. The distinction between being discredited or discreditable is important to Goffman, as it is the interaction between stigmatized individuals with their social environments and the ensuing methods of impression management and information control that is the focus of his analysis. In the case of discredited persons, the stigmatizing attribute is either physically evident or widely known among a given individual’s own social circles, resulting in status loss and marginalization. For these individuals, social interaction may be consumed by managing the tension, discomfort or ambiguity that develops in the presence of others. In contrast, individuals possessing a potentially stigmatizing attribute that is neither immediately apparent nor easily discernable through observation are discreditable, and may go to great lengths to manage information about their identity to avoid being devalued by their social world. Central to the information management strategies of discreditable individuals is the act of passing as a ‘normal’ in a particular social context or interaction, so that they can attain the benefits associated with this designation.

While the compatibility between Bourdieu’s emphasis on the dialectical relationship between subjective experience and objective social structure and Goffman’s analyses of impression management and information control undertaken in social interaction may not be immediately evident, I view the work of both theorists as complementary. Specifically, the manner in which the participants of the study position and/or represent themselves to each other and myself and
their efforts to dissociate themselves from problematic identities associated with a diagnosis of HIV-infection may reveal aspects of their own social constitution (i.e. habitus) and the broader discursive and socio-cultural fields they inhabit. In this manner, Goffman and Bourdieu become commensurable, as the insights offered by the former’s interest in the nuances and performative aspects of social interaction and impression management aid in the analysis of the subjective nature and broader social structures inherent to Bourdieu’s framework of structural constructivism.

1.5.3 Methodology

Because the epistemological and theoretical perspectives guiding the process of inquiry lie within the tradition of constructivism, it is important that the study methodology selected reflects the tenets of these underpinnings. Specifically, the methodology must be consistent with the positions that data are generated through the collective interaction between study participants and that the resultant knowledge is an interpretation put forth by the researcher that is grounded in the data but simultaneously influenced by theoretical proclivities and the researcher’s specific points of departure when analyzing the data. For these reasons, the methodology employed in the study was constructionist grounded theory as described by Kathy Charmaz.125,126

Grounded theory methodology was first described by Glaser and Strauss in their 1967 book, The Discovery of Grounded Theory: Strategies for Qualitative Research.127 By providing social scientists with a template for doing qualitative research that had its own analytic procedures and logic, Glaser and Strauss validated qualitative inquiry as a legitimate enterprise that could generate mid-range explanatory theories of complex social processes directly from the data at
hand. In their book, Glaser and Strauss articulated the key characteristics of the grounded theory methodology, including the simultaneous involvement of the researcher in data collection and analysis, the creation of analytic codes and categories directly from the data rather than preconceived hypotheses, the development of theory to explain behaviour and processes, memo-writing, sampling for theory construction rather than statistical representation (i.e. theoretical sampling) and delay of the literature review. As a result, perhaps the most significant contribution of Glaser and Strauss was in providing qualitative researchers with methodological procedures for developing and refining concepts from their data, thereby challenging the prevailing view of the mid-1960s that qualitative research encompassed a range of unsystematic methods that could produce only descriptive observations, rather than explanations of complex social phenomena.

However, the iteration of grounded theory put forth by Glaser and Strauss draws upon post-positivist notions of science and knowledge, presumably because it was developed during a period where qualitative research was facing criticism as an impressionistic science lacking in rigour. For example, Glaser and Strauss treat the data collected in a qualitative study as objective facts about a world that is fully knowable to the researcher. From this perspective, the categories and concepts are inherent in the data, waiting to be discovered by the researcher. This view exists in contrast to the constructionist turn taken by Charmaz in moving grounded theory away from its post-positivist origins. Instead, Charmaz views the data, categories and concepts as products generated through the interaction between the participants, and acknowledges the fundamental role of the researcher in creating theory through interpretation. This shift in paradigmatic orientation has fundamental implications for the manner in which I
applied grounded theory when interrogating my data. For instance, rather than asking what the participants were saying in a given exchange, I would ask what the participants might be doing in a particular segment or question the circumstances and conditions producing a given stream of talk, thereby focusing on how and why participants construct certain meanings and not others. Therefore, in alignment with a constructionist perspective, Charmaz’s grounded theory provides an analytic methodology that treats the research data as constructions that are generated through participant interaction and shaped by the social context in which they are produced, rather than objective facts to be sorted into ‘emergent’ categories. In addition to the manner in which the data are viewed and analyzed, Charmaz differs from Glaser and Strauss with respect to the role and position of the researcher in generating theory. In keeping with their post-positivist inclinations, Glaser and Strauss imply that a researcher approaches their data with as few pre-determined expectations as possible, thereby remaining impartial during the application of the grounded theory methodology. From this perspective, grounded theory is purely an inductive method, and the influence of prior interpretive frames is minimized, or ideally, absent. For Charmaz, this position is untenable. She argues that “no qualitative method rests on pure induction”, and that researcher interests, biography and theoretical assumptions contribute to the interpretations put forth by researchers.

“Similarly, our conceptual categories arise through our interpretations of data rather than emanating from them or from our methodological practices.

Thus, our theoretical analyses are interpretive renderings of a reality, not objective reportings of it”
Accordingly, I applied constructionist grounded theory in a manner wherein I moved iteratively between the data and my theoretical frameworks, thereby constructing concepts that related the participants’ accounts with aspects of the social environment in which help is provided and discourses that were reproduced in the focus groups. That is, theory acted as the lens through which I constructed abstractions from the data that could then be used to explain the subjective experiences of the participants. In this manner, congruence is maintained between the paradigmatic and theoretical underpinnings of the study and the methodological approach to analyzing and interpreting the data.

1.5.4 Method of data generation

The final consideration in maintaining the internal consistency of the study was the selection of methods of data generation. Because I am interested in studying the co-constructive relationship between the subjective experiences of heterosexual men living with HIV and broader objective social structures in which these experiences are embedded utilizing an approach that integrates constructivist grounded theory with the perspectives of Pierre Bourdieu and Erving Goffman, a means of generating data through social interaction was required. For this reason, I have selected focus groups as the means of data generation. Specifically, the induction and simulation of naturally occurring talk within a group setting resonates with the constructionist view that knowledge and the reality of everyday life are produced through social interaction that occurs under the constraints of objective social structures that are themselves reproduced through interaction. Data generated by means of focus groups therefore lends itself well to analysis by constructivist grounded theory and interpretation through the theoretical lenses of Bourdieu and Goffman. That is, by asking questions of the group interaction (e.g. ‘What are the
participants doing in this segment?’, ‘What discourse is reproduced in this interaction?’) which are informed by my paradigmatic and theoretical positions, focus groups as a method of data generation become connected to and congruent with the paradigmatic, theoretical and methodological aspects of the study.

1.5.5 Data Management and Analysis

All focus groups were recorded using a digital recorder and transcribed by a hired transcriptionist or myself. Transcripts were supplemented by memos written immediately following each focus group, the purpose of which was to reflect upon aspects of the social context of each group, what the participants chose to discuss and not discuss, who did most of the speaking and the possible impact of my presence on the generated data.

Analysis began from the outset of data collection. For each focus group, I reviewed the written transcript while playing back the audio recording to re-familiarize myself with the context of the group and make additional notes regarding tone, silences, and any utterances on my part that may have influenced the nature of what was being discussed. I subsequently proceeded to analyze the data using two analytic devices: coding and memo-writing.

Coding and memo-writing

According to Charmaz, “coding is the pivotal link between collecting data and developing an emergent theory to explain these data. Through coding, you define what is happening in the data and begin to grapple with what it means.”\textsuperscript{125, p46} For this study, I used a combination of line by
line coding to construct codes inductively from the data and theoretical coding to assign labels to data segments which drew upon the interpretive framework of the study. Through the process of coding, I was able to break apart the transcripts into groupings of data that formed the ‘bones’ of the analysis. The integration of theoretical insights with the groupings of data occurred through the process of memo-writing.\textsuperscript{125,126} That is, I wrote memos throughout the process of analysis to ask theoretically laden questions of coded segments of data and to facilitate the process of making comparisons and connections across codes and categories of data. Multiple iterations of coding and memo-writing were used, moving back and forth between the data and theory, until well developed concepts were constructed which provided a theoretically informed analysis which was grounded in the data.

In the early stages of the analysis, I used these analytic devices in a manner analogous to Pamphilon’s ‘zoom in, zoom out’ model for analyzing qualitative data, with coding and memo-writing representing the ‘micro-zoom’ and ‘macro-zoom’ levels of analysis, respectively.\textsuperscript{133} That is, I used coding as the ‘up-close’ means by which to interact with and label segments of data in ways which were analytically and theoretically relevant to the research question. For each section of coded data, I produced a corresponding memo that was cross-referenced by transcript, page and line numbers. These early memos took note of elements of the group interaction which might provide insight into what the participants might be ‘doing’ in the context of the focus group (e.g. presenting themselves in a certain way) and the circumstances that may have contributed to the production of this data.
Following these early passes at the data, similarly coded data were extracted from their transcript and aggregated together using standard word-processing software, with individual quotes being cross-referenced to their focus group of origin and initial memo. These ‘data clusters’ were then interrogated through the use of conceptual memos with questions such as “What is this an instance of?”, and “What discourse is being taken up?”. The purpose of memo-writing in this fashion was to further the process of theorizing, using my interpretive framework to re-constitute and think about the segments of coded data as rudimentary categories and concepts which could explain the help-seeking experiences of participants. I subsequently reviewed these categories to check their ‘fit’ with the coded segments of data (i.e. was my interpretation making sense?) from which they were constructed, and to look for connections with other groupings of data. Data which were re-constituted as categories underwent additional iterations of coding and conceptual memo-writing to further develop concepts and to facilitate making comparisons and connections across different categories. The process of coding, conceptual memo-writing and constant comparison was repeated until I felt I had developed well characterized and theoretically informed interpretations of the accounts of participants.

1.5.6 Study Rigour

As with issues of study methodology and method of data collection and analysis, study rigour cannot be separated from the paradigmatic and theoretical foundations of the study. Accordingly, traditional post-positivist criteria of validity, generalizability and reliability would be inappropriate if applied to a study such as this, which is situated largely within the constructivist paradigm. Indeed, scrutiny of the study utilizing traditional post-positivist concepts of internal and external validity and researcher objectivity may doom the findings to
appear as lacking in methodological rigour and being biased by my own subjectivity.\textsuperscript{134,135} Similarly, post-hoc assessment of study findings utilizing methods such as triangulation and member checking is limited in ensuring that the study has been conducted in a rigorous manner. In fact, it is possible that triangulation and member checking (interpreted as verification of results with participants) may actually constitute threats to the rigour of this study.\textsuperscript{134,135} For example, triangulation as a means of ensuring rigour is based on the premise that the credibility of the findings is strengthened if the themes or patterns observed by a single scientist or by using a single method are also observed when ‘triangulated’ by a different analyst or by using a different means of data generation. However, this claim to credibility is rooted in the idea that triangulation by methods, sources or analysts will converge on a single claim of the ‘truth’.\textsuperscript{134} Clearly, this approach to ensuring rigour is more in alignment with the post-positivist tenet of an external, objective reality that can be approximated with research rather than the constructivist paradigm within which the current study is situated. Verification of study findings with participants in the study is fraught with similar concerns for research conducted within a constructivist paradigm.\textsuperscript{135} An over-emphasis on the extent to which the participants agree with the interpretations made by the researcher can potentially undermine the findings of research conducted within a constructivist paradigm in which reality is assumed to be constructed through interaction. Therefore, because of the revisionist nature of narratives, the role of the multiple social contexts of the focus groups in shaping the findings, and my own role in the analysis and interpretation of the data, member checking or participant verification is inherently limited and possibly even inappropriate for use as a means for ensuring the rigour of this study.\textsuperscript{135} As an alternative to the aforementioned evaluative, post-hoc methods, study rigour will be assured in a manner that is consistent with the approach endorsed by Morse and colleagues, in that
mechanisms for study verification will be built into every facet of the study. The specific approaches for ensuring that rigour is maintained as an ongoing process during study implementation and analysis include maintaining epistemic-theoretical-methodological coherence, iterative interaction between data and analysis, and ongoing strategies for maintaining procedural rigour.

*Paradigmatic-Theoretical-Methodological-Method Coherence*

An important aspect of ensuring rigour is to design and conduct a study that is internally consistent with respect to paradigm, theoretical framework, methodology and methods of data generation. That is, rigour becomes built into the study, rather than being assessed as an outcome at the end with techniques such as triangulation or member checking. In this manner, cohesion and congruence are maintained throughout the research process, and the internal consistency and logic employed at all stages of study development and implementation are rendered visible. In this chapter, I have stated my epistemological and ontological positions, and have articulated how this informs my theoretical orientation, choice of methodology and method of data generation.

*Iterative Approach to Sampling, Data Generation and Analysis*

Throughout the study, I moved iteratively between sampling, data generation and analysis. The process of generating concepts and findings simultaneously with the generation of data through focus groups facilitated verification of preliminary ideas and ongoing theoretical sampling of
participants and/or social contexts that differed from those informing the emerging analysis. Thus, by moving back and forth between data generation, analysis and sampling, I remained active and responsive to my data at all stages of the research process. According to Morse, the “lack of responsiveness of the investigator at all stages of the research process is the greatest hidden threat to validity and one that is poorly detected using post hoc criteria of ‘trustworthiness’.”  

_Procedural rigour_

Procedural rigour refers to the internal checks and balances undertaken by the researcher to ensure the credibility of the analysis and the findings. Specific strategies that I employed to maintain the procedural rigour of the study included establishing an audit trail of field notes and reflexive memos following each focus group, extensive memo writing in concert with line-by–line coding of the focus groups transcripts, thereby permitting early theorizing that was directly grounded in the data I had just finished coding, and providing sufficient excerpts of data in the final manuscript to demonstrate the connection between subjective experience and broader social relations and discourses. In addition, preliminary findings were reviewed with several audiences throughout the history of the study, including my committee, a community advisory board of five heterosexual men living with HIV and peers and professors in various qualitative methodology courses undertaken as part of my graduate training.  

In summary, I have described the paradigmatic, theoretical and methodological underpinnings of a qualitative research study intended to characterize the help-seeking experiences of heterosexual
men living with HIV and the social relations and discourses in which these experiences are embedded. The goal of the study was to generate a theoretically informed interpretation that was grounded in the available data and which could be transferable to contextually similar settings.

1.6 Chapter Summary

The objective of this thesis is to use methods of quantitative and qualitative research to examine various dimensions of the health services utilization of marginalized PLWH. The remainder of the dissertation is organized as follows:

Chapter 2: Validation of case-finding algorithms derived from administrative data for identifying adults living with HIV infection.

This chapter describes the test characteristics of 48 case-finding algorithms derived from administrative data for ascertainment of HIV-infection.

Chapter 3: Socioeconomic- and gender-based disparities in rates of hospitalization among HIV-infected patients in a setting of universal access to health care: a population-based study

This study uses a combination of ecological and individual-level analyses to identify disparities in hospitalization rates among PLWH living in Ontario.

Chapter 4: ‘Waiting at the dinner table for scraps’: a qualitative study of the help-seeking experiences of heterosexual men living with HIV infection
This qualitative study draws on the theoretical insights of Erving Goffman and Pierre Bourdieu to analyze and interpret the experiences of heterosexual men living with HIV in relation to the objective social relations and discourses in which they are produced.

Chapter 5: Summary and Synthesis

The final chapter of the dissertation synthesizes the findings from the three studies into a discussion of the clinical and policy-related implications of this research, as well as for the future of HIV-related health services research in Ontario.
Table 1.1: Studies evaluating the impact of highly active antiretroviral therapy on hospitalization of HIV-infected patients

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Patients</th>
<th>Results</th>
</tr>
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<tbody>
<tr>
<td>Yehia et al. Inpatient health services utilization among HIV-infected adult patients in care 2002-2007. Journal of Acquired Immune Deficiency Syndromes 2010;53:397-404.</td>
<td>Analysis of records of HIV-infected adult patients enrolled at one of 12 of 21 sites comprising the HIV Research Network. Analyses were based on data collected from January 1, 2002 to December 31, 2007.</td>
<td>Number of patients increased from 14,496 in 2002 to 15,368 in 2007. In all years, 71% were male, 47-48% were African-American, 42-43% had a median CD4 count of 201-500 cells/mm³, 35-38% were insured through Medicaid, 12-13% were insured through Medicare and 73-78% were in the non-IDU risk category. The proportion of study participants aged 50 and over increased from 17% to 29% over the study period.</td>
<td>Rates of annual hospitalization decreased significantly from 35 to 27 per 100 persons between 2002 and 2007. After multivariable adjustment, rates of hospitalization were significantly lower in 2005 (IRR 0.87; 0.82 to 0.93), 2006 (IRR 0.91; 0.86 to 0.97) and 2007 (IRR 0.90; 0.84 to 0.96) vs. 2002. Hospitalization rates were higher among women vs. men (IRR 1.23; 1.17 to 1.30), patients 50 years or older vs. 18-30 years old (IRR 1.45; 1.3 to 1.58) and among IDUs vs. non-IDUs (IRR 1.46; 1.38 to 1.54). Hospitalization rates also higher for patients with Medicaid (IRR 2.18; 1.98 to 2.39), Medicare (IRR 2.15; 1.93 to 2.40) and dual Medicaid/Medicare (IRR 2.38; 2.07 vs. 2.74) vs. private insurance.</td>
</tr>
<tr>
<td>Bozette et al:</td>
<td>National probability sample of 2864 adults with HIV infections who made at least one visit for regular care at a health care facility in January or February 1996. Sample selected in three stages: a) Random selection of 28 cities and 25 clusters of rural counties. b) From these areas, random selection of 90 urban and 22 rural physicians who care for HIV-infected patients. c) Random selection of patients from lists of patients. Participants underwent structured interview.</td>
<td>2864 patients at baseline (median date: June 1996). Follow-up interviews with 2466 patients (March 1997), 2265 patients (November 1997) and 1915 patients (October 1998). Patient characteristics: 77% male 88% &lt; 50 years old 20% uninsured 63% unemployed 24% had CD4+ cell count below 50 cells/mm^3 Impact of protease inhibitor based therapy: 43% ↓ expenditures related to inpatient care between January 1996 and mid-1997 (i.e. from $878 to $500 per patient per month). However, by end of the study period, hospital costs had increased to $594 per patient per month.</td>
<td></td>
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<tr>
<td>Gebo et al.</td>
<td>Retrospective cohort study of HIV-infected patients receiving primary care at the John Hopkins University AIDS Service between January 1, 1994 and December 31, 1998. Total patients: 2,151 67% male Mean age: 37 years Risk group: 50% injection drug use 28% men who have sex with men Baseline CD4+ cell count: Quadratic relationship between hospitalization rates and time, such that there was a significant ↓ in hospitalization rates between 1995 and 1996, corresponding to introduction of cART, followed by an ↑ in rates between 1997 and 1998 [incidence rate ratio (IRR) for calendar time^2 = 1.02; p =</td>
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</tr>
<tr>
<td>CD4 Count</td>
<td>Percentage</td>
<td>Description</td>
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<tr>
<td>&lt; 50 cells/mm³</td>
<td>25%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50 – 199 cells/mm³</td>
<td>24%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>200 to 499 cells/mm³</td>
<td>32%</td>
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<td></td>
</tr>
<tr>
<td>&gt; 500 cells/mm³</td>
<td>19%</td>
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<td></td>
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</tbody>
</table>

In multivariate regression, female sex (IRR 1.45; p < 0.001) and injection drug use (IRR 1.36; p < 0.001) were predictors of total hospitalization, while receipt of HAART decreased risk (IRR 0.61; p < 0.001).

African-Americans at lower risk of opportunistic infection related hospitalization relative to White ethnicity (IRR 0.49; p < 0.001).

Female sex (IRR 1.45; p < 0.001) and African-American ethnicity (IRR 1.22; p = 0.05) were predictive of higher hospitalizations for non-opportunistic infections.

CD4 < 50 cells/mm³ predictive of total, OI and non-OI related hospitalizations.

<table>
<thead>
<tr>
<th>Source</th>
<th>Study Description</th>
<th>Total Patients</th>
<th>Risk Factors</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gebo et al</td>
<td>Costs of HIV medical care in the era of highly active antiretroviral therapy. AIDS 1999;13:963-9.</td>
<td>Retrospective cohort study of HIV-infected patients enrolled in Maryland Medicaid program and receiving care from the John Hopkins HIV Service</td>
<td>Total patients: 695 63% male Mean age: 34 years 86% African-American Risk group:</td>
<td>Significant ↓ in hospital inpatient costs in all strata of CD4+ counts for patients receiving protease inhibitor based cART.</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Patients</td>
<td>Significant Results</td>
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<tr>
<td>Keiser et al.</td>
<td>Retrospective analysis of patients receiving care at the Dallas Veteran Affairs Medical Center between January 1, 1995 and June 30, 1998.</td>
<td>Total patients: 300 100% male</td>
<td>Significant ↓ in mean monthly hospital days, from 102 per 100 patients to 35 per 100 patients (p &lt; 0.01). Significant ↓ in inpatient costs, from $1257.51 to $466 per patient per month (p &lt; 0.01)</td>
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<tr>
<td>Keiser et al.</td>
<td>Retrospective analysis of patients receiving care at the Dallas Veteran Affairs Medical Center between January 1, 1995 and July 31, 1997.</td>
<td>Total patients: 148 100% male</td>
<td>Significant ↓ in mean monthly hospital days, from 102 per 100 patients to 35 per 100 patients (p &lt; 0.01). Significant ↓ in inpatient costs, from $1257.51 to $31.586 per patient per month (p &lt; 0.01)</td>
<td></td>
</tr>
<tr>
<td>HIV Research Network.</td>
<td>Analysis of records of HIV-infected patients receiving care at one of nine primary and specialty care sites across the United States in 1999.</td>
<td>Total patients: 5,255 74% male Median age: 40 years 48.3% African-American</td>
<td>Use of cART was associated with significantly lower rate of hospital utilization compared with non-use (265 vs. 320 days per 100 persons; p &lt; 0.05)</td>
<td></td>
</tr>
<tr>
<td>Keiser et al.</td>
<td>Long-term impact of highly active antiretroviral therapy on HIV-related health care costs. Journal of Acquired Immune Deficiency Syndromes 2001;27:14-19.</td>
<td></td>
<td>In multivariate analysis, protease inhibitor based cART associated with significantly lower inpatient hospital payments after adjustment for CD4 count, race and sex (coefficient: - 0.57; p = 0.0001)</td>
<td></td>
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<tr>
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</table>

60% injection drug use
23% men who have sex with men
18% heterosexual
<table>
<thead>
<tr>
<th>Year</th>
<th>Analysis of records of HIV-infected adult patients enrolled at one of 11 of 17 sites comprising the HIV Research Network (6 sites excluded because they did not collect data on resource utilization.)</th>
<th>Total patients by year: 13,392 (69.9% male) – 2000 15,211 (69.8% male) – 2001 14,403 (71.2%) – 2002</th>
</tr>
</thead>
<tbody>
<tr>
<td>2002</td>
<td>Median age: 40 years in 2000, 41 years in 2001 and 2002. Risk factors: 36.2% men who have sex with men 32.4% heterosexual 15.2% injection drug use CD4+ count: 11.3% : &lt; 51 cells/mm³ 19.8% : 51 to 200 cells/mm³ 40.5% : 201 to 500 cells/mm³ 28.5% : &gt; 500 cells/mm³</td>
<td>Following multivariable adjustment, no significant change in hospitalization rate [adjusted rate ratio (aRR) 0.96 (0.91 to 1.01) and 0.95 (0.90 to 1.010) for 2001 and 2002, respectively, relative to 2000. Admission rates higher for women vs. men (aRR 1.25; 1.17 to 1.34), black ethnicity vs. white ethnicity (aRR 1.21 (1.12 to 1.30), injection drug use vs. men who have sex with men (aRR 1.61; 1.47 to 1.76) and for Medicaid (aRR 1.63; 1.47 to 1.80) or Medicare (aRR 1.66; 1.49 to 1.85) vs. private insurance.</td>
</tr>
<tr>
<td>2002;30:21-6.</td>
<td>Demographic breakdown of hospitalizations over 5-year</td>
<td>HIV-related admissions decreased 33% across the 7</td>
</tr>
<tr>
<td>Study</td>
<td>Description</td>
<td>Results</td>
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<td>----------------------------------------------------------------------</td>
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<tr>
<td>Fleishman et al.</td>
<td>Associations between outpatient and inpatient service use among persons with HIV infection: a positive or negative relationship? Health Services Research 2008;43:76-95, Analysis of records of HIV-infected adult patients enrolled at one of 10 of 17 sites comprising the HIV Research Network. Analyses were based on data collected from January 1, 2001 to December 31, 2004.</td>
<td>In multivariable regression, adjusted odds ratios for hospitalization higher for women vs. men (aOR 1.22; 1.14 to 1.32), heterosexual transmission vs. men who have sex with men (aOR 1.73; 1.53 to 1.96), black ethnicity vs. white (aOR 1.31; 1.0 to 1.43) and having no outpatient visits in a three month period. However, a linear association between number of outpatient visits and any inpatient admission (aOR 1.05; 1.04 to 1.06).</td>
</tr>
<tr>
<td>Floris-Moore et al.</td>
<td>Gender and hospitalization</td>
<td>Hospitalization rates higher among women than men in first period (1992 to 1996); n = 450 (58% male)</td>
</tr>
</tbody>
</table>


median age: 42 years
Ethnicity
Hispanic: 67%
African-American: 21%
Caucasian: 12%
CD4+ count:
30.0% : < 200 cells/mm³
35.0% : 200 to 499 cells/mm³
35.0% : > 500 cells/mm³
Second period (1997 to 2000)
n = 154 (62% male)
median age: 39 years
Ethnicity
Hispanic: 67%
African-American: 22%
Caucasian: 9%
CD4+ count:
40.0% : < 200 cells/mm³
36.0% : 200 to 499 cells/mm³
23.0% : > 500 cells/mm³
(p = 0.01) and second periods (p = 0.001). Women had higher hospitalization rates in cART era vs. pre-cART era (68.1 vs. 49.4 per 100 person-years; p = 0.01). No difference for men (39.1 vs. 40.2 per 100 person-years; p = 0.41).

In multivariable analysis, use of cART was associated with reduced risk of hospitalization during the 1997 to 2000 period (RR = 0.56; 0.33 to 0.93). Women were at greater risk of hospitalization than men during this period (RR = 1.72; 1.24 to 3.44)

| Hellinger. The changing pattern of hospital care for | Analysis of hospital discharge data obtained from the | Demographics of hospitalized patients (2000): | Over the four years, there was a 20% decrease in inpatient |
Ethnicity:  
White: 24%  
Black: 51%  
Hispanic: 16%  
Other: 9%  
Insurance:  
Medicaid: 52%  
Medicare: 22%  
Private: 15%  

Demographics of hospitalized patients (2004):  
Median age: 43 years 66% men  
Ethnicity:  
White: 24%  
Black: 51%  
Hispanic: 18%  
Other: 7%  
Insurance:  
Medicaid: 49%  
Medicare: 25%  
Private: 12%  

Betz et al. Patterns of diagnoses in 2001 hospitalization data from Total sample: 8,376 patients  
admissions by persons living with HIV despite a 28% increase in number of persons living with HIV.  
Between 2000 to 2004, the average number of admissions per person living with HIV decreased 39% across the six states.  
A total of 1787 patients had at least one inpatient admission. |
<table>
<thead>
<tr>
<th>Source</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital admissions in a multistate cohort of HIV-positive adults in 2001. Medical Care 2005;43:III3-III14.</td>
<td>the HIV Research Network, a consortium of 17 sites providing care to HIV-positive patients in 14 cities in the United States. Data for this analysis came from six sites that also included information on health utilization.</td>
</tr>
</tbody>
</table>

| Characteristics | Median age: 42 years 68.8% men | Ethnicity: White: 25.9% Black: 46.9% Hispanic: 24.6% Other: 2.7% | Risk factors: 32.3% men who have sex with men 32.0% heterosexual 15.0% injection drug use CD4+ count: 7.9% : < 50 cells/mm³ 17.0% : 51 to 200 cells/mm³ 21.0% : 201 to 350 cells/mm³ 43.4 : > 350 cells/mm³ |

| | AIDS-related opportunistic infections were most common causes of hospitalization (8.63 per 100 person-years). |
| | In multivariable regression, women had increased rate of hospitalization for AIDS-related opportunistic infection (IRR = 1.50; 1.25 to 1.79) and gastrointestinal diseases (IRR = 1.52; 1.15 to 2.00) vs. men. |
| | Patients hospitalized more likely to be unemployed (82% vs. 58%; p < 0.001), have a history of injection drug use (24% vs. 17%; p = 0.023), have self-report of health as fair or poor (46% vs. 29%; p < 0.001) and not receive follow-up from a physician experienced in managing HIV (31% vs. 24%; p = 0.036). |
| | In multivariable analysis, |
Krentz et al.  

<table>
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<tr>
<th>Admission to hospital associated with being unemployed (aOR = 2.64; 1.66 to 4.20), previous admission (aOR = 2.30; 1.53 to 3.46), viral load (aOR 1.45; 1.16 to 1.80), being an injection drug user (aOR = 1.63; 1.02 to 2.62) and having an experienced physician aOR 1.98; 1.29 to 3.03).</th>
</tr>
</thead>
</table>
The comparative populations included HIV-infected individuals who were never hospitalized and all adult individuals from the general population in the region who were hospitalized at least once during this time period. |
| A total of 455 patients hospitalized during the study period.  
Median age: 38 years  
83% male  
78% Caucasian  
Median CD4 count: 193 cells/mm$^3$  
HIV exposure category:  
MSM: 51%  
Heterosexual: 14%  
IDU: 29%  
Other: 6%  
684 patients from Southern Alberta Clinic Programme never hospitalized.  
Median age: 37 years  
87% male  

Introduction of cART associated with reduced hospitalization rates. All cause hospitalization rates decreased from 31 to 16 per 100 person-years between 1995 and 1998, and increased back to 18 per 100 person-years in 2003.  
In-hospital mortality declined from 8.8 per 100 patients in pre-cART era to 2.6 per 100 patients in cART period.  
Increase in number of IDU’s hospitalized over time.  
Accounted for 20% of all-cause admissions in pre-cART era and 50% in cART era. |
| Buchacz et al.  
Rates of hospitalizations and associated diagnoses in a large multisite cohort of HIV patients in the United States, 1994-2005. AIDS 2008;22:1345-56. | Analysis of data from 7155 HIV-infected patients participating in the HIV Outpatient Study (HOPS), which is an ongoing, open prospective cohort study comprised of 10 clinics in eight cities in the United States. 
Analysis covers patients who were seen at least twice between January 1, 1994 and December 31, 2005. | A total of 7155 patients  
Median age: 40 years  
80.5% male  
HIV exposure category: 
MSM: 58.5%  
Heterosexual: 23.6%  
IDU: 13.2%  
Other: 2.3%  
Unknown: 2.4%  
Race: 
White: 56.2%  
African-American: 29.8%  
Hispanic: 11.2%  
Unknown/other: 2.7%  
Median CD4+ count: 360 cells/mm³ | Rates of hospitalization fell from 24.6 to 11.8 per 100 person-years between 1994 and 2005 (p < 0.0001).  
Rates of hospitalizations for AIDS opportunistic infections fell from 7.6 per 100 person-years (1994 to 1996) to 1.0 per 100 person-years (2003 to 2005) (p < 0.0001).  
In multivariable regression analysis, older age (adjusted odds ratio: 1.15 per 10 year increase; 1.04 to 1.28) and history of substance use (adjusted odds ratio 1.32; 1.04 to 1.68) associated with hospitalization in the cART era. Women at higher risk only during the period spanning 2000 to 2002 (adjusted odds
<table>
<thead>
<tr>
<th>Study</th>
<th>Methodology</th>
<th>Participants</th>
<th>Hospitalization predictors</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Falster et al: Hospitalizations in a cohort of HIV patients in Australia, 1999-2007. AIDS 2010;24:1329-39.</td>
<td>Retrospective cohort study of the Australian HIV Observational Database cohort, which includes 27 sites in six of the eight states/territories in Australia. The data for current analysis were from two states, and were linked with the hospital admissions data.</td>
<td>A total of 842 patients in the analysis.</td>
<td>Predictors of hospitalization during the study period included: History of AIDS at baseline [incidence rate ratio (IRR) 1.71; 1.24 to 2.35], viral load (IRR 1.16 per 1 log increase; 1.11 to 1.21), CD4+ count (IRR 0.91 per 100 cell increase; 0.89 to 0.93), duration of HIV infection [IRR for 5-7, 7-12, and &gt; 12 years vs. 0-4 years were 2.48 (2.00 to 3.07), 2.48 (1.92 to 3.20) and 2.34 (1.82 to 3.31) and calendar year [IRR for 2005 and 2006-2007 vs. 1999-2000 were 1.27 (1.05 to 1.54) and 1.55 (1.27 to 1.89).</td>
<td>No longer associated with hospitalization in later period (i.e. 2003 to 2005).</td>
</tr>
<tr>
<td>Crum-Cianflone et al. Trends and causes of hospitalizations among HIV-infected persons during the late HAART era: what is the impact of CD4 counts and HAART use? Journal of Acquired Immune Deficiency Syndromes 2010;54:248-57.</td>
<td>Analysis of data collected from participants in the U.S. Military HIV Natural History Study, which is a multicenter, prospective, observational study of military personnel and beneficiaries with HIV infection. This study used data collected between 1999 to 2007.</td>
<td>A total of 2,429 participants. Mean age at diagnosis: 30 years 91% male Ethnicity: 45.5% African-American 41.5% Caucasian 8.7% Hispanic Mean CD4+ count: 554</td>
<td>No significant change in age-adjusted hospitalization rates over time (RR 0.98; 0.96 to 1.01).</td>
<td>Factors associated with risk of hospitalization included CD4 count (RR 0.67 for &gt; 500 vs. &lt; 350; 0.56 to 0.81) and chronic hepatitis C (RR 1.46; 1.05 to 2.03).</td>
</tr>
<tr>
<td>Study Reference</td>
<td>Study Design</td>
<td>Study Findings</td>
<td>Additional Information</td>
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</tr>
<tr>
<td>Mocroft et al. Changes in hospital admissions across Europe: 1995-2003. Results from the EuroSIDA study. HIV Med 2004;5:437-47.</td>
<td>Analysis of inpatient data collected from one of 72 European centres comprising the EuroSIDA study. For this analysis, patients were identified for whom information on hospital admission was available.</td>
<td>Data were available regarding hospital admissions for 7868 patients over the time period. The proportion of patients admitted declined from 7.4% in 1995 to 2.6% in 2003. In addition, the median duration of admission declined 58% over this period.</td>
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</table>
After adjustment for demographic variables, use of HAART, hepatitis C status and CD4+ count, the proportion of patients admitted declined by 5.5% per year (95% CI: 2.5% to 8.5%; p = 0.0004).

There was no association between hospitalization and either gender, race or risk group.
Chapter 2: Validation of case-finding algorithms derived from administrative data for identifying adults living with human immunodeficiency virus infection

Published in manuscript form:

2.1 Abstract

Objective

We sought to validate a case-finding algorithm for human immunodeficiency virus (HIV) infection using administrative health databases in Ontario, Canada.

Methods

We constructed 48 case-finding algorithms using combinations of physician billing claims, hospital and emergency room separations and prescription drug claims. We determined the test characteristics of each algorithm over various time frames for identifying HIV infection, using data abstracted from the charts of 2040 randomly selected patients receiving care at two medical practices in Toronto, Ontario as the reference standard.

Results

With the exception of algorithms using only a single physician claim, the specificity of all algorithms exceeded 99%. An algorithm consisting of three physician claims over a three year period had a sensitivity and specificity of 96.2% (95% CI 95.2% - 97.9%) and 99.6% (95% CI 99.1% - 99.8%), respectively. Application of the algorithm to the province of Ontario identified 12,179 HIV-infected patients in care for the period spanning April 1, 2007 to March 31, 2009.

Conclusions
Case-finding algorithms generated from administrative data can accurately identify adults living with HIV. A relatively simple ‘3 claims in 3 years’ definition can be used for assembling a population-based cohort and facilitating future research examining trends in health service use and outcomes among HIV-infected adults in Ontario.
2.2 Introduction

The impact of antiretroviral therapy (ART) on the natural history of infection with the human immunodeficiency virus (HIV) has been indisputable.\textsuperscript{1,2} Specifically, the marked reductions in HIV-related morbidity and mortality attributable to the widespread adoption of ART have transformed the disease from one associated with near universal fatal outcomes to a chronic illness amenable almost exclusively to outpatient management. In parallel with this transformation, the epidemiology of HIV-infection is changing, such that increases in the numbers of women and individuals from countries with a high HIV prevalence living with the virus have been reported in several jurisdictions.\textsuperscript{137-140} In this context of change in both the epidemiology and natural history of HIV infection, accurate population-based estimates of disease incidence and prevalence are essential for facilitating ongoing surveillance, health care planning and research evaluating health service utilization and outcomes among individuals living with HIV.

Administrative data are one means by which a population based surveillance system can be assembled. Along with their relative ease of access, perhaps the most notable strength of administrative databases lies in the breadth of coverage provided, such that information describing the health service utilization of an entire population within a specific geographical area can be accessed in an efficient and timely manner. However, because administrative data are not generated specifically for chronic disease surveillance or undertaking research, and there is no financial incentive associated with accuracy when physicians provide diagnostic data for billing, it is important to assess the validity of these data prior to deploying them for the aforementioned initiatives.
While numerous studies have been performed utilizing administrative data for health services research in individuals living with HIV, there has been little preliminary work to validate these sources, particularly in the ART era. Because of the risk of misclassification error associated with using administrative data for population-based research, the validation of these data has recently been identified as a priority by an international consortium of health services researchers. We therefore sought to develop and validate a case-finding algorithm using administrative data to identify adults living with HIV infection in Ontario.

2.3 Methods

2.3.1 Study Overview

We conducted a retrospective study to validate administrative data for the detection of HIV infection. We identified HIV-infected cases and non-cases from the charts of two primary care clinics, linked these data to five administrative databases, and finally determined the validity of 48 case-finding algorithms over various timeframes for the detection of HIV infection.

2.3.2 Primary Care Chart Data

The sampling frame for the collection of primary care chart data was two family practice clinics located in downtown Toronto with a prevalence of HIV-infected adults that is higher than that found in the general population of Ontario. Because HIV primary care in Ontario is largely clustered within a few clinics, we purposively selected these sample sites to ensure that an adequate number of HIV-infected patients would be included in the validation sample. Within each practice, we generated a random sample of adult patients (> 18 years) using either the electronic billing system or the electronic medical record of each site, according to the following
inclusion criteria: over the age of 18 years, has a valid Ontario Health Insurance Plan (OHIP) card number, first visited the participating physician at least 3 years before the date of chart abstraction, and seen on at least 2 occasions or for 1 complete physical examination during the 3 year period spanning April 1, 2005 to March 31, 2008.

We trained two chart reviewers to extract data from patient medical records through discussion and review of 25 charts with at least one investigator. The chart abstractors subsequently reviewed the laboratory results and medication profiles of each chart from the period spanning April 1, 2005 to March 31, 2008, and entered data directly into a password protected database stored on a secure server. Variables that were collected during the chart abstraction included patient date of birth, OHIP number, sex, postal code and laboratory evidence of HIV infection. We assigned all individuals a unique study identifier, and maintained separate files for the storage of personal identifiers and HIV-related information. We classified individuals as having a diagnosis of HIV infection if one of the following criteria were met during the study interval: positive HIV antibody test, detectable HIV RNA viral load, or undetectable HIV RNA viral load while receiving antiretroviral therapy for more than one month. We assessed inter- and intra-rater reliability for the designation of ‘HIV infection’ based on a reabstraction of a random sample of 10% of the charts. Intra-rater reliability was assessed by randomly reinserting a sample of charts for duplicate abstraction, while inter-rater reliability was calculated at the end of the chart abstraction by the principal investigator. In both instances, agreement was expressed as a kappa statistic.
Given the low prevalence of HIV infection in the province of Ontario, we based our sample size calculation on the need for an algorithm that maximizes specificity. Using the binomial distribution, we determined that approximately 1,567 HIV-negative controls would be required to generate an algorithm with 99% specificity and a lower 95% confidence limit > 0.98, with 0.95 probability. Because the HIV prevalence at both clinics was approximately 20%, we planned to review the charts of 2000 randomly selected patients (1000 per site) to secure the required number of HIV-negative controls.

2.3.3 Sources of administrative data

We used the administrative databases available at the Institute for Clinical Evaluative Sciences (ICES) through a data sharing agreement with the Ontario Ministry of Health and Long Term Care. OHIP numbers were encrypted and converted into unique identifiers that are common among the various databases and which were used to link the chart data with administrative data for the period April 1, 2005 to March 31, 2008. The linked administrative data included: 1) physician billing information from the Ontario Health Insurance Plan (OHIP); 2) acute care hospitalization records from the Canadian Institute for Health Information Discharge Abstract Database (DAD); 3) records regarding hospital emergency department visits from the Canadian Institute for Health Information National Ambulatory Care Reporting System (NACRS); 4) computerized pharmacy records of the Ontario Drug Benefit program (ODB); and 5) basic demographic information and vital statistics from the Registered Persons Database (RPDB).

The OHIP is a provincially funded program which reimburses physicians for the provision of medically necessary procedural, diagnostic and laboratory services to all permanent residents of the province of Ontario. Consequently, the OHIP database contains administrative data
generated from all inpatient and outpatient physician billings. In order to receive payment for services rendered, physicians must submit the name, date of birth and OHIP card number of the individual patient seen, the service provided (i.e. a service code), and a single diagnosis code on each claim. For OHIP claims, the diagnosis code is a truncated three-digit version of the corresponding ICD-9 code, and service codes are four-digit, alphanumeric codes that describe the specific service that has been provided. Since service codes are more directly connected to physician reimbursement and are subject to audit by OHIP, these codes may be more accurately coded than the diagnostic code. Approximately ninety-four percent of Ontario physicians submit claims data to OHIP. 97 For this study, we used the OHIP database to identify physician claims for an HIV-related visit.

The DAD contains information abstracted from all acute care hospital separations (i.e. discharge, sign-out, transfer to different facility, death) and day surgeries in the province of Ontario. 100 Variables abstracted from patient charts and thereby included in the database are the patient OHIP number, dates of admission and discharge from the hospital, the diagnosis representing the condition that is accountable for the greatest portion of the length of stay or greatest use of resources (i.e. the most responsible diagnosis) and up to twenty-four additional secondary diagnoses and/or complications. 100 As HIV infection may not be classified as the most responsible diagnosis accounting for a given admission, we examined all diagnosis fields in the DAD for evidence of HIV-related hospitalization. Similarly, we searched all ten diagnostic fields in the NACRS database for emergency room visits attributable to HIV infection. 103 In the case of both the DAD and NACRS, abstraction of patient charts is undertaken by trained health information professionals using standard diagnosis and procedure codes.
We used the prescription drug records of the ODB to identify claims for antiretroviral medications. The ODB provides drug coverage for eligible groups of Ontarians, including those over the age of 65, recipients of social assistance, and individuals who have high prescription drug costs in relation to their income. Drugs which are covered by the ODB program are listed in a provincial drug formulary by their unique drug identification numbers (DINs), which delineate the exact strength and dosage form of a given medication dispensed. With the exception of maraviroc and enfuvirtide, all antiretrovirals are covered without restriction in the province of Ontario. Since lamivudine, emtricitabine and tenofovir can also be used for the management of non-HIV associated chronic hepatitis B infection, we excluded prescription claims for these drugs from our algorithms.

The Ontario RPDB is an electronic registry of all individuals who are eligible for provincial health insurance for a given year. We used the RPDB to identify demographic information such as age, sex and postal code.

### 2.3.4 Algorithm Development and Testing

We determined the sensitivity, specificity, kappa statistic and area under the Receiver Operating Characteristic (ROC) curve of 48 case-finding algorithms (combinations of physician billing codes, hospitalizations, emergency department visits and prescription claims, over various time frames) using the chart audit as the reference standard (see supplemental table 2.1, which provides full list of algorithms). We defined sensitivity as the proportion of individuals with evidence of HIV infection in their chart that were identified as having HIV in the administrative data, and specificity as the proportion of individuals without evidence of HIV infection in their
chart identified as not having HIV using administrative data. We used the kappa statistic to assess agreement between the two data sources, and the area under the ROC curve as a global measure of algorithm performance. A test that accurately discriminates between HIV infected and non-infected patients would have a sensitivity and specificity approximating 100%, and a kappa statistic and an area under the ROC of close to 1.0.

We identified patients with HIV infection in the administrative databases using the relevant ICD-9 (042, 043, 044) and ICD-10 (B20 – B24) codes, and used both single and multiple years of data based on previous research which has shown that algorithm sensitivity can be enhanced as the observation period is extended. We calculated 95% confidence intervals (CI) using a binomial probability distribution, and selected the algorithm with the highest specificity while maximizing sensitivity over the shortest interval of time. We applied this algorithm to the population of Ontario to determine the number and basic demographic characteristics of HIV infected patients in care in the province. All statistical analyses were performed using SAS version 9.2 (SAS Institute, Cary, North Carolina).

We obtained ethics approval from the Institutional Review Boards of all participating centers (i.e. Sunnybrook Health Sciences Centre, St. Michael’s Hospital and Women’s College Hospital). Specifically, we obtained approval from the Research Ethics Board (REB) of Sunnybrook Health Sciences Centre to access the administrative databases at ICES, and from the REBs of St. Michael’s Hospital and Women’s College Hospital for the chart abstraction portion of the study. Informed consent was waived by the REBs of the chart abstraction sites (St.
Michael’s Hospital and Women’s College Hospital) due to the retrospective nature of the data collection.

2.4 Results

We abstracted data from the charts of 2040 patients, of whom 471 (23.1%) had a diagnosis of HIV infection. The mean age of patients in our validation cohort was 47.5 years (standard deviation = 12.2), and 28.9% were women. The kappa statistics for inter- and intra-rater reliability were 0.98 (95% CI 0.94 – 1.0) and 1.00, respectively.

Overall, the agreement between the primary care chart review and administrative data exceeded 90% for all case-finding algorithms. With the exception of definitions based on only a single physician claim, the specificity of all algorithms exceeded 99%. Extension of the observation period beyond one-year increased the sensitivity and area under the ROC curve of the case-finding algorithms, with negligible detrimental effects on specificity. The case finding algorithms with the highest specificities while maximizing sensitivity are summarized in Table 2.1. Three physician claims over a three year period accurately detected a diagnosis of HIV infection with a sensitivity and specificity of 96.2% (95% CI 95.2% - 97.9%) and 99.6% (95% CI 99.1% - 99.8%), respectively. Additional physician claims increased the specificity slightly to 99.7%, but were associated with reductions in algorithm sensitivity. The inclusion of hospital separations, emergency room visits, HIV service codes or prescription drug claims did not appreciably augment the sensitivity or specificity of algorithms based solely on physician claims data.
Application of the three claims in three years algorithm to the province of Ontario identified 12,179 HIV-infected patients in care for the fiscal period spanning April 1, 2007 to March 31, 2009 (Table 2.2). As expected, the majority (81.2%) of HIV-infected patients in Ontario were men.

2.5 Discussion

Our study demonstrates that administrative data can detect HIV-infected individuals who receive regular primary care with a high degree of sensitivity and specificity. Of the 48 algorithms examined over multiple periods of observation, the ‘3 claim within 3 consecutive years’ rule was selected as the preferred case definition when using administrative data for defining HIV-infection in Ontario. The very high specificity of the algorithm indicates that individuals without HIV-infection are unlikely to be misclassified as such, an important consideration when utilizing administrative data for the surveillance of a low prevalence illness in the population of interest. The demographic profile of the individuals identified as being HIV-positive when the algorithm was applied to the provincial population supports the latter point. That is, the distribution of HIV-infection by sex, age and region is reasonably consistent with provincial public health estimates.137 Because HIV-associated hospitalizations have declined with the availability of potent antiretroviral therapies, it was not surprising that hospital admissions did not augment the validity of claims based case-definitions. Similarly, as patients comprising our validation cohort were by definition required to be ‘in care’ to be eligible for inclusion in the study, the finding that prescriptions for antiretrovirals did not enhance the validity of algorithms based solely on physician claims was not unexpected. Our preferred case definition for HIV infection compares favourably with those used for the surveillance of other chronic diseases in Ontario, and can be
used to facilitate the execution of research examining the utilization and quality of health care for HIV-infected patients in the province.\textsuperscript{31-37}

Our findings extend those of earlier studies examining the validity of administrative data for the detection of HIV-infection.\textsuperscript{44-50} Notably, we considered a broad array of permutations when constructing case-finding algorithms from our administrative databases when compared with earlier studies. To our knowledge, this study therefore represents the most comprehensive effort to determine the accuracy of administrative data for detecting HIV-infection in the ART era. Furthermore, we considered the importance of varying the timeframe when examining the validity of our algorithms. Previous validation research with other chronic diseases has indicated that errors in estimates of population prevalence can be decreased with the use of case-finding algorithms of sufficient duration to generate an adequate number of health care visits.\textsuperscript{142,143} By varying our timeframe over three years, we were able to increase the sensitivity of our algorithms. In addition, the specificity of HIV case-definitions derived from administrative data could not be determined in some previously published validation studies due to the lack of HIV-negative controls.\textsuperscript{46,47} However, ascertaining the specificity of case finding algorithms for diseases of low prevalence is critical in order to minimize the risk of falsely classifying healthy individuals as being HIV-infected. For example, if there are 5,000 HIV-infected patients in a population of 1,000,000 individuals, even a slight 1% decrease in the specificity of a case finding algorithm could falsely classify approximately 10,000 additional healthy individuals as being HIV-positive. In contrast, a 1% decrease in sensitivity would fail to identify merely 50 individuals who are truly HIV-infected. For this reason, we placed greater emphasis on maximizing the specificity of our algorithms relative to their sensitivity.
Several limitations of our work merit emphasis. As the prevalence of HIV infection in our administrative databases is less than that of our validation cohort, we elected to not report positive (PPV) and negative predictive values (NPV) for our algorithms. Because these indices of validity are dependent on the prevalence of the disease in the population of interest, the PPV of our algorithms would be expected to be much lower when applied to the population of Ontario relative to patients in our high-prevalence validation cohort. However, this limitation is not unique to our study. A recent review of validation studies found that the prevalence of disease was similar in the validation cohort and administrative data in only 34% of studies reporting PPV and NPV. In addition, our analysis was based on a review of the charts at two sites where there is extensive HIV-related clinical experience, and can therefore not be considered a true population-based sample. It is therefore possible that physician billing and coding practices at these clinics may not be representative of those in clinics with less familiarity with HIV disease, and that estimates of algorithm sensitivity and specificity derived in our study would not be applicable at centers with a lower prevalence of HIV infection. However, the dependence of sensitivity and specificity on prevalence is mitigated in the context of a binary outcome with a homogenous probability of misclassification. As our algorithm was validated for discriminating HIV infection status based on criteria for which there are no competing diagnoses, it is possible that our estimates of sensitivity and specificity would be stable for sites with a lower prevalence of HIV infection. Further research is warranted to verify this hypothesis. Furthermore, our validation cohort was comprised of patients who regularly accessed primary care services, and the validity of our case-finding algorithm among patients who use health services less frequently is unknown. Therefore, estimates of the provincial prevalence of HIV infection would likely be below the ‘true’ prevalence when the algorithm is applied to the
population of Ontario. Although the use of public health laboratory data would obviate this concern, as all patients with a positive HIV antibody test who are alive in Ontario would be represented, these data were not available at the time this study was conducted and would require a linkage with Ontario’s administrative databases for the purpose of conducting population-based research. Finally, while our findings provide insight into the validity of administrative data for the case ascertainment of HIV-infection in Ontario, they may not be applicable in other jurisdictions. Most notably, our methodology and findings are likely not transferable to resource poor countries with a high prevalence of HIV infection lacking in the capacity to collect and/or link administrative databases. However, this limitation applies equally to all studies validating administrative data for chronic disease surveillance.

In conclusion, we have demonstrated the validity of a relatively simple ‘3 claim in 3 years’ case finding algorithm for the identification of patients with HIV-infection in Ontario’s health administrative databases. The findings of our study represent the initial stage in establishing a population-based surveillance program that will ultimately render it possible to examine trends in health services utilization and quality of care among HIV-positive individuals in Ontario. Such research can have considerable implications for both health policy and in improving the health of HIV-positive patients in the province.

2.6 Conflicts of Interest and Financial Disclosure

Tony Antoniou has received unrestricted research grants from Glaxo-Smith-Kline Inc, Merck and Pfizer for different studies.

2.7 Funding/Support
Tony Antoniou is supported by a scholarship from the Canadian Observational Cohort (CANOC) Collaboration. Mona Loutfy is supported by a Canadian Institutes of Health Research New Investigator Award. This project was supported by the Institute for Clinical Evaluative Sciences (ICES), which is funded by an annual grant from the Ontario Ministry of Health and Long-Term Care (MOHLTC), and by research funds from the Department of Family and Community Medicine, St. Michael’s Hospital. The sponsors had no role in the design and conduct of the study; in the collection, analysis, and interpretation of the data; or in the preparation, review, or approval of the manuscript. The opinions, results and conclusions reported in this paper are those of the authors and are independent from the funding source. No endorsement by ICES, the Ontario MOHLTC or the Department of Family and Community of St. Michael’s Hospital is intended or should be inferred.

2.8 Acknowledgements

We thank Kamyab Ghatan and Molly Gamble for their assistance with data collection. We thank Ina Sandler and Jane Polsky for their assistance with generating the validation cohort at the participating sites. We thank Brogan Inc., Ottawa for use of their Drug Product and Therapeutic Class Database.
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*Rx, prescription claim for antiretroviral*
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Chapter 3: Socioeconomic- and gender-based disparities in rates of hospitalization among HIV-infected patients in Ontario: a population-based study

Published in manuscript form:

3.1 Abstract

Background

Because hospitalization of persons living with HIV-infection (PLWH) in the era of combination antiretroviral therapy (cART) may be an indicator of inadequate community-based care, population-based assessments of inpatient service utilization are a necessary component of the evaluation of the quality of HIV-related care.

Methods

Using a validated algorithm, we identified all PLWH in Ontario’s administrative health-care databases aged 18 years and older between 1992 and 2008, and conducted a population-based study using ecologic and longitudinal individual-level analyses to quantify the immediate impact of cART on hospitalization rates and analyze recent trends (2002 to 2008) in rates of total and HIV-related hospitalizations.

Results

The introduction of cART in 1996/97 was associated with more pronounced reductions in rates of total (-89.9 vs. -60.5 per 1000 PLWH; p = 0.003) and HIV-related hospitalizations (- 56.9 vs. - 36.3 per 1000 PLWH; p < 0.001) among men relative to women. Between 2002 and 2008, higher rates of total hospitalization were associated with female sex [adjusted relative rate (aRR) 1.15; 95% CI: 1.05 to 1.27] and low socioeconomic status (aRR 1.21; 95% CI: 1.14 to 1.29).
Higher rates of HIV-related hospitalizations were associated with low socioeconomic status (aRR 1.30; 95% CI: 1.17 to 1.45). Recent immigrants had lower rates of both total (aRR 0.70; 95% CI 0.61 to 0.80) and HIV-related hospitalizations (aRR 0.77; 95% CI 0.61 to 0.96).

**Interpretation**

Despite universal access to health care and overall declines in hospitalizations, we observed important gender- and socioeconomic-based disparities in hospitalization rates among PLWH living in Ontario, Canada.
3.2 Introduction

Patterns of health services utilization among patients infected with the human immunodeficiency virus (HIV) have been demonstrably altered by the introduction and widespread availability of combination antiretroviral therapy (cART) during the latter half of the 1990s.\textsuperscript{73,79,80,83,89} Most notably, large declines in the rates of hospitalization for HIV-associated opportunistic infections were observed in the years immediately following the adoption of cART as the standard of care for HIV. However, more recent studies examining the utilization of inpatient services by persons living with HIV (PLWH) have described stabilizing or increasing rates of hospitalization, particularly among patients for whom the effects of HIV infection intersect with socially and structurally mediated barriers to care, such as women and ethnic minorities living with the disease.\textsuperscript{57,72,81,82,85} These data are especially salient for the evaluation of hospitalization trends among PLWH residing in the province of Ontario, where important changes in the demographic composition of this population have been observed over the preceding decade. Specifically, the proportion of diagnoses comprised by women has increased from less than 3\% in the early years of the epidemic to 22\% in 2008.\textsuperscript{23} Similarly, the prevalence of HIV among persons immigrating to Ontario from HIV-endemic countries has increased 62\% since 2003.\textsuperscript{23} In this context of pronounced change in both the treatment and demography of HIV infection, accurate population-based estimates of health services utilization are required by clinicians, researchers, and policy makers who are involved in the provision, evaluation and funding of HIV-related care. However, these data are presently lacking for Ontario, home to over 40\% of Canada’s population of PLWH and recipient of approximately half of all immigrants to Canada on an annual basis.\textsuperscript{21}
Because hospitalization for HIV-related illness in the era of cART can be considered an indicator of inadequate community-based care, ongoing assessment of trends in inpatient service utilization is a necessary component of the evaluation of the quality of care for PLWH. We therefore conducted a population-based study of the temporal trends in hospitalization rates among PLWH in the province of Ontario. We hypothesized that, because of socially and structurally rooted challenges in accessing care among marginalized PLWH, rates of hospitalization in the modern era of cART (2002 to 2008) would be disproportionately higher among women, recent immigrants and PLWH living in low income neighborhoods.

3.3 Methods

3.3.1 Study Design

We used a validated case-finding algorithm derived from administrative data to identify all PLWH aged 18 years and older who were receiving care in the province of Ontario between April 1, 1992 and March 31, 2008. The development and test characteristics of the algorithm have been described in detail elsewhere. Briefly, an algorithm of three physician claims with an International Classification of Diseases, Ninth Revision (ICD-9) code for HIV infection (042, 043, 044) within a three year period achieved a sensitivity and specificity of 96.2% (95% CI 95.2% - 97.9%) and 99.6% (95% CI 99.1% - 99.8%), respectively. We chose the end of the 2008 fiscal year for our analyses to meet the three-year ‘look forward’ criterion of the algorithm when assembling our cohort. We then conducted a retrospective, population-based study using both ecologic and individual level analyses to examine temporal trends in the rates of hospitalization among this cohort. Specifically, we used interrupted time series analysis to isolate and quantify the impact of the introduction of cART on hospitalization rates among PLWH in Ontario and methods of longitudinal data analysis to examine trends and predictors of
hospitalization during the era of ‘modern cART’, defined as the period spanning April 1, 2002 to March 31, 2008. We selected this period for the longitudinal analyses because it corresponds to important changes in the demographic composition of PLWH in Ontario and to the availability of antiretrovirals with enhanced potency and ease of administration relative to earlier iterations of these drugs.\textsuperscript{23,148}

3.3.2 Data Sources and Outcomes

We used the Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD) to determine the annual number of hospitalizations for each individual in our population-based cohort of PLWH. The CIHI-DAD contains information abstracted from all acute care hospital separations (i.e. discharge, sign-out, transfer to different facility) in the province of Ontario by trained health information professionals using standard diagnosis and procedure codes, including the dates of admission and discharge from the hospital, the diagnosis representing the condition that is accountable for the greatest portion of the length of stay or greatest use of resources during the hospitalization (i.e. the most responsible diagnosis) and secondary diagnoses and/or complications contributing to the admission. We calculated annual crude rates of total and HIV-related hospitalizations per 1000 population of PLWH aged 18 and over. HIV-related hospitalizations were defined as those admissions in which the most responsible diagnosis was coded as being attributable to HIV infection or an associated opportunistic infection using the relevant ICD-9 and 10\textsuperscript{th} revision codes (ICD-10). We excluded obstetrical admissions and elective surgeries from our calculation of hospitalization rates.

We used the Ontario Registered Persons Database, a registry of all residents eligible for provincial health insurance, to identify individual demographic information such as age, sex,
date of OHIP eligibility, and postal code. We determined patient SES at the neighborhood level for each year of follow-up using postal code information and Statistics Canada census data. We defined recent immigrants as all adults who were first issued an OHIP card within three years of becoming a prevalent member of our cohort. The use of date of issue of an OHIP card has been used as a proxy for the date of arriving in Ontario in other studies.\textsuperscript{149}

3.3.3 Statistical analyses

In order to examine the impact of cART on hospitalization rates during the period spanning 1992 to 2008, we conducted an interrupted time series analysis using autoregressive integrated moving average (ARIMA) models with an indicator variable for the fiscal year 1996/1997, corresponding to the first full year that cART was widely available in Ontario.\textsuperscript{87,150} We performed subgroup analyses to determine if the impact of cART on both total and HIV-related hospitalization rates varied according to sex and SES, and used the Ljung-Box $\chi^2$ statistic to examine autocorrelation of the model residuals.\textsuperscript{92}

For the longitudinal analyses, we evaluated temporal trends in the rates of hospitalization during the years 2002 to 2008 using multivariable generalized estimating equation (GEE) models with a log link function and autoregressive correlation structure.\textsuperscript{89} Because GEE is not a likelihood based method, we used the quasilikelihood under the independence model information criterion measure (QIC and QICu) to ascertain both the appropriateness of the autoregressive correlation structure relative to other working correlation matrices and to assess the fit of our regression models.\textsuperscript{151} We also evaluated the data for overdispersion by comparing the Poisson and negative binomial distributions.
We conducted separate analyses for total hospitalization rates and rates of HIV-related hospitalizations. All multivariable analyses included fiscal year as the main predictor, along with variables for sex, immigrant status and income quintile group (low vs. high), because of our a priori hypotheses that differences in access to care may contribute to an increased rate of hospitalizations among these groups. We estimated adjusted relative rates (aRR) from the model using calendar year as both a continuous variable and as a categorical variable. In the former case, trends are reported as percentages per year, while in the latter, aRRs were used to compare annual changes in the rate of hospitalization relative to the reference year of 2002. We considered additional variables as confounders based on a plausible association with our outcomes of interest and if they changed the estimate for fiscal year by at least 10%. Variables meeting this criterion included patient age, annual number of physician visits, geographic residence (urban versus rural), years with HIV infection and level of co-morbidity. We used the Johns Hopkins Adjusted Clinical Group case-mix assignment software (Sun Microsystems Inc., Santa Clara, CA) to determine the level of comorbidity for each patient based on diagnostic codes listed in hospitalization records and physicians’ services claims from each year during the study period. This methodology is described in detail elsewhere. We assessed the potential for collinearity between covariates using a threshold tolerance of $>0.4$ and a variance inflation of $<2.5$. We also examined interactions between sex, SES and immigrant status with year in separate models. We included interaction terms in the final model if they were statistically significant and if their inclusion improved the goodness-of-fit of the model by at least 10%.
All statistical analyses were conducted using SAS statistical software, version 9.2 (SAS Institute Inc., Cary, NC).

3.3.4 Ethics approval

We obtained ethics approval for this study from the Research Ethics Board of Sunnybrook Health Sciences Centre and the Ethics Review Committee of the University of Toronto.

3.4 Results

3.4.1 Ecologic analyses

The sex- and SES-stratified temporal trends in both total and HIV-related hospitalization rates between 1992 and 2008 are shown in Figures 3.1 and 3.2. Over the sixteen year study period, crude annual rates of total and HIV-related hospitalizations decreased from 392.4 to 123.9 per 1000 PLWH and 247.6 to 32.2 per 1000 PLWH, respectively. As expected, the introduction of cART was associated with significant reductions in rates of both total [- 86.1 per 1000 PLWH; 95% confidence intervals (CI): - 77.1 to - 95.1 per 1000 PLWH; p < 0.001] and HIV-related hospitalizations [- 54.1 per 1000 PLWH; 95% CI: - 48.4 to - 59.8 per 1000 PLWH; p < 0.001).

In sub-group analyses, significant reductions in hospitalization rates were associated with the introduction of cART for both men and women living with HIV, as well as PLWH living in both high and low income neighborhoods. However, the impact of cART was more pronounced among men relative to women for both total (-89.9 vs. -60.5 per 1000 PLWH; p = 0.003) and HIV-related hospitalizations (- 56.9 vs. - 36.3 per 1000 PLWH; p < 0.001). In contrast, no difference in the immediate impact of cART on total (-91.3 vs. -83.5 per 1000 PLWH; p = 0.36) or HIV-related hospitalization (-57.4 vs. -53.7 per 1000 PLWH; p = 0.25) rates was observed in low relative to high SES patients.
3.4.2 Multivariable Analysis of Hospitalization Trends

The demographic characteristics of the population of PLWH living in Ontario during the years 2002 to 2008 are presented in Table 3.1. For each year, most patients were male, lived in Ontario’s large urban centres and were between the ages of 36 and 50 years old. The proportion of PLWH that were women increased from 16.4% in 2002 to 19.5% in 2008. Similarly, the numbers of individuals aged 51 and older increased longitudinally, accounting for 15.8% of PLWH in 2002 and 25.2% in 2008.

Crude and adjusted rates of total hospitalization among PLWH in Ontario decreased 2.5% (95% CI: 1.1% to 4.0%) and 2.3% (95% CI: 0.8% to 3.8%) per annum between the years 2002 and 2008. Over the six year study period, adjusted rates of total hospitalization were higher among women relative to men (aRR 1.15; 95% CI: 1.05 to 1.27) and PLWH living in low versus high income neighborhoods (aRR 1.21; 95% CI: 1.14 to 1.29). In contrast, recent immigrant status was associated with reduced rates of total hospitalization (aRR 0.70; 95% CI: 0.61 to 0.80) (Table 3.2).

Crude and adjusted rates of HIV-related hospitalizations remained relatively stable among PLWH in Ontario between 2002 and 2008, changing by – 1.0% (95% CI: -3.3% to 1.4%) and + 0.9% (95% CI: - 1.6% to + 3.4%) per annum, respectively. In contrast to total hospitalizations, an association with gender was not evident for this outcome. However, significant associations between HIV-related hospitalizations and both low SES and immigration status were observed (Table 3.2).
3.5 Discussion

In our population-based study, we observed a striking reduction in the rates of total and HIV-related hospitalizations associated with the availability of cART between the years 1992 and 2008. Although these benefits were observed in all sub-groups examined, the effect of cART was attenuated among women relative to men. In the modern era of cART, sustained reductions in the rates of total hospitalization among PLWH were observed, while rates of HIV-related hospitalizations remained relatively unchanged during this six year period of follow-up. However, because numbers of HIV-related hospitalizations were relatively low, we cannot discount the possibility of a type II error when analyzing temporal trends in this outcome. We also identified several disparities in the risk of hospitalization among PLWH in Ontario following multivariable adjustment for sociodemographic variables, level of co-morbidity and annual number of outpatient physician visits. Specifically, female sex and low SES were significantly associated with higher rates of total hospitalization, with the latter variable also being associated with a heightened risk of HIV-related hospitalization. In contrast to our initial hypothesis, recent immigrants were less likely to be hospitalized in the era of modern cART relative to the reference population of PLWH in Ontario.

Our findings of decreasing rates of hospitalization among PLWH in the era of modern cART are similar to previous studies which have analyzed these trends in other regions. In addition, our work corroborates previous investigations highlighting inequity in hospitalization rates among certain groups, most notably, women. However, unlike other settings, our study was conducted within a context of universal coverage for all medically necessary physician, laboratory and inpatient services. Consequently, varying rates of hospitalization according to
gender, SES or immigration status should not be confounded by health insurance status, thereby implying a role for other biological, social or structural factors in contributing to these disparities. While the underlying basis of the observed differences cannot be discerned directly from our administrative databases, several explanations are possible. With respect to women living with HIV, a comprehensive body of literature exists describing various barriers impeding access to regular HIV-related care, including lack of transportation, depression, a history of physical and/or sexual abuse and the responsibility of caring for children and other family members who may be living with the virus. In addition, compared with men, women living with HIV have been noted to be more likely to delay initiating cART and less likely overall to begin treatment. Furthermore, several antiretroviral toxicities are noted to occur at greater frequency among women relative to men, including severe hypersensitivity reactions and lipodystrophy. As a result, women may be more likely to discontinue cART when compared with men. While individuals living in low income neighborhoods undoubtedly share some of the obstacles to care faced by women, other structurally mediated inequities are important determinants of health among these patients. Specifically, instability with respect to housing status and food security have been both documented to undermine adherence to antiretroviral therapy and contribute to poor outcomes among PLWH. Furthermore, despite the availability of various programs intended to mitigate the expense of cART for PLWH in Ontario who lack alternative sources of drug coverage, individuals who do not qualify for provincially-funded social assistance must assume a share of the cost of their treatment in the form of a co-payment that may be prohibitive when evaluated against competing demands for food and housing. Finally, reduced hospitalization rates among recent immigrants may be partially attributable to a health immigrant effect and/or policy changes in 2002 mandating HIV-
antibody testing of all prospective applicants to Canada, thereby prompting these patients to seek care.

Several strengths and limitations of our work merit emphasis. First, our study is truly population-based in nature, and therefore representative of all HIV-infected patients receiving care in the province of Ontario over the sixteen year study period. In addition, because we used administrative data, we were able to evaluate temporal trends and disparities in hospitalization rates among PLWH while considering variation in place of residence, outpatient health care utilization and extent of co-morbidity, important covariates that have not been traditionally considered in the study of this phenomenon. Nonetheless, our administrative databases are limited by their lack of clinical information, thereby precluding us from examining the role of variables such as stage of illness and adherence to cART in accounting for the observed disparities. However, this limitation is common among studies using administrative data for the conduct of health services research. Furthermore, because our administrative databases lack individual level measures of income, we used neighborhood income as a proxy for patient SES. However, this approach has been previously validated as a measure of household income and social deprivation. In addition, residential neighborhood may exert effects on health and outcomes that are independent of those ascribed to individual income. Finally, the potential for misclassification is always a consideration when using administrative data for health services research. To address this concern, we used a validated algorithm with excellent test characteristics for discriminating between HIV-infected and non-infected individuals to assemble our cohort of PLWH. Although the use of date of enrolment in OHIP as a surrogate for recency of immigration has not been validated and may be obfuscated by inter-provincial
migration of Canadian citizens, any misclassification of immigration status would have likely attenuated our findings. To our knowledge, this is the first population-based study using a validated case-finding algorithm to examine hospitalization trends in PLWH.

In summary, despite universal access to health care, we observed significant disparities in the rates of hospitalization among certain groups of PLWH living in Ontario. Our findings have important implications for researchers, clinicians and policy makers involved in the provision of HIV-related care. As HIV-related hospitalizations are largely preventable by the receipt of cART, these admissions should be considered indicators of failure to access appropriate medical care in the outpatient setting. In addition, persistent differences in rates of total hospitalization among specific groups of PLWH imply that gaps may exist within the existing complement of community-based health and social services that render the most marginalized HIV-infected patients vulnerable to poor health outcomes. Continued collaborations between the community of PLWH, researchers and policy makers will be essential to generate the qualitative and quantitative data required to elicit and address the social and structural factors that modify access to care among PLWH, and which may ultimately lead to greater parity in the quality of care received by all HIV-infected individuals.

3.6 Conflicts of Interest and Financial Disclosure

During the past three years, Tony Antoniou has received unrestricted research grants from Merck and Pfizer for different studies and Mona Loutfy from Abbott Laboratories, Merck Frosst Canada Ltd, Pfizer, and ViiV Healthcare. All other authors declare (1) no support from any company for the submitted work; (2) no relationships with any companies that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children
have no financial relationships that may be relevant to the submitted work; and (4) no non-financial interests that may be relevant to the submitted work.

3.7 Funding/Support

This project was supported by the Institute for Clinical Evaluative Sciences (ICES), which is funded by an annual grant from the Ontario Ministry of Health and Long-Term Care (MOHLTC). The sponsors had no role in the design and conduct of the study; in the collection, analysis, and interpretation of the data; or in the preparation, review, or approval of the manuscript. The opinions, results and conclusions reported in this paper are those of the authors and are independent from the funding source. No endorsement by ICES or the Ontario is intended or should be inferred.

Tony Antoniou is supported by a fellowship from the Primary Health Care System Program and a post-doctoral fellowship from the Ontario HIV Treatment Network. Carol Strike and Mona Loutfy are the recipients of salary support from the Ontario HIV Treatment Network and the Canadian Institutes for Health Research, respectively.

3.8 Acknowledgements

We thank Dr. Rahim Moineddin for his advice regarding the statistical analysis.
Table 3.1: Characteristics of participants by years of follow-up (2002 to 2008)

<table>
<thead>
<tr>
<th>Variables (%)</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n = 10,850)</td>
<td>(n = 11,439)</td>
<td>(n = 12,072)</td>
<td>(n = 12,702)</td>
<td>(n = 13,319)</td>
<td>(n = 13,893)</td>
<td>(n = 14,516)</td>
</tr>
</tbody>
</table>

Age (years)

18 to 35       | 2,973 (27.4%) | 2,854 (24.9%) | 2,788 (23.1%) | 2,763 (21.8%) | 2,771 (20.8%) | 2,713 (19.5%) | 2,714 (18.7%) |
36 to 50       | 6,161 (56.8%) | 6,618 (57.9%) | 7,068 (58.5%) | 7,424 (58.4%) | 7,697 (57.8%) | 7,953 (57.2%) | 8,150 (56.1%) |
51 to 66       | 1,513 (13.9%) | 1,732 (15.1%) | 1,954 (16.2%) | 2,220 (17.5%) | 2,512 (18.9%) | 2,829 (20.4%) | 3,178 (21.9%) |
66+            | 203 (1.9%)    | 235 (2.1%)    | 262 (2.2%)    | 295 (2.3%)    | 339 (2.5%)    | 398 (2.9%)    | 474 (3.3%)    |

Sex

Female         | 1,781 (16.4%) | 1,961 (17.1%) | 2,160 (17.9%) | 2,340 (18.4%) | 2,506 (18.8%) | 2,674 (19.2%) | 2,824 (19.5%) |
Male           | 9,069 (83.6%) | 9,478 (82.9%) | 9,912 (82.1%) | 10,362 (81.6%)| 10,813 (81.2%)| 11,219 (80.8%)| 11,692 (80.5%)|

Socioeconomic Status

Low            | 5,877 (54.2%) | 6,196 (54.2%) | 6,353 (52.6%) | 6,706 (52.8%) | 7,075 (53.1%) | 7,340 (52.8%) | 7,661 (52.8%) |
High          | 4,973 (45.8%) | 5,243 (45.8%) | 5,719 (47.4%) | 5,996 (47.2%) | 6,244 (46.9%) | 6,553 (47.2%) | 6,855 (47.2%) |
<table>
<thead>
<tr>
<th>Variables (%)</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n = 10,850)</td>
<td>(n = 11,439)</td>
<td>(n = 12,072)</td>
<td>(n = 12,702)</td>
<td>(n = 13,319)</td>
<td>(n = 13,893)</td>
<td>(n = 14,516)</td>
</tr>
<tr>
<td>Recent immigrant</td>
<td>556 (5.1%)</td>
<td>627 (5.5%)</td>
<td>705 (5.8%)</td>
<td>793 (6.2%)</td>
<td>860 (6.5%)</td>
<td>878 (6.3%)</td>
<td>874 (6.0%)</td>
</tr>
<tr>
<td>Urban residence</td>
<td>10,401 (95.9%)</td>
<td>10,970 (95.9%)</td>
<td>11,594 (96.0%)</td>
<td>12,194 (96.0%)</td>
<td>12,808 (96.2%)</td>
<td>13,337 (96.0%)</td>
<td>13,934 (96.0%)</td>
</tr>
<tr>
<td>No. outpatient visits</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 to 2</td>
<td>3,940 (36.3%)</td>
<td>4,208 (36.8%)</td>
<td>4,471 (37.0%)</td>
<td>4,500 (35.4%)</td>
<td>4,856 (36.5%)</td>
<td>5,255 (37.8%)</td>
<td>5,801 (40.0%)</td>
</tr>
<tr>
<td>3 to 6</td>
<td>2,854 (26.3%)</td>
<td>3,065 (26.8%)</td>
<td>3,301 (27.3%)</td>
<td>3,414 (26.9%)</td>
<td>3,642 (27.3%)</td>
<td>3,994 (28.7%)</td>
<td>4,189 (28.8%)</td>
</tr>
<tr>
<td>7 to 10</td>
<td>1,676 (15.4%)</td>
<td>1,783 (15.6%)</td>
<td>1,908 (15.8%)</td>
<td>2,146 (16.9%)</td>
<td>2,166 (16.3%)</td>
<td>2,224 (16.0%)</td>
<td>2,210 (15.2%)</td>
</tr>
<tr>
<td>11+</td>
<td>2,380 (21.9%)</td>
<td>2,383 (20.8%)</td>
<td>2,392 (19.8%)</td>
<td>2,642 (20.8%)</td>
<td>2,655 (19.9%)</td>
<td>2,420 (17.4%)</td>
<td>2,316 (16.0%)</td>
</tr>
</tbody>
</table>
Table 3.2: Multivariable regression for hospitalization rates

<table>
<thead>
<tr>
<th>Variables</th>
<th>Total Hospitalization Rates</th>
<th>HIV-related Hospitalization Rates</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adjusted Relative Rate (95% Confidence Interval)*</td>
<td>Adjusted Relative Rate (95% Confidence Interval)*</td>
</tr>
<tr>
<td><strong>Year</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2002 (reference)</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>2003</td>
<td>0.89 (0.81 to 0.97)</td>
<td>0.83 (0.70 to 0.98)</td>
</tr>
<tr>
<td>2004</td>
<td>0.93 (0.85 to 1.01)</td>
<td>0.88 (0.74 to 1.05)</td>
</tr>
<tr>
<td>2005</td>
<td>0.92 (0.84 to 1.01)</td>
<td>1.09 (0.93 to 1.27)</td>
</tr>
<tr>
<td>2006</td>
<td>0.82 (0.74 to 0.90)</td>
<td>1.00 (0.84 to 1.18)</td>
</tr>
<tr>
<td>2007</td>
<td>0.84 (0.76 to 0.93)</td>
<td>0.93 (0.78 to 1.17)</td>
</tr>
<tr>
<td>2008</td>
<td>0.88 (0.79 to 0.97)</td>
<td>0.98 (0.83 to 1.17)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male (reference)</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Female</td>
<td>1.15 (1.05 to 1.27)</td>
<td>0.96 (0.82 to 1.12)</td>
</tr>
<tr>
<td><strong>Socioeconomic Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High (reference)</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Low†</td>
<td>1.21 (1.14 to 1.29)</td>
<td>1.30 (1.17 to 1.45)</td>
</tr>
<tr>
<td>Variables</td>
<td>Total Hospitalization Rates</td>
<td>HIV-related Hospitalization Rates</td>
</tr>
<tr>
<td>-------------------</td>
<td>-----------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>Recent Immigrant</td>
<td>0.70 (0.61 to 0.80)</td>
<td>0.77 (0.61 to 0.96)</td>
</tr>
</tbody>
</table>

*Models also adjusted for age, years HIV-positive, number of outpatient visits per annum, geographic residence (urban vs. rural) and level of co-morbidity using the Johns Hopkins Adjusted Clinical Group case-mix assignment software. Because number of outpatient visits may be on the causal pathway to the outcome, we repeated our analyses without this variable and attained similar estimates.

† Patients in lowest two lowest quintile groups.
**Figure Legends**

Figure 3.1: Hospitalization Rates among Persons Living with HIV in Ontario, 1992 -2008, stratified by sex

Figure 3.2: Hospitalization Rates among Persons Living with HIV in Ontario, 1992-2008, stratified by socioeconomic status (SES)
Chapter 4: “Waiting at the dinner table for scraps”: a qualitative study of the help-seeking experiences of heterosexual men living with human immunodeficiency virus infection

Published in manuscript form:

4.1 Abstract

Objectives
To characterize the help seeking experiences of heterosexual men living with human immunodeficiency virus (HIV) infection and explain these experiences in relation to the broader social relations and discourses in which they are embedded.

Design
Qualitative study using focus groups and theoretically informed constructivist grounded theory.

Setting
With one exception, focus groups were conducted in the offices of community-based AIDS service organizations across Ontario, Canada.

Participants
40 HIV-infected heterosexual men aged 18 years or older.

Results
Heterosexual men living with HIV perceive themselves to be relegated to the margins of a health care and social service field that was developed historically within a context that privileges the priorities of gay men and heterosexual women living with the virus. Specifically, gay men are better positioned than heterosexual men when vying for the services and recognition of AIDS service organizations due to their social capital within these agencies, thereby benefiting by virtue of their membership with the group perceived to control the decision-making apparatuses
when resource allocation and program development are at stake. Relative to women, heterosexual men are poorly positioned due to their negative symbolic capital, derived from being perceived as the ‘guilty’ parties in the context of heterosexual HIV transmission. As a result, the material and support needs of women have been prioritized, while those of heterosexual men living with HIV remain largely unaddressed.

Conclusions

Heterosexual men living with HIV are operating within a health and social service field that has not kept pace with their increased representation among the population of persons living with the virus. Researchers, clinicians and policy makers should strive to integrate heterosexual men living with HIV in decision making and community-based research initiatives that build capacity among this group while simultaneously generating a research and policy agenda specific to the concerns of this growing demographic.
4.2 Introduction

Globally, approximately 34 million people are estimated to be living with the human immunodeficiency virus (HIV). Although unprotected sex between men remains the predominant mode of transmission in most of the developed countries of North America and Western Europe, the number of new infections attributable to heterosexual transmission has been steadily increasing in these jurisdictions over time. However, despite the increasing importance of heterosexual transmission in sustaining the HIV epidemic in developed countries, very little empirical research exists describing the health and help-seeking experiences of heterosexual men living with the illness. This gap in the literature is important for several reasons. First, there has been a marked increase in the prevalence of HIV infection among men infected through heterosexual transmission, such that approximately 18.8% of patients accessing HIV-related care in the United Kingdom in 2009 were men infected via heterosexual sex. Similarly, though this group accounted for fewer than 5% of all cases of HIV prior to 1990 in the province of Ontario, Canada, heterosexually infected men represented 13.8% of HIV diagnoses among men in 2008. These trends are likely to continue in parallel with the increasing numbers of HIV-infected individuals immigrating to Canada and the United Kingdom from countries with a high prevalence of infection, the majority of whom acquire the virus via heterosexual transmission. Furthermore, the profound impact of combination antiretroviral therapy on the prognosis of HIV infection has resulted in a substantial decrease in disease-related mortality in Western countries. As a result of this improved outlook, the need for health care and support services for HIV-infected heterosexual men is likely to increase. Finally, because currently funded HIV-related health and support programs were rooted largely in the political mobilization of gay and lesbian communities in the early years of the epidemic,
and informed further by subsequent socio-political action on the part of women living with HIV, the existing array of services may be ill equipped to provide care and support for the increasing numbers of heterosexual men living with the virus. However, empirical research examining the experiences of heterosexual men living with HIV when navigating the available complement of HIV-related treatment and support services is presently lacking. These data have important implications for clinicians, policy makers and researchers who work with HIV-infected heterosexual men and who are involved in the planning, coordination and financing of HIV-related services.

In order to address this large gap in contemporary HIV knowledge and to inform continued policy on how best to provide care for the evolving and diverse community of people living with HIV, we undertook a qualitative study which sought to characterize the help seeking experiences of heterosexual men living with HIV, and explain these experiences in relation to broader social relations and discourses. That is, we wanted to understand what it is like to be a heterosexual man living with HIV trying to access help, and theorize about the basis of any challenges associated with this process.

4.3 Methods

4.3.1 Theoretical Framework

The theoretical framework used to inform the analysis of our data drew upon the commensurable perspectives of Erving Goffman’s pioneering work on stigma and identity management and Pierre Bourdieu’s conceptual framework of ‘structural constructivism’ (see e-appendix). Structural constructivism provides an analytic framework and conceptual arsenal that relates the subjective accounts and experiences of participants with aspects of the
social environment (i.e. social relations) and discourses in which help is provided. By discourse, we refer to language, images, systems of thought, and symbols that represent and/or construct individuals and aspects of their social world.\textsuperscript{179} From this perspective, we were interested in how participants drew upon and/or resisted particular discourses when characterizing their experiences.

4.3.2 Data generation – Sampling and Recruitment

We conducted eight focus groups (4 – 6 participants per group) with heterosexual men living with HIV who were sampled with the assistance of community-based AIDS service organizations (ASOs) in Ontario, Canada. We used non-probabilistic, purposive sampling to recruit self-identified heterosexual men living with HIV who were over the age of 18 years and could speak to the experience of seeking HIV-related care at an ASO or within the broader health care system.\textsuperscript{180,181} We set a minimum quota of two focus groups comprised exclusively of men who had immigrated to Canada from Africa or the Caribbean, and altered our sampling approach mid-way through the project to focus on recruitment of men living in small urban centers lacking a strongly visible gay and lesbian community to identify concepts and experiences that might be in exception to those generated by the analysis undertaken to that point. Our sampling approach was developed to seek variation in social background and context, rather than generalizability to the entire population of heterosexual men living with HIV.\textsuperscript{180,181}

We used focus groups to generate the group interaction and raw accounts that would undergo subsequent analysis and interpretation.\textsuperscript{129} With the exception of a single focus group held at a
teaching hospital in downtown Toronto, focus groups were conducted in the offices of the ASOs. We developed our focus group guide in collaboration with a community advisory board of five heterosexual men living with HIV. Discussion among the participants was facilitated by a male researcher (TA) utilizing open-ended questions regarding the availability, accessibility and quality of existing services for heterosexual men living with HIV. However, most of the conversation produced in the focus groups was instigated by the dynamic interaction between the participants. As part of the focus group, we asked all participants to complete a brief sociodemographic questionnaire. Each focus group lasted approximately two hours, and was audiotaped and transcribed for subsequent analysis.

4.3.3 Data Analysis Procedures

We integrated aspects of constructionist grounded theory with our theoretical frameworks to analyze the focus group transcripts, and conducted our analyses concurrently with data generation to both pursue concepts being developed and adapt our sampling approach to seek out cases and experiences that could deviate from emerging patterns.\textsuperscript{125,126}

For each focus group, one of us (TA) reviewed the written transcripts while listening to the audio recording to supplement the transcripts with notes regarding tone, silences, and group interaction. Following this initial pass at the data, we used line-by-line coding and memo-writing to analyze the transcripts, moving iteratively between the data and our theoretical framework. Initial codes were derived both from the words of the participants (e.g. “gay disease”, “discrimination”) and from interpretations of data segments as being representative of socially constructed phenomena or identities (e.g. ‘stigma’). For each section of coded data, we
produced a memo that was cross-referenced by transcript, page and line numbers. Memos were written to elaborate on line-by-line coding and interrogate the participants’ accounts and group interaction with theoretically driven questions such as “How are participants’ identities being constructed?”, “How is the particular help-seeking environment discussed being characterized?”, “What is this segment an instance of?”, “What discourses are reproduced and/or resisted?”, “What circumstances produce this action and/or interaction?”, “Why this pattern of narrative?” and “What are the participants doing in this segment?”. Using word processing software, similarly coded data were extracted from the entire transcript corpus and re-assembled into data clusters that were assigned analytic labels representing the varied dimensions of the help seeking experiences of heterosexual men living with HIV and the different manners in which this phenomenon was understood by the participants. We repeated the process of coding and memo-writing, cycling iteratively between the focus group data and theoretical frameworks until we had developed well theorized concepts that related the accounts of the participants with the objective social relations and discourses in which they were embedded. In this manner, we produced an analysis that was theoretically informed but always grounded in and tethered to the data at hand.

4.3.4 Ethical Considerations

We obtained written informed consent from all participants. Because of the potentially sensitive nature of the study, we verbally reinforced the importance of respecting the privacy of co-participants once outside the confines of the focus group setting. We obtained approval for the study from the Ethics Review Committee of the University of Toronto and the Research Ethics Board of Women’s College Hospital.
4.4 Results

4.4.1 Characteristics of the participants

The demographic characteristics of the participants are summarized in Table 4.1.

4.4.2 Concepts and Findings

Spatially acquired stigma: the discrediting potential of help-seeking

For most participants, the perception that HIV is an infection harboured within the ‘tainted’ bodies of gay men, injection drug users and sex trade workers is reproduced and reinforced among their own social networks, and in the broader heteronormative social sphere. Because of this potential association with ‘problematic’ identities, seeking HIV-related health care or support services becomes potentially discrediting for heterosexual men living with HIV. That is, the stigma associated with the problematic imputations that come with being HIV-positive becomes grafted upon the clinics and ASOs that provide care to individuals living with the virus. Therefore, participants are wary of being seen engaging with these sites for fear that it may inadvertently undermine their efforts at controlling information pertaining to their illness among their own social networks.

I: Do you think that could deter some people though, from coming in, like some infected guys from coming in?

P1: I hear a lot, you know, for sure, definitely. Yeah, yeah. “I’m not going there.”

P2: This is one of the first groups I’ve ever been to.

P3: The same with thing with the hospital, like a doctor. Like, if-
Help-seeking at HIV clinics or ASOs therefore becomes a threat to the ability to balance disclosure and manage a complex discreditable identity among heterosexual men living with HIV. However, the discrediting potential of help-seeking for participants extends beyond the subversion of disclosure containment strategies. In addition, participants are fearful of potentially calamitous consequences associated with being seen entering or exiting sites that are constructed in their social circles as “AIDS buildings”. Specifically, the participants were concerned that being seen engaging with an agency or clinic known to provide HIV-related care could prove deleterious to their livelihoods or jeopardize relationships with family and friends, a reality endorsed by some participants in the study. Furthermore, the potential for transmitting this spatially acquired stigma to children was of particular concern for participants who were fathers:

P: I, um, I won’t go anywhere with a sign that says ‘HIV’ or ‘positive’. I have kids, so I worry about parents of my kids friends, who now won't want them to play with my kids because they, because I have HIV “I don't want you to hang around, cause his dad -” sort of thing.

In this manner, spatially acquired stigma becomes potentially transferable to children through lineage in a manner akin to the tribal stigmas of race, nation and religion described by Erving Goffman. These concerns were especially salient for men of African and Caribbean origin, for
whom the stigmatizing consequences of seeking help at community organizations which cater to their particular racial demographic were potentially transferable to their families both at home and abroad.

*Spatial marginalization: mismatched and poorly positioned at ASOs*

Because of the centrality of ASOs in the HIV-related help-seeking arena, it was not surprising that a great deal of talk generated in the focus groups related to experiences accessing care from these agencies. The gaps in health care for which heterosexual men living with HIV most commonly sought the assistance of an ASO were in the realm of counselling and social support, although these sites were also occasionally utilized for accessing HIV-related care provided by physicians and nurses working on-site. However, help-seeking at an ASO occurs within a network of social relations and discourses that converge to produce a perception of being mismatched and marginalized in these agencies. Specifically, participants described being out of sorts or ill at ease in the social space of an ASO, which is dominated mostly by gay men in terms of clientele, staff and decision makers, and frequently conflated these agencies with the ‘gay community’ at large, seeing the former as a microcosm of the latter:

P1: Support exactly what he's saying. Even the AIDS organizations that we have in Toronto, go to the offices, I don't want to mention names, but go to the offices. All the people, the staff, everybody that you get there, they're gay.

P2: Yeah, there are gay communities.

P3: It is the gay community (note: underline added to denote participant emphasis)
The perception of ASOs as an extension of the gay community is most palpable among participants living in large urban centres, where the identity of these agencies remains closely connected with the history of political activism on the part of local gay and lesbian communities that marked the early years of the epidemic.

P1: Some of us aren't going anywhere. We go to the same, the organization.

P2: The same gay organizations.

P3: Yeah, we go to the same organizations, but you can't blame them, they created this stuff. They were the ones in the crisis, you know? It's like, they were the ones who needed it and they fought for it. And now we're looking to them for helping right?

When viewed in concert with other data (e.g. “this space is for gay people”) and filtered through a constructionist lens, heterosexual men are reconstituting and reproducing ASOs as ‘gay terrain’, or spaces in which they do not “really fit in” or belong, and are therefore not comfortable availing themselves of the various counselling or supportive services provided by the predominantly gay male staff. The men describe this perception of ASOs as ‘gay terrain’ as being prevalent in the heteronormative social world in which they usually reside, and sustained by durable perceptions of HIV as a ‘gay disease’ within their social circles.

P1: It was just, you’re just labelled 'gay'. You know, if you tell anybody you come here, they just think, for sure, you're a hundred percent gay -

P2: Yeah, must be gay.

P3: Yeah.

P2: -because you gotta be.
P1: Yeah, a hundred percent.

P2: You just gotta be. You know?

P3: Yeah. How else could you have gotten it?

Importantly, the men believe that ASOs are reinforcing this association by developing HIV associated programs and educational materials which target principally the gay community.

P: So the public out there, they even, now they have all the gay men club, gay men this, gay men club, even the ASO also think that, ah, the disease is for gay men. So they have programs for gay men, they don't, they don't, they don't think outside of the box, ah, the disease is no more a gay man disease.

As a result of the construction and perception of ASOs as ‘gay terrain’, a lack of congruence develops between the distinctive set of heteronormative ‘masculine’ dispositions acquired and internalized by the focus group participants throughout their personal histories and the social environment they must navigate when seeking HIV-related help. In effect, there is a mismatch between the social constitution of heterosexual men and the social space of an ASO. In response to this mismatch, participants would frequently draw upon discourses of a hegemonic masculinity to create a social context within the focus group that is more closely aligned with their heterosexual disposition. For example, in the following segment, the men ‘do’ gender by transforming the ambivalence of P1 at receiving a massage from a “gay guy” into an opportunity to re-assert a group masculinity by convivially invoking gendered and sexualized stereotypes of the ‘female masseuse’:
P1: Like for myself, I haven't actually used any of those services. I've looked, and I thought it would be nice to go get a massage, and I've said “Okay, except, this would be awfully weird, to go, you know, have a massage by a gay guy and then be all -” And I was looking, don't bother, right?
P2: You're assuming that it's a male…
P1: Yeah, ah, or, it's just that, ah, I just thought, okay, it's too weird…
P2: Cause there is women that do it too – just saying….
P4: Oh yeah, that’s nice…

(laughter)

In effect, the men utilize language and imagery to re-construct the focus group as a ‘masculine space’, thereby demarcating, albeit transiently, a heterosexual zone within the gay terrain of the ASO that more closely resembles a social milieu with which they are accustomed and at ease. These actions are enacted both in the local context of the focus group (and perhaps ‘performed’ in reaction to the presence of the male researcher) and mirrored by attempts to claim designated space and time within ASOs that could be allotted for peer support groups and social functions that provide opportunities for connecting with other heterosexual men living with the virus, much in the same manner that gay men and heterosexual women are able to secure these same opportunities for social connection within these organizations. However, efforts to satisfactorily carve out such space and identity within an ASO are undermined through spatial intrusions by heterosexual women and gay men during structured activities that are designated for heterosexual men only, incursions that they feel would be met with repercussions if repeated by them:
P: But if you try to walk in a women's group, or a gay men's group, oh, you're gonna hear about it. But us, it's like, ach, they're just six straight guys, don't worry about them.

Participants believed that, short of receiving government funding for an ASO that caters to the concerns of heterosexual men and their families, their best chance for securing a share of resources allotted to existing agencies is contingent on improving their position within the social hierarchy of these organizations. However, the mismatch between the identity of a heterosexual man and the social space of an ASO also has consequences when these men attempt to improve their social and political positions within these organizations. For example, concerted attempts by heterosexual men to increase their group visibility and affect programmatic change within an ASO through volunteering are seen as being largely in vain, given their perceived lack of access to the decision making apparatuses controlled by the dominant social network of gay male staff within these organizations:

P: Instead of having one particular, ah, ah, status of people dominating the entire services, controlling what the policy. And therefore, they have very little for us, without us having an impact.

A similar problem ensues when seeking paid positions within an ASO. Although heterosexual men do not describe overt discrimination based on questions about sexual orientation when applying for jobs at an ASO, social disadvantage is created during this process through the use of interview questions eliciting the degree of comfort with doing outreach work at bathhouses or counselling gay male clients about safer sexual practices. Thus, heterosexual men see themselves as tacitly lacking in the social qualifications required to compete for work at an ASO,
even if all other criteria in terms of educational background or skill are met. In the segment that follows, the disadvantage becomes embodied, in that gay men are perceived to have acquired a corporeal knowledge that provides a practical edge in the social space of an ASO when materialized as body language:

\[ P: \text{We got the same NGO, but the environment, even people, the hiring committee are all} \]
\[ \text{gay men. So they know their partner; they know the body language of a gay man, all} \]
\[ \text{these things. They serve as an indicator that.} \]

Without the social connections and qualifications considered essential for improving their position within ASOs, heterosexual men perceive themselves as being relatively powerless when attempting to gain any traction establishing social support programs for their respective demographic. As a result, these agencies can become sites of contention and frustration for heterosexual men living with HIV.

\[ P1: \text{And we wanted something here.} \]
\[ P2: \text{I think it was a fight for funding.} \]
\[ P1: \text{Yeah. But we just, like, he says, we feel like we're the minority. And now we're like} \]
\[ \text{the gay men back in the early seventies, that we're fighting for whatever we can get.} \]
\[ P3: \text{Yeah.} \]
\[ P1: \text{If we get it, we get it. If not, well, we're, there's not enough of us to fight.} \]

“\text{I'm in a safe environment now}”: the modifying effect of social context
A less tense relationship between ASOs and heterosexual men living with HIV is apparent in the narratives of participants living in cities where these organizations are less closely identified with gay political activism. In these smaller urban centres, the identity of the ASO itself is managed in a manner that disentangles the agency from both HIV and the local gay and lesbian community. For men living in these cities, ASOs are less likely to be perceived as ‘gay terrain’ and are instead viewed as sites of asylum from a ‘mainstream’ social world in which the consequences of disclosure and its resultant association with problematic identities could be devastating. Therefore, while help-seeking can still be discrediting for these men if they are seen using the services of an ASO, these agencies were less often characterized as sites of contention by participants living in these cities and were instead seen as safe spaces in which refuge could be found from a world in which they risk being judged and socially ‘othered’.

P: I came in here and nobody said they have HIV. Nobody asked me if I had HIV. Somehow they are, I think I may have went through the HIV thing one time, to file or whatever. But after that, everything was like, 'Okay, I'm in a safe environment now. And these people then are going to try to look after me.' So I felt comforted there.

However, participants in these cities still lamented on the lack of positions and services for heterosexual men living with HIV within ASOs. Like their counterparts from larger urban centres, participants in smaller cities felt that the addition of peer support and a heterosexual male presence in the form of counselors, support workers and prevention workers could augment the resources available to their demographic and simultaneously challenge the prevailing notion that HIV is a ‘gay disease’ among the mainstream social world they feel forced to hide from.
P1: But you know, we need more straight guys, filling some seats, offering the care, because it's a lot easier to talk to somebody, (laugh) who's at the same orientation. Like, it's just easier to communicate. (laugh) You know what I mean?
P2: I think it's a good idea to see HIV, like in general.
P3: Yeah, it's not a gay disease. It's an everybody disease

“Women are the heterosexual face of HIV”: Lacking symbolic appeal when seeking help

Heterosexual men characterize HIV-related health and social support services as having been ‘feminized’, such that clinics and agencies privilege the needs of heterosexual women living with the virus. That is, women are perceived to receive greater priority than men in areas such as social support, housing, financial assistance and reproductive and sexual health. This disadvantage manifests itself both in ASOs and within the health care system, where specialized services for women living with HIV are seen to have proliferated.

P: We've got the Women's Hospital, the women’s clinics, everything here is about ah, women, women all the time. And I think it's now time that, ah, really we men are also address the ah, I feel honoured that I'm participating in this group. Thank you.

However, in contrast to their poor positioning relative to gay men, it is not lack of membership in a dominant group that fuels disadvantage in the help-seeking arena, but rather, contextual transformation of the identity of heterosexual men into the ‘problem’ of HIV infection in women. That is, heterosexual men have taken up, and in some cases, internalized the discourse of the ‘vulnerable’ woman in the field of HIV help-seeking. The vulnerability discourse, or
paradigm, recognizes the role of gender inequality and structural disadvantage (e.g. poverty, violence) in driving the risk of HIV acquisition among heterosexual women, particularly in the developing countries of the world. While this discourse has been instrumental in advancing the social and medical concerns of women living with HIV, the images and language used to construct the ‘vulnerable’ woman have positioned heterosexual men as categorically responsible for HIV infection in women.

P1: It's equated with, ah, women. So like there was recently, I saw this list, of like, priorities for some, it was some policy research thing. And, they listed all the different areas of priority and all the different groups. So, um the you know, when it comes to sort of the category of heterosexual, the only thing that was represented was just women. But you see gay men, MSM, ah, - but women are, women are the heterosexual face of HIV in some way.

P2: Yeah.

P3: Mmm-hmm.

P4: Yeah.

I: How do you think this has happened, like how has that -

P3: Because they are, they are classified and they are always the victims. And we are the ones to blame. We have all brought it home.

It was fairly common for heterosexual men to take up a discourse where women were “victims” and they were constructed as “predators” or “victimizers” in the context of the continued heterosexual transmission of HIV. Thus, while both heterosexual men and women may be stigmatized by HIV-infection, heterosexual men also become morally ostracized through their
discursively constructed identity of being “guilty” of creating HIV-positive “victims” for whom sympathy and protection are warranted. Although some men in the focus groups resisted this identity for themselves, the construction of the heterosexual female “victim” was nonetheless largely accepted as pervasive in the HIV service field by the men, and interpreted by them as the underlying reason for which women have become “the heterosexual face of HIV”. Because of the negative image imparted to heterosexual men by this discourse, the participants perceive themselves to be poorly positioned relative to women when seeking help in an environment that affords the latter group greater symbolic appeal than the former. Heterosexual men therefore become aware of and describe their sense of place relative to women.

P: But I'm saying men are last. And when they say men last, they don't mean all men. They mean heterosexual men are last. You know what I mean, they don't look at men, heterosexual men as men with families, and men that, they're responsible. We're looked as men that, that we carry the worst of everything.

Consequently, because of their greater symbolic appeal, women are perceived by men to receive greater priority by funding bodies, community-based researchers and providers when health and social support services for heterosexuals living with HIV are developed. That is, for these participants, their material and support needs as heterosexual men who are also fathers, husbands and, in many cases, socially isolated, remain largely unaddressed while similar concerns for women become prioritized by HIV researchers, clinicians and policy makers.
I: But why do you think there are more services for straight women than men?

P1: It's more accept, it's accepted a lot more by mainstream community, a HIV positive woman, [I: Okay] than, than an HIV positive man.

P2: Yeah, it’s like, it’s kind of like you don’t help the guilty, you, you help the, victim.

*Capital and Strategic Practices*

Considered as a whole, heterosexual men describe a help-seeking field in which their composition and volume of capital positions them poorly in relation to gay men and heterosexual women living with HIV. Specifically, gay men are better positioned than heterosexual men when vying for the resources and recognition of an ASO due to their social capital within the space, thereby benefiting by virtue of their membership with the group that occupies the decision-making positions within these agencies. Relative to women, heterosexual men are poorly positioned due to their negative symbolic capital, derived from being produced as the guilty parties in the context of heterosexual HIV transmission. The net effect of their poor configuration of capital relative to both heterosexual women and gay men is that heterosexual men perceive themselves to be an afterthought when funding for health services, social support or ASO programs is at stake. As a result, these men resign themselves to accepting whatever they can get in the way of services after the priorities of gay men and heterosexual women are addressed. Lacking in the social capital of gay men and endowed with negative symbolic capital in relation to heterosexual women, one participant summarized the lot of heterosexual men seeking help as follows:
P: This might be a little extreme, but I feel like the dog waiting at the dinner table for scraps, cause that's all we're getting.

In response to their poor positioning in the help-seeking field, participants pursued several strategies that can be interpreted as efforts to accumulate the capital required for improving their position. For instance, in an effort to acquire the social capital necessary to improve their positions within ASOs, heterosexual men volunteer within these organizations to increase their visibility as a group and gain recognition from the predominantly gay male staff perceived to control the decision-making apparatuses within these agencies.

P1: We all volunteer, almost every straight guy that's here, volunteers here. That says a lot.

P2: But that's the way we can also get attention, is by being here and doing stuff like that. That's how we get recognized by the staff.

In contrast to gaining social capital through volunteering, other men seek to acquire the embodied capital of gay men. That is, some participants attempt to emulate corporeal traits and gestures perceived to be hallmarks of the body language of gay men, thereby trying to gain “membership in the club”.

P: It's, it's smart. You're like, like, when some benefit will come, say for gay men, and they ask “Okay. Are you gay?” Myself, sometimes, I, yeah, I do sometimes lie. Because like, I got dozens of gay friends, I go to the gay village; I watch the way they talk and move. So when I will go somewhere, and they say “Oh, this service is for gay men”, I can
act gay, (laughter), because I have no option eh? If I don't lie, I won't benefit from that opportunity there.

These men characterize this form of identity management as a survival strategy within the social space of an ASO, as “like takes care of like”. Strategies directed at countering negative perceptions about the implied culpability of men in the heterosexual transmission of HIV were not apparent in the data.

4.5 Discussion

In our qualitative study, we have used the theoretical insights of Pierre Bourdieu and Erving Goffman to analyze and interpret the experiences of heterosexual men living with HIV in relation to the objective social relations and discourses in which they are produced.\textsuperscript{120,122-124} Overall, our results indicate that heterosexual men living with HIV are relegated to the margins of a health and social service field that was developed historically within a context that privileges the priorities of gay men and heterosexual women. Furthermore, without the symbolic appeal of women and the social connections of gay men, heterosexual men have neither the requisite composition nor volume of capital required to benefit fully from or improve their position within the HIV health and social service fields. The net effect of their poor positioning manifests in various ways, ranging from resignation to engagement in strategic practices aimed at maximizing their opportunities within the hierarchy of the various fields in which HIV-related care is provided.
A key concept that emerged from our analysis was the mismatch between the ‘habitus’ of heterosexual men living with HIV and the social contexts, or fields, in which HIV-related care is provided. As a set of deeply inculcated dispositions reflecting the social conditions within which they were acquired, the habitus is at once both structured by the social forces which produced it (e.g. gender, class) and structuring, in that it provides individuals with a sense of how to act and respond in certain circumstances (i.e. a ‘feel for the game’). As with other ingrained dispositions of the habitus, gender becomes embodied, materializing as gestures, talk, and other aspects of body comportment thought to be ‘natural’ and socially constructed as either ‘masculine’ or ‘feminine’, and in this context, ‘gay’ or ‘straight’. From a Bourdieusian perspective, practice, and in this case, experience, can by analyzed and understood by examining encounters between the habitus of heterosexual men living with HIV and the fields in which HIV-related help is provided. Our findings indicate that the gendered dispositions of heterosexual men living with HIV are frequently out of phase with the ‘gay terrain’ of an ASO and the increasingly feminized context of the HIV epidemic that has prioritized the needs of heterosexual women living with the virus. Because of this mismatch, heterosexual men living with HIV do not benefit fully from the existing array of services developed for other groups living with HIV and lack the capital necessary to advocate for more recognition from the clinicians, researchers and ASO staff perceived to influence decisions about funding and policy. Bourdieu uses the term ‘hysteresis’ to describe this discrepancy between an individuals’ acquired set of dispositions and a particular field. When viewed through this lens, the concepts of spatially acquired stigma, spatial marginalization and negative symbolic capital are rooted in ‘hysteresis’, or the poor congruence between a habitus acquired in a heteronormative, ‘mainstream’ social field and an HIV service field developed by and for the groups historically
affected most by the epidemic. In this manner, we believe that our research extends Bourdieu’s concept further by illustrating a ‘spatial hysteresis’, or a condition in which one field (i.e. HIV health and service field) has not kept pace with changes in another field or trends in demography.

Our study has several important implications. In keeping with the principle of Greater Involvement of Persons with HIV (GIPA), a declaration signed by 42 countries including Canada and the United Kingdom, researchers and policy makers should strive to involve and integrate heterosexual men living with HIV in decision making and community based research initiatives that build capacity among this group while simultaneously generating a research and policy agenda specific to the concerns of this growing demographic. The benefits of contributing to research and policy formulation among individuals living with HIV are well documented, and include establishing feelings of self-worth, mitigating stigma, and increasing independence and personal empowerment. We argue that the same opportunities to realize these benefits should be extended to heterosexual men living with the virus. Furthermore, ASOs should invest in the creation of peer support, educational programs and prevention initiatives that are staffed by and speak to the heterosexual community of men affected by or at risk of HIV infection. Such initiatives may begin to challenge mainstream constructions of HIV as a ‘gay disease’ and perceptions of ASOs as ‘gay terrain’. The establishment of such initiatives will also grant these men the opportunity to reproduce the camaraderie cited as a highlight of participation in the focus group by participants in the study. Frequently, these men contrasted their own isolation with the numerous structured opportunities for social engagement available for women and gay men living with HIV, and voiced their desire for similar opportunities for bonding and peer support. Additionally, it is imperative that the identity of heterosexual men living with HIV
become emancipated from the image of the HIV predator that was perhaps inadvertently created by the ‘vulnerability’ paradigm and is currently reinforced by media constructions of the HIV ‘monster’ when characterizing men who are convicted of transmitting the virus to unknowing partners.\textsuperscript{191} It is noteworthy that strategies directed at countering the problematic construction of heterosexual men in relation to women were not evident in the talk of the participants. This may reflect a difficulty in openly challenging a discursive construction that is embedded in language and imagery, and to some extent, internalized by the participants themselves. We therefore encourage providers, researchers and policy makers to acknowledge the plural identities of these men, such as fathers and husbands, when considering the support and health care needs of this group, and confront a prevailing discourse in which heterosexual men living with HIV are categorically constructed as a threat to their communities.

Several strengths and limitations of our work merit emphasis. First, our study was intra-paradigmatically congruent, in that internal consistency was maintained between our critical ontology, relativist epistemology, theoretical framework and methods of data collection and analysis. Intra-paradigmatic congruence is considered the cornerstone of designing and executing rigorous qualitative research.\textsuperscript{111,136} As with all qualitative studies, our research is not intended for statistical generalizability. However, we believe that our concepts of spatially acquired stigma, spatial marginalization and negative symbolic capital are contextually transferable, and would be applicable in other jurisdictions where the development of HIV-related services is historically linked with that of gay activism and the symbolic appeal of helping women living HIV. In addition, our concepts may be transferable to the study of other illnesses where there is a mismatch between the gendered dispositions of heterosexual men and
the fields and contexts in which help is available, such as for men living with breast cancer and fibromyalgia. Because we did not interview HIV researchers, clinicians, policy makers or ASO staff, we are unable to consider the perspectives of these stakeholders as they pertain to the HIV service arena and heterosexual men living with the disease. However, we elected to focus on the experiences of the men because this topic is unexplored and un-theorized in the current literature. To our knowledge, this is the first in-depth, critical examination of the help-seeking experiences of heterosexual men living with HIV. In addition, our sample was comprised of men who use existing HIV-related services. Our findings may therefore not be transferable to heterosexual men who are less engaged with ASOs or the health care system. Furthermore, the sampling strategy used in the study may have resulted in a greater emphasis among the participants on providing accounts arising from their encounters with social service agencies relative to the broader health care system. Finally, it is possible that some accounts and interactions between participants were influenced by the presence of the male researcher facilitating the focus groups. However, our paradigmatic and theoretical assumptions posit that all accounts are co-constructed through interaction and contingent on context. Therefore, rather than attempting to ‘control’ for the presence of the male researcher, an otherwise impossible endeavor, such interactions were incorporated in the analysis by interrogating the group interaction itself (see earlier ‘masseuse’ example). In this manner, the group dynamic and manner in which the men portray themselves becomes as integral to the analysis as their actual words.

As the epidemiology of the HIV epidemic evolves, it is imperative that health and social support services do not lag behind changes in the demographic composition of individuals living with the
virus. The strong tradition of community involvement in policy and program development is a distinctive feature of the response to the HIV epidemic in Western countries, and has been instrumental in designing a health and support field that has been appropriate for the individuals historically burdened most with the physical and symbolic weight of the illness. Our findings indicate that heterosexual men living with HIV are operating within a service arena that has not kept pace with their increased representation among the population of persons living with the virus. In keeping with principles such as GIPA, policy makers, researchers, and ASOs should endeavor to involve heterosexual men living with HIV at decision-making and policy-making levels by supporting training and capacity-building among this group. Such partnerships will represent an important step towards greater parity within the HIV service arena and the generation of a research and policy based agenda grounded within the concerns of heterosexual men living with HIV.

4.6 Conflicts of Interest and Financial Disclosure

During the past three years, Tony Antoniou has received unrestricted research grants from Glaxo-Smith-Kline Inc, Merck and Pfizer for different studies and Mona Loutfy from Abbott Laboratories, Merck Frosst Canada Ltd, Pfizer, and ViiV Healthcare. All other authors declare (1) no support from any company for the submitted work; (2) no relationships with any companies that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (4) no non-financial interests that may be relevant to the submitted work.

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4.8 Acknowledgements

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Table 4.1: Characteristics of focus group participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Focus group participants (n = 40)</th>
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</thead>
<tbody>
<tr>
<td>Median (Interquartile Range) age (years)</td>
<td>48.5 (42.0 – 55.0)</td>
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<tr>
<td>Years HIV-positive (Median, interquartile range)</td>
<td>7.5 (4.0 – 12.0)</td>
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<tr>
<td>Country/region of birth</td>
<td></td>
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<tr>
<td>Canada</td>
<td>19 (47.5%)</td>
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<tr>
<td>Africa</td>
<td>9 (22.5%)</td>
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<tr>
<td>Caribbean</td>
<td>4 (10.0%)</td>
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<td>Separated/divorced</td>
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<tr>
<td>Number of dependents</td>
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<tr>
<td>0</td>
<td>18 (45.0%)</td>
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<tr>
<td>1</td>
<td>4 (10.0%)</td>
</tr>
<tr>
<td>2</td>
<td>1 (2.5%)</td>
</tr>
<tr>
<td>3</td>
<td>5 (12.5%)</td>
</tr>
<tr>
<td>( \geq 4 )</td>
<td>6 (15.0%)</td>
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<td>Full-time</td>
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<tr>
<td>Part-time</td>
<td>6 (15.0%)</td>
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<tr>
<td>Unemployed</td>
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</tr>
<tr>
<td>Volunteer</td>
<td>1 (2.5%)</td>
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<tr>
<td>Student</td>
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<tr>
<td>Retired</td>
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<td>Social assistance</td>
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<tr>
<td>Self-employed</td>
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<tr>
<td>Incomplete</td>
<td>3 (7.5%)</td>
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<tr>
<td>Highest Level of Education</td>
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### Focus group participants (n = 40)

<table>
<thead>
<tr>
<th>Characteristic</th>
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<tr>
<td>Less than grade 9</td>
<td>6 (15.0%)</td>
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<tr>
<td>High school</td>
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<tr>
<td>Trade/technical school</td>
<td>1 (2.5%)</td>
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<tr>
<td>College</td>
<td>11 (27.5%)</td>
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<tr>
<td>University</td>
<td>4 (10.0%)</td>
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<tr>
<td>Incomplete</td>
<td>4 (10.0%)</td>
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<tr>
<td><strong>CD4+ Cell Count</strong></td>
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<tr>
<td>&gt; 200 cells/mm³</td>
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<td>12 (30.0%)</td>
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<tr>
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<td>1 (2.5%)</td>
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<tr>
<td><strong>Viral Load</strong></td>
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<tr>
<td>&lt; 50 copies/mL</td>
<td>20 (50.0%)</td>
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<tr>
<td>&gt; 50 copies/mL</td>
<td>1 (2.5%)</td>
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<tr>
<td>Don’t know</td>
<td>17 (42.5%)</td>
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<tr>
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<td>2 (5.0%)</td>
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<tr>
<td><strong>Ever hospitalized for HIV-related illness</strong></td>
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<tr>
<td>Yes</td>
<td>15 (37.5%)</td>
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<tr>
<td>No</td>
<td>21 (52.5%)</td>
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<td><strong>Current use of antiretrovirals</strong></td>
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<td>Yes</td>
<td>35 (87.5%)</td>
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<td>3 (7.5%)</td>
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Chapter 5: Summary and Synthesis

The purposes of this chapter are to:

1. Briefly summarize the three studies comprising this dissertation.
2. Synthesize the findings of the dissertation.
3. Discuss the implications of the dissertation for HIV-related health services research in Ontario.
4. Review the general limitations of the dissertation.

5.1 Introduction

The overall goals of this dissertation were to contribute to the field of HIV-related health services research in the province of Ontario and to investigate aspects of the health services utilization of marginalized PLWH, including women, immigrants, heterosexual men and individuals living in low income neighborhoods. These goals were achieved by developing and validating an algorithm to identify HIV-infected adults in Ontario’s administrative databases, applying the algorithm towards conducting a population-based examination of inpatient service use among PLWH, and examining the experiences of heterosexual men seeking care in the existing HIV-service arena. The purpose of this chapter is to summarize and synthesize the findings from the three projects comprising this dissertation, identify areas of further research that build on these projects and highlight some of the limitations among the three studies.

5.2 Summary of research studies
5.2.1 Validation of a case-finding algorithm for identifying adults living with HIV (Chapter 2)

In this study, we found that a relatively simple algorithm of three physician claims for HIV infection within a three year period accurately detected PWLH in Ontario’s administrative databases, with a sensitivity and specificity of 96.2% (95% CI 95.2% - 97.9%) and 99.6% (95% CI 99.1% - 99.8%), respectively. The inclusion of hospital and emergency department separation records or prescription drug claims did not appreciably augment the performance of algorithms based solely on physician claims. This study had several limitations, including the use of a validation cohort derived from two clinics with extensive experience in the clinical management of HIV-infection and with a prevalence of HIV-infection that exceeds that of the population of Ontario. Nonetheless, by assessing multiple algorithms over varying time frames, this study represents the most comprehensive examination to date of the feasibility of using administrative data for HIV-related population-based research. Application of the algorithm to the population of Ontario for the three year period spanning 2007 to 2010 identified a cohort of PLWH with demographic characteristics that were similar to estimates provided by the Public Health Agency of Canada and the Ontario HIV Epidemiologic Monitoring Unit.

5.2.2 Hospitalization of HIV-infected patients in Ontario (Chapter 3)

Using the case-finding algorithm developed in Chapter 2, we conducted a population-based cohort study examining rates of total- and HIV-related hospitalizations among all PLWH who were receiving care in Ontario during the years 1992 to 2008. We used interrupted time series analysis to isolate and quantify the impact of the introduction of cART on hospitalization rates, and generalized estimating equations to analyze trends and predictors of hospitalization during the era of ‘modern cART’, defined as the period spanning the years 2002 to 2008. This study
demonstrated that the introduction of cART was associated with a significantly larger reduction in rates of hospitalization among men relative to women. Furthermore, higher rates of total hospitalization were associated with female sex [adjusted relative rate (aRR) 1.13; 95% CI: 1.02 to 1.24] and low socioeconomic status (aRR 1.22; 95% CI: 1.14 to 1.30) in the era of modern cART. Higher rates of total hospitalization were also associated with low socioeconomic status (aRR 1.25; 95% CI: 1.12 to 1.40). Unexpectedly, recent immigrants had lower rates of both total (aRR 0.70; 95% CI 0.61 to 0.80) and HIV-related hospitalizations (aRR 0.76; 95% CI 0.60 to 0.96). These results suggest that important disparities exist in the risk of hospitalization among certain groups of PLWH living in Ontario.

5.2.3 Help-seeking experiences of heterosexual men living with HIV (Chapter 4)

The results of this study suggest that heterosexual men living with HIV are relegated to the margins of a health care and social service field that was developed within a context that privileges the priorities of gay men and heterosexual women living with the virus. Using the theoretical insights of Pierre Bourdieu and Erving Goffman, we surmised that this disparity arises because heterosexual men lack both the social capital required to compete within the social space of community-based AIDS service organizations (ASOs) and the symbolic appeal of HIV-infected heterosexual women when decisions about program development and allocation of funding are made. The experiences of heterosexual men in ASOs structure certain practices aimed at acquiring the capital required to improve their positioning within these agencies, including volunteering and attempting to pass as gay men, the group perceived to occupy the dominant decision making positions within the HIV service field. These results demonstrate the
important role of social relations and larger discourses in generating disparities in the HIV-related health and service field.

5.3 Synthesis: Conceptualizing Health Disparities

Health disparities are defined as “systematic, plausibly avoidable health differences adversely affecting socially disadvantaged groups”. Through the application of quantitative and qualitative methods, the findings from the research projects comprising this dissertation coalesce into a unifying theme of persistent disparity in health services utilization and outcomes among disadvantaged populations of PLWH in Ontario. Most notably, although each study differed in its focus and mode of investigation, the notion that factors reflecting the economic and social resources available to PLWH are important determinants of the observed disparities resonated throughout this dissertation. That is, unlike ‘downstream’ determinants of health characterized by individual risk factors for poor outcomes among PLWH, such as smoking, adherence to antiretrovirals and routine determinations of HIV viral load, this dissertation highlighted the important role of larger structural factors related to social and economic organization in generating disparities among marginalized PLWH living in Ontario. In this manner, the findings of this thesis can be brought together and conceptualized using the theory of fundamental causes advanced by social epidemiologists Bruce Link and Jo Phelan.

According to Link and Phelan, social determinants of health such as gender, socioeconomic status, race/ethnicity and interpersonal connections influence a given individuals’ ability to command resources that may prevent illness or mitigate the consequences of disease should it occur. Consequently, because these social factors involve access to resources such as money, knowledge and social connections, they are considered by Link and Phelan to be fundamental
causes of health disparities that maintain a persistent association with poor health despite any improvements in intervening risk factors connecting these ‘upstream’ determinants of health with disease. Following this logic, public health interventions that target individual risk factors for disease or which focus on severing the links perceived to connect upstream social conditions with downstream health outcomes would not eliminate health disparities because the fundamental causes mediating access to resources would remain unchanged by such measures. For example, the ability to marshal resources associated with higher socioeconomic status were probably equally as advantageous in avoiding the most dire sanitation and industrial conditions of the 19th century as they are in shaping access to housing in ‘healthy’ neighborhoods in the present. In other words, because of the transposable nature of resources like knowledge and money, fundamental causes maintain persistent effects on population health despite temporal changes in social circumstances. Accordingly, policies which seek to reduce inequities in health must address the social conditions, or fundamental causes, that produce and reproduce these disparities across time.

In keeping with this framework, the social determinants associated with hospitalization of PLWH and which underpin the help-seeking experiences of heterosexual men living with HIV can be conceptualized as fundamental causes of disparity. That is, these determinants, including socioeconomic status, gender, and social capital, operate as upstream antecedents of access to care and health services utilization that perpetuate disparity because of their association with resources that influence a given individuals’ ability to minimize the consequences of their illness. For example, participants in the qualitative study perceive themselves to be disadvantaged in ASOs because they lack the social connections necessary to advocate for the
funding and recognition required to develop programs and services that cater to the needs of their demographic. As a result, because of its association with resources such as social connections and power, social capital becomes a fundamental cause of disparity in the HIV-related service field for heterosexual men living with the virus. Similarly, PLWH who are in the higher bracket of socioeconomic status are more likely to have the resources to ensure uninterrupted access to antiretroviral drug therapy and live in housing and neighborhoods characterized by social conditions that are less noxious relative to PLWH who are of low socioeconomic status.

Although Link and Phelan do not include discourses in their scholarly work regarding fundamental causes, this dissertation highlighted the important role played by the ‘vulnerability’ or ‘victimization’ discourse in creating disparity in the HIV health and service field. Specifically, like other fundamental causes, this discourse is associated with access to a particular resource (i.e. symbolic capital) that imparts advantage to one group relative to another when funding for program development and community-based research is at stake, thereby creating inequity in the HIV health and service field.

Viewing the findings of this dissertation through the framework of fundamental causes carries implications when considering the nature of interventions or policies required to rectify the observed disparities in health services and outcomes. Because the fundamental causes model prioritizes the role of meta-mechanisms distal to health outcomes in creating inequity, interventions designed to reduce disparities must dilute the ability of these social factors to create a health advantage for one group relative to another. In the context of this dissertation, interventions designed with this goal in mind must be available to and benefit all PLWH in Ontario irrespective of their individual social or economic resources. An example of such an
initiative would be a program of universal access to antiretroviral therapies for all PLWH in Ontario regardless of social circumstances, thereby eliminating gradients in treatment access that could be introduced by lack of money for co-payments or the need to enroll in provincial programs such as the Ontario Disability Support Program (ODSP). Although the ODSP provides a mechanism for securing access to antiretroviral therapy, the application process itself can be a source of disparity for marginalized PLWH (e.g. homeless, cognitively impaired) who may have difficulty completing the required forms and lack access to advocates experienced in navigating the ODSP system. In contrast, provincially funded antiretroviral therapy to all PLWH circumvents the production of inequity associated with access to resources such as money or knowledge of the system. Furthermore, another central tenet of the fundamental causes framework is that individuals endowed with contextually appropriate resources such as social connections and prestige are able to gain a health advantage relative to individuals lacking in these resources. Therefore, along with developing interventions that benefit all PLWH regardless of their access to resources, a second means by which disparities can be remedied is through initiatives that increase the resources available to resource-poor individuals experiencing a particular health inequity. Consequently, because heterosexual men living with HIV lack the requisite forms of capital for improving their positioning within the HIV-related health and social services field, interventions which facilitate capacity-building and community development are required to propagate the social connections and advocacy needed to counter the fundamental causes of disparity affecting this particular population of PLWH.

However, while Link and Phelan’s fundamental causes framework provides a useful model for conceptualizing meta-mechanisms such as socioeconomic status as targets of intervention in
their own right, the key processes, mechanisms and pathways driving inequality downstream from these larger determinants of health remain obscured by this model. That is, by de-emphasizing the pathways which link larger fundamental causes to their downstream consequences, the explicit mechanisms accounting for why women with HIV and PLWH living in low income neighborhoods are hospitalized at a higher rate than their reference populations remain unclear. While several reasons were postulated for these associations in Chapter 4, additional research is required to move this area of inquiry beyond speculation and exploratory associations towards generating explanations of how gender, socioeconomic status and/or neighborhood effects work to produce disparities in the risk of hospitalization. Without such research, the causal pathways linking these fundamental causes to higher rates of hospitalization remain hidden, thereby hindering the development of actionable policies and interventions which can begin to address these disparities. In addition, these causal pathways may be more readily amenable to public health interventions than structural fundamental causes such as societal gender inequality or poverty. In this manner, the study of health disparities among marginalized PLWH would be optimally undertaken by adopting a complex systems approach that integrates the principal of structural causation represented by the fundamental causes model with additional research that explicates the mechanisms mediating the relationship between larger determinants of health and specific health disparities.

5.4 Implications and future research directions

In addition to laying the foundation for further research examining the causal pathways contributing to health disparities among women with HIV and PLWH living in low income neighborhoods, the studies comprising this dissertation make two additional important contributions to the future of HIV-related health services research in Ontario. First, the
validation of a case-finding algorithm for identifying PLWH in Ontario’s administrative databases facilitates further population-based HIV research in the province. With this algorithm, we have assembled a provincial cohort of all PLWH receiving care in the province of Ontario that can be updated annually and which has become the basis of a population-based study examining trends in the incidence and prevalence of HIV-infection in Ontario, as well as changes in mortality rates among these patients. Furthermore, the establishment of this cohort and linkages to new databases (e.g. Citizenship and Immigration Canada Database, Vital Statistics) will render it possible to ask a myriad of questions regarding the appropriateness, cost and patterns of health services utilization among the heterogeneous population of Ontario’s PLWH. A planned linkage with the Ontario HIV Treatment Network Cohort Study (OCS), a database that includes clinical, behavioural and detailed demographic data about a cohort of PLWH in Ontario, will further expand the range of research questions possible. Such endeavors will afford novel opportunities for collaboration between the Institute for Clinical Evaluative Sciences (ICES) and the scientists, community members and ASOs who have cultivated a rich tradition of community-based HIV research in Ontario. As a recent example of one such enterprise, a team of researchers from ICES and the Interdisciplinary HIV Pregnancy Research Group have been awarded a grant to study HIV-associated maternal and neonatal health outcomes using Ontario’s administrative databases.

The second important contribution made by this thesis is the advancement of knowledge regarding the ‘fit’ between existing HIV-related services and the growing population of heterosexual men living with HIV. Although the findings themselves are significant, in that they fill a conspicuous gap in the HIV literature and represent the most extensive analyses conducted
to date pertaining to this question, the most critical aspect of this study may prove to be the successful engagement of a population that has been historically underrepresented in the provincial community-based research landscape. A key concern for the focus group participants and the five men constituting the community-advisory board was to maintain the momentum instigated by this first study, and to continue to meaningfully engage heterosexual men living with HIV in initiatives that increase the visibility of this population to policy makers and other stakeholders who apportion funds for HIV-related services and prevention initiatives. To this end, we have been successful in securing a grant that will be allotted towards the planning and execution of a summit for heterosexual men living with HIV, the goal of which will be to develop a research and policy agenda that outlines the concerns of this population. In addition to generating a specific deliverable, the goal of this summit is to continue to build research capacity and social capital among this group by training peer research assistants, developing a plan for community advocacy and forging partnerships with AIDS service organizations who have expressed an interest in taking up this cause.

5.5 General limitations of dissertation

Although the specific limitations of each study are outlined in the respective chapters, several global limitations of the dissertation merit emphasis and reiteration. Because the case-finding algorithm validated during the course of this work is applicable only to HIV-infected adults receiving care in Ontario, we cannot speculate how it would perform for the ascertainment of HIV infection among children or in the administrative databases found in other provinces. Further validation research would be required to address these limitations. In addition, the findings of this dissertation are applicable only to PLWH who are receiving regular care. Our research is therefore not applicable to PLWH who do not access HIV-related health and social
support services routinely and who have not been retained in care. However, the establishment of a provincial cohort of PLWH using administrative data and the proposed link with the OCS will render it possible to evaluate factors associated with retention in care among PLWH and to characterize risk factors associated with leaving care. Finally, the potential for residual confounding due to unmeasured covariates is a potential limitation of the hospitalization study and future population-based studies conducted using the administrative databases at ICES. Specifically, we did not have access to clinical variables such as viral load and CD4+ cell count, and the previously described challenges associated with the use of the Ontario Drug Benefit database precluded our ability to account for adherence to antiretroviral therapy. However, these limitations are common to all studies using administrative databases for health services research, and must be balanced against the merits of using these data for this purpose, including long-duration of follow-up, large sample size, and generalizability to the entire population of PLWH in care.24,25,29 Future linkages with the OCS and/or Public Health Ontario may obviate some of the concerns regarding residual confounding by enriching the data repositories held at ICES with virologic data, medication histories and sociodemographic variables pertaining to employment history, housing status and stigma.

5.6 Conclusions

As discussed throughout this thesis, the preceding decade has been marked by important changes in the demographic profile of PLWH in Ontario and improvements in the life expectancy of these patients. Most notably, the increased representation of women of child-bearing age, heterosexual men, individuals from a country with a high prevalence of HIV and individuals over the age of 50 among the provincial population of PLWH will require that a dynamic program of health services research aimed at evaluating the adequacy and quality of HIV-related
care be developed. This dissertation contributes to this goal by engaging a previously
underrepresented population in research and validating a case-finding algorithm that can be used
for future population-based studies of PLWH in Ontario. In addition, utilizing both qualitative
and quantitative analyses, we identified several fundamental causes of disparity in health
services utilization among marginalized PLWH living in Ontario. Further research will be
required to elucidate the mechanisms driving these disparities and evaluate interventions which
aspire to mitigate, or ideally, eliminate inequities in service access and outcomes among PLWH.
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